Understanding and supporting occupational therapists clinical decision-making for the management of upper limb post stroke sensory impairment

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A thesis submitted for the degree of Doctor of Philosophy at The University of Queensland in 2015
School of Health and Rehabilitation Sciences
Abstract

Background
Stroke survivors form the largest client group seen by occupational therapists and a large proportion of these stroke survivors experience upper limb post-stroke sensory impairments (ULPSSI) which impact upper limb function and participation. This thesis addresses the clinical decision-making (CDM) of occupational therapists when managing ULPSSI. No appraised and synthesised summary of the research evidence related to the effectiveness of interventions for ULPSSI is available to support therapists’ CDM. Information on occupational therapists’ practice choices and decisions about managing ULPSSI and the survivors’ perspective on ULPSSI is scant. This information could support occupational therapists CDM when addressing ULPSSI and potentially improve stroke survivors’ outcomes.

Thesis Aims
This thesis aims to:

1. Synthesise the effectiveness of interventions for ULPSSI;
2. Explore how occupational therapists make and manage decisions regarding ULPSSI management;
3. Describe practice choices occupational therapists commonly make when managing ULPSSI and the sources of information they use to make these decisions;
4. Compare current assessment choices and intervention practices with recommendations from the research evidence and clinical practice guidelines;
5. Describe the stroke survivors’ perspective with regard to ULPSSI; and
6. Design and pilot an evidence-based, theory-driven educational intervention to support occupational therapists’ CDM when addressing ULPSSI.

Thesis Methods
Five distinct studies addressed the above aims.

- A Cochrane systematic review evaluated the evidence for the effectiveness of ULPSSI interventions.
• Twelve occupational therapists participated in a qualitative descriptive study exploring therapists’ practice choices and CDM related to ULPSSI.

• Based on the qualitative study, a survey of 187 occupational therapists described therapists’ current practice choices regarding ULPSSI management and factors impacting CDM.

• A qualitative descriptive study using semi-structured interviews with 15 stroke survivors explored their experience of ULPSSI and the associated rehabilitation encounter.

• Finally, based on the need for training expressed by the survey participants, a one group pre- and post-test design, feasibility study evaluated the effect of a one day, theory-based educational intervention on 19 occupational therapists’ knowledge, perceived behavioural control, attitudes and intended behaviour regarding ULPSSI management, research utilisation, and shared decision-making. Workshop content incorporated information from the prior research studies forming this thesis.

**Results**

A Cochrane systematic review located 13 randomised controlled trials (RCTs) addressing ULPSSI interventions, with benefit shown from individual RCTs evaluating mirror therapy, a graded thermal stimulation, and intermittent pneumatic compression. Other single RCTs reporting statistically significant results for repetitive peripheral magnetic stimulation, early intensive task-orientated training and graded sensory rehabilitation were found but lacked sufficient data to determine effects sizes.

Therapists in the qualitative study expressed considerable uncertainty when managing ULPSSI and focused on searching for knowledge especially from peers, reasoning by analogy, and trialling interventions to manage this uncertainty. Therapists described clinical and contextual factors influencing their CDM.

The majority of survey respondents reported frequently assessing sensation but failed to use standardised measures. Just over half of the respondents frequently provided ULPSSI interventions, primarily providing non-specific sensory stimulation followed by compensatory strategies differing from those in recent research. Most therapists provided
patient/caregiver safety education. Therapists cited lack of knowledge and skills, patients’ short length of stay, and lack of time as barriers to utilising ULPSSI interventions. Most therapists reported not being up-to-date with current research requesting continuing education to support practice.

Survey respondents’ lack of awareness of interventions, believing that interventions for motor impairments addressed ULPSSI, and lack of time most commonly led to the decision not to use ULPSSI interventions. Clients’ cognitive status, ULPSSI severity, and time since stroke impacted therapists’ choice between compensatory or remedial approaches. Prior personal experience, trialling interventions, and consulting other therapists most commonly influenced specific intervention choice.

Stroke survivors clearly articulated how ULPSSI impacted upper limb functional use. Survivors saw the recovery process extending years beyond current rehabilitation time frames and necessitating considerable work, though many survivors felt they were left on their own to address upper limb impairments. They reported little involvement in decision-making regarding their rehabilitation.

A feasibility study of a theory-driven educational intervention demonstrated potential to significantly change therapists knowledge, attitudes and perceived behavioural control, and changes from current behaviour to intended behaviour regarding ULPSSI management, using research, and shared decision-making.
Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Susan Doyle
Publications during candidature

Peer Reviewed Papers


Book Chapters

- Bennett, S., O’Connor, D., Hannes, K., & Doyle, S.D. (2013) Appraising and understanding systematic reviews of quantitative and qualitative evidence. In T. Hoffmann, S. Bennett, & C. Del Mar, (Eds.), Evidence-based Practice across the Health Professions. 2nd Ed. (pp. 283-312) Sydney, Australia: Elsevier.

**Commentaries**


**Conference Abstracts**

- Doyle, S.D. Implementing evidence-based practice. 8 hr Preconference Institute Washington Occupational Therapy Association, Annual Conference. Wenatchee, WA. October 2012


- Scherer, R., & Doyle, S.D. Increasing occupational therapy's participation in the Cochrane Collaboration. 2 hr Invited Key Note Address at American Occupational Therapy Association (AOTA), Program Directors Educational Program. St Louis MO April 2007.


Other publications

Publications included in this thesis

Six jointly authored works are included in the thesis:


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This manuscript is incorporated in Chapter 4 of this thesis.

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Doyle, S.D., Bennett, S., & Gustafsson, L. (2013). Clinical decision making when addressing upper limb post-stroke sensory impairments. *British Journal of Occupational Therapy*. 76(6), 254-263. This manuscript is incorporated in Chapter 6 of this thesis.

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**Note:** The published manuscripts have been incorporated into the thesis as manuscripts which have been expanded to aid with the development and layout of the thesis. Tables and figures have been imbedded in the text; spelling and formatting has been changed to allow for consistency throughout the thesis while references for each manuscript are provided in the reference list at the end of the thesis. Headings and numbering have been adjusted to maintain consistency throughout the thesis.
Contributions by others to the thesis

The PhD candidate led all studies in this thesis. She was responsible for the project design; gaining ethical approval; conception and design of all intervention materials; choice of all assessment materials; participant recruitment; data collection, analysis and interpretation; and manuscript preparation. However, significant contributions have been made by the following people to the thesis as a whole:

Dr Kryss McKenna had substantial input into the concept and design of the Cochrane Systematic review and therapist qualitative study.

Dr Sally Bennett had substantial input into the concept and design of the survivor qualitative study, survey, and educational program, data analysis and interpretation for each of the studies and critical revision of all the written work.

Dr Susan Fasoli had substantial input into the design of the Cochrane Systematic Review, data analysis and interpretation and critical revision of written work related to the systematic review.

Dr Patty Lynott had initial input into the design of the therapist qualitative study.

Dr Brian Dudgeon had input into the design of the survivor qualitative study and data analysis and interpretation and critical revision of written work related to the therapists’ and survivors’ qualitative studies.

Dr Louise Gustafsson had input into the design of the survey study and review of the written work related to this study and well as critical review of written work related to thesis documents.
To the best of my knowledge and belief, no person who has offered contributions consistent with the above has been excluded as an author. Persons who have contributed to the work but not at a level that constitutes authorship have been acknowledged in the text.

Statement of parts of the thesis submitted to qualify for the award of another degree

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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>BCB</td>
<td>Byl-Cheney-Boczai Sensory Discriminator</td>
</tr>
<tr>
<td>CDM</td>
<td>Clinical decision making</td>
</tr>
<tr>
<td>CPE</td>
<td>Continuing Professional Education</td>
</tr>
<tr>
<td>CPSP</td>
<td>Central Post-Stroke Pain syndrome</td>
</tr>
<tr>
<td>EmNSA</td>
<td>Erasmus modified NSA</td>
</tr>
<tr>
<td>EBP</td>
<td>Evidence based practice</td>
</tr>
<tr>
<td>HASTe</td>
<td>Hand Active Sensation Test</td>
</tr>
<tr>
<td>LACI</td>
<td>Lacunar Anterior Circulatory Infarct</td>
</tr>
<tr>
<td>MTP</td>
<td>Moving Touch Pressure test</td>
</tr>
<tr>
<td>NSA</td>
<td>Nottingham Sensory Assessment</td>
</tr>
<tr>
<td>PACI</td>
<td>Partial Anterior Circulatory Infarct</td>
</tr>
<tr>
<td>POCI</td>
<td>Posterior Circulatory Infarct</td>
</tr>
<tr>
<td>RASP</td>
<td>Rivermead Assessment of Somatosensory Performance</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>SDM</td>
<td>Shared decision-making</td>
</tr>
<tr>
<td>S-I</td>
<td>Primary Somatosensory Cortex</td>
</tr>
<tr>
<td>S-II</td>
<td>Secondary Somatosensory Cortex</td>
</tr>
<tr>
<td>STI</td>
<td>Shape Texture Identification Test</td>
</tr>
<tr>
<td>STP</td>
<td>Sustained Touch Pressure</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
</tr>
<tr>
<td>TACI</td>
<td>Total Anterior Circulatory Infarct</td>
</tr>
<tr>
<td>TPB</td>
<td>Theory of Planned Behaviour</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>ULPSSI</td>
<td>Upper Limb Post Stroke Sensory Impairment</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
</tr>
<tr>
<td>VP</td>
<td>Ventral Posterior Nucleus of the thalamus</td>
</tr>
<tr>
<td>VPL</td>
<td>Ventral Posterior Lateral nucleus of the thalamus</td>
</tr>
<tr>
<td>VPM</td>
<td>Ventral Posterior Medial nucleus of the thalamus</td>
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<tr>
<td>WPST</td>
<td>Wrist Position Sense Test</td>
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CHAPTER 1: THESIS INTRODUCTION

Chapter one provides the rationale and justification for the topic of understanding and supporting occupational therapists’ clinical decision making (CDM) for the management of upper limb post stroke sensory impairments (ULPSSI). This Chapter also outlines the specific aims of the thesis. Five main studies will be outlined and the structure of the thesis explained. It is important for the reader to note that this PhD was completed part-time and therefore the studies that are reported were designed between 2004 and 2010 and conducted between 2005 and 2011. Therefore, it was important that the information presented within the early Chapters of this thesis were consistent with timeframe of study development. Subsequent studies and their implication are reported in the latter sections of the thesis.

1.1. Overview of the Thesis Topic

This thesis focuses specifically on the CDM of occupational therapists when addressing ULPSSI. While it is understood that other members of the multi-disciplinary team often use similar evidence and at times similar CDM strategies, this thesis will concentrate on the perspective of the occupational therapist. To understand and support occupational therapists’ CDM regarding ULPSSI management one must first understand what is known about ULPSSI, occupational therapists’ current management of ULPSSI, what is known about CDM in general and the sources of evidence therapists utilise in their decision-making. This overview will summarise this information, addressing the implications for supporting occupational therapists’ CDM regarding ULPSSI management.

1.1.1. Upper limb post stroke sensory impairments.

Stroke survivors specifically report upper limb impairments, changes in movement and sensation, as impacting their ability to participate in daily living and leisure tasks (Heart and Stroke Association of Ontario, 2001). ULPSSI have not received as much
attention in the literature as motor impairments (Acerra, 2007) despite being associated with decreased safety (Yekutiel, 2000), decreased quality of motor control and decreased spontaneous upper limb use (Dannenbaum & Jones, 1993; Nowak et al., 2007; Rand, Gottlieb & Weiss, 2001; van der Lee et al., 1999; Yekutiel, 2000), decreased fine motor control, object manipulation, and grasp force (Aruin, 2005; Blennerhassett, Matyas, & Carey, 2007; Carey, 1995; Nowak et al., 2007; Robertson & Jones, 1994; Welmer, Holmqvist, & Sommerfeld, 2008; Yekutiel, 2000). Sensory impairments are also associated with increased length of hospitalisation; decreased numbers discharged home, lower functional levels at discharge, decreased long term participation, and increased mortality rates (Carey, 1995; Rand et al., 2001; Tyson, Hanley, Chillala, Selley, & Tallis, 2008; Yekutiel, 2000). Unlike motor impairments, sensory impairments and their impact are often less frequently reported by survivors. For example, Acerra (2007) found that although only 16% of stroke survivors reported sensory impairment the actual incidence identified by formal testing was between 53 – 89%. While sensory impairments impact the whole body, the upper limb, especially the hand, is a key sensory tool and essential for dexterity and everyday function. In addition, the upper limb recovers more slowly than the lower limb and is vulnerable to non-use due to ULPSSI (Yekutiel, 2000). Hence it is important that research focuses specifically on the upper limb and therefore is of particular interest in this thesis.

1.1.2. Occupational therapists’ management of ULPSSI.

Stroke survivors compose the largest diagnostic group seen by occupational therapists (National Board for Certification in Occupational Therapy Inc., 2004). Occupational therapists are key members of the stroke survivors’ rehabilitation team, often aiming to increase participation through facilitating independence in basic self-care tasks and improving upper limb functional use (Richards et al., 2005). Given that ULPSSI significantly impact not only upper limb functional use (Nowak et al., 2007; Rand et al., 2001) but also outcomes (e.g. independence in self-care, mobility, or participation) for stroke survivors (Desrosiers et al., 2003; Rand et al., 2001;
Tyson et al., 2008) it would appear that ULPSSI management would be an important component of occupational therapy practice.

There have been some recommendations in texts and clinical practice guidelines, from non-randomised and randomised controlled studies regarding ULPSSI management. There are also a few systematic reviews (Schabrun & Hillier, 2009; Steultjens et al., 2003) that have identified a number of randomised controlled trials (RCTs) testing the effects of interventions for ULPSSI but no comprehensive systematic review of RCTs has been undertaken on this issue. A systematic review of interventions for ULPSSI is needed to provide clinicians with a clear statement about the status of existing evidence.

Insights into how therapists currently assess and treat people with ULPSSI, perceived barriers therapists might experience in providing rehabilitation, and their use of existing research and other sources of information in this area, are important for both informing development of assessments and interventions for ULPSSI and for understanding how to support therapists’ CDM in this area. Walker, Drummond, Gatt and Sackley (2000) found therapists more frequently chose a Bobath treatment approach when treating stroke survivors if their client had a sensory impairment but did not described any treatment approaches that specifically addressed sensory impairments. No further studies specifically identifying management or practice choices occupational therapists commonly make when addressing ULPSSI were found prior to the start of the studies forming this thesis. It is therefore unclear how therapists currently practice, what information they use to inform their decisions, or what barriers they face in this practice area.

1.1.3. Occupational therapists’ decision making and evidence-based practice.

ULPSSI management is complex and requires therapists to access, interpret, and weigh up different types of information from multiple sources to make decisions
about the best care for their clients. Such decisions might include which sensory measures to use, whether or not to provide interventions, determining the most effective interventions to use, or when to try alternative intervention strategies.

Making choices about a course of action in clinical practice is known as CDM (Smith, Higgs, & Ellis, 2008). Evidence-based practice (EBP) is a CDM framework that encourages health professionals to integrate the best available research evidence with clinical experience and client’s preferences and circumstances when making decisions (Sackett, Rosenberg, Muir Gray, Haynes, & Richardson, 1996).

Decisions in clinical practice are often complex and involve considerable uncertainty (Smith et al., 2008; Copley, Bennett, & Turpin, 2010). Limited availability of research also contributes to therapists’ uncertainty in deciding on the management of upper limb impairments (Kuipers & McKenna, 2009). There is some research investigating how occupational therapists make and manage clinical decisions in practice, including for example, areas such as referrals in community mental health (Harries & Gilhooly, 2003); management of upper limb hyper tonicity in children and adolescents with cerebral palsy (Rassafiani, Ziviani, Rodger, & Dalgleish, 2008); and management of upper limb performance dysfunction following brain injury (Kuipers, McKenna, & Carlson, 2006). Rassafiani et al. (2008) argues that information obtained from studies of CDM with one client group cannot be generalised to another client group as expertise is domain specific. Thus exploring how occupational therapists make and manage decisions regarding ULPSSI management is pivotal to supporting therapists working in this area.

Evidence-based CDM requires therapists not only use the existing research evidence and clinical experience when making decisions but to also consider the clients’ perspective (Sackett et al., 1996). Qualitative research can play a pivotal role in understanding the stroke survivor’s perspective, thus enabling health professionals to consider how best to address survivor’s needs. Although the amount of qualitative research regarding stroke may be sizeable (McKevitt, Redfern, Mold, & Wolfe, 2004), research that specifically considers the stroke survivor’s experience of ULPSSI is lacking.
Priorities related to stroke research were identified in a review commissioned by the UK Department of Health and included the need for further research evaluating the effectiveness of stroke rehabilitation methods, current service delivery models, and to identify rehabilitation professionals training needs (Wolfe, Rudd, McKeivitt, Heuschmann, & Kalra, 2008). It is clear that research is specifically needed to understand CDM regarding ULPSSI management, and for this we need an understanding of the following:

- the status of existing research evidence regarding ULPSSI management;
- how therapists make and manage decisions regarding ULPSSI management;
- what management or practices choices occupational therapists commonly make when addressing ULPSSI;
- the information sources they use to inform their decisions; and
- the stroke survivor’s perspective and experience of ULPSSI and rehabilitation

This information may then inform support for occupational therapists working in this area.

1.1.4. Conclusions and implications for the thesis.

Given the high incidence of ULPSSI, their impact on outcomes and stroke survivors’ quality of life, and the frequency with which occupational therapists treat stroke survivors, greater understanding of CDM in this practice area is required. This thesis explores ULPSSI management using the lens of evidence-based CDM. To build this knowledge, this thesis will summarise the available evidence for sensory measures, interventions for ULPSSI, describe occupational therapists’ CDM and current practices when addressing ULPSSI, and explore stroke survivors’ perspective on ULPSSI. This thesis then culminates in a feasibility study of an evidence-based, theory-driven educational intervention to support occupational therapists’ CDM and practice regarding ULPSSI management, developed in response to findings from the initial studies within this thesis.
1.2. Aims of the Research

Specifically the research in this thesis addresses the following aims:

1. To synthesise studies testing the effects of interventions for ULPSSI;
2. To explore how occupational therapists make and manage decisions for the ULPSSI management (with an emphasis on intervention decisions);
3. To describe practice choices occupational therapists commonly make when managing ULPSSI and the sources of information they use to make these decisions;
4. To compare current intervention practices with the available evidence for assessment and interventions for ULPSSI;
5. To describe the stroke survivors’ perspective with regard to ULPSSI and its rehabilitation.

The findings from these studies then highlighted the need for CPE to support occupational therapist’s understanding and management of ULPSSI and CDM. Therefore, the aim of the final study was:

6. To design and pilot an evidence-based, theory driven educational intervention for occupational therapists to address the discrepancies noted between current evidence and practice patterns when addressing ULPSSI.

1.3. Structure of the Thesis

This thesis is structured as a combination of published manuscripts and thesis Chapters providing background to the manuscripts. The manuscripts were reformatted with respect to headings, tables and figure headings, and page numbers to improve the consistency of formatting throughout the thesis and additional information consistent with the needs of a thesis was added as needed. References are provided at the end of the thesis, except for references for the studies connected with the Cochrane Review.
1.4. Content of the Thesis

This thesis explores the topic of understanding and supporting occupational therapists’ CDM regarding ULPSSI management, particularly focusing on intervention decisions. Five studies formed the basis for this thesis. A summary of the aims and methods for each of these studies follows.

Study one: This study was a Cochrane Systematic Review of the effectiveness of interventions for ULPSSI.

This study aimed to synthesise RCTs testing the effects of interventions for ULPSSI. Thirteen RCTs met the inclusion criteria. The risk of bias in each study was evaluated using the Cochrane Risk of Bias Assessment tool. Data was extracted and where possible effect sizes were calculated using the tools in RevMan5. If inadequate data was present, further data was requested from the trial authors.

Study two: This study was a qualitative descriptive study of occupational therapists’ CDM regarding ULPSSI.

Specifically, the research aimed to: (a) identify interventions occupational therapists use when addressing ULPSSI and their reasons for choosing them, (b) describe the factors influencing intervention decisions, and (c) to explore how therapists manage the CDM process. Twelve occupational therapists that regularly treat stroke survivors were recruited to participate in a semi-structured, tape-recorded interview to explore how they address ULPSSI. Tapes were transcribed and data entered into EthnographV6 and analysed using qualitative content analysis. Codes were derived from the interview data and reviewed by all team members individually and then collaboratively. Themes were then developed based on patterns that developed from the coded data.

Study three: This study was a survey of American occupational therapists.
This study aimed to describe current practice choices and factors influencing occupational therapists’ CDM when addressing ULPSSI. Information obtained from studies one and two were used to design the survey questions. A mailed survey with an online response option was sent to 500 American Occupational Therapy Association Physical Disabilities Special Interest Section members. Data was entered into PASW Statistics 18 for analysis. The data was also compared to the results of the first two studies. The data also provided the basis for designing the continuing education program (Study five). This study is reported across two papers with the first paper describing practice choices and the second exploring factors influencing CDM.

Study four: This study was a qualitative study of stroke survivors’ perspectives of ULPSSI and its rehabilitation.

This study used a qualitative descriptive methodology with the aim of describing the stroke survivors’ perspective of experiencing impaired upper limb sensation and associated rehabilitation. Fifteen stroke survivors were recruited from local stroke support groups in the Pacific Northwest of the USA. They were interviewed using a semi-structured interview guide and interviews were then transcribed. Data was entered into EthnographV6 and coding was completed using qualitative content analysis. Themes were derived from the patterns emerging from the codes. The codes and themes were then reviewed by the participants in a focus group and adjustments made based on the participants’ feedback. The results of this study were used to assist with designing part of the content of the educational intervention for occupational therapists (Study five).

Study five: This study was a feasibility study of an evidence-based, theory driven educational intervention designed to address the concerns raised by occupational therapists regarding ULPSSI management.
Based on the results of the previous four studies it was determined that therapists were requesting, and may benefit from, an education program that addressed issues related to ULPSSI. This study focused on designing an educational intervention that would impact therapists’ knowledge about ULPSSI, its management, and the nature of evidence available. It also addressed CDM, managing uncertainty in decision-making, as well as shared decision making (SDM) skills to build their confidence in this area. It was based on the Theory of Planned Behaviour, Adult Learning Theory, and evidence-based information regarding ULPSSI.

Nineteen therapists participated in a quasi-experimental pre/post-test feasibility study that included an eight hour theory driven evidence-based workshop on ULPSSI management. Changes in knowledge, attitudes, perceived behavioural control and intended behaviours regarding ULPSSI management, research utilisation and SDM were measured.

1.5. Chapters in the Thesis

Chapter 1: Introduction

Chapter 1 outlines the significance of the topic and the specific aims of the thesis. The five research studies that form the body of the thesis are outlined and the thesis structure described as a hybrid of Chapters and published manuscripts.

Chapter 2: Upper Limb Post Stroke Sensory Impairments

Chapter 2 provides a general review of somatosensation defines ULPSSI, describes the incidence and impact on functional upper limb use, recovery, and management of ULPSSI.

Chapter 3: Interventions for sensory impairment of the upper limb after stroke

Chapter three is a published, peer reviewed Cochrane Systematic Review which aims to synthesise RCTs testing the effects of interventions for ULPSSI. The results of this study also inform the analysis of the results from the next two studies and part
of the content for the final study in this thesis. This Chapter addresses the first aim of this thesis.

**Chapter 4: Sensory impairment after stroke: Exploring therapists’ clinical decision making.**

Chapter four is based on a peer reviewed publication in the *Canadian Journal of Occupational Therapy* and reports the results of a qualitative descriptive study that aimed to describe occupational therapists’ CDM regarding ULPSSI management. The results of this study were used to design the questionnaire for the survey described in Chapters 5 and 6, and to inform the content of the educational intervention for the final study (Chapter 8). This Chapter addresses the second aim of this thesis.

**Chapter 5: Occupational therapy for upper limb post-stroke sensory impairments: A survey.**

This Chapter presents the first part of study three: a survey of 187 occupational therapists in manuscript form published in the *British Journal of Occupational Therapy*. The study used a purpose designed questionnaire, based on results of the qualitative study (Chapter 4) and literature to ascertain the current practice patterns of occupational therapists related to ULPSSI. The results of this study informed the content of the educational intervention addressing the needs of occupational therapists (Chapter 8). Aims two, three and four of the thesis were addressed in this Chapter.

**Chapter 6: Clinical decision making when addressing Upper Limb Post-stroke Sensory Impairments.**

Chapter six is based on a manuscript published in the *British Journal of Occupational Therapy* reporting the results of part two of the survey undertaken as the third study. This paper specifically focused on the factors influencing CDM by occupational therapists when addressing ULPSSI. Questions in the questionnaire were designed to explore therapists CDM based on the results obtained from study two (Chapter 4). The results of this paper were also used to inform the content of study five (Chapter 8). This Chapter also addresses aims two, three and four of the thesis.
Chapter 7: Upper limb post-stroke sensory impairment: The survivors’ perspective.

This Chapter is based on a manuscript published in the *Disability and Rehabilitation* Journal that reports the results of a qualitative study of 15 stroke survivors. The survivors’ perspectives of experiencing ULPSSI and associated rehabilitation were explored using a semi-structured interview guide. Findings from this study also informed part of the content for the educational program used in study five (Chapter 8). This Chapter addresses the fifth aim of this thesis.

Chapter 8: Feasibility and effect of a professional education workshop for occupational therapists’ management of ULPSSI

This Chapter is based on a manuscript published in the *American Journal of Occupational Therapy* and addresses the sixth aim of this thesis. This paper reports the development and results of a feasibility study of an evidence-based, theory driven educational intervention designed to address concerns raised in previous studies related to therapists’ lack of knowledge about and confidence in CDM related to ULPSSI. Results from the first four studies were incorporated into the design and content of the educational intervention. In the prior studies (Chapters 4, 5 & 6), therapists requested continuing education programs related to ULPSSI, identifying a need for information regarding sensory measures and intervention strategies, understanding ULPSSI and educating stroke survivors and their caregivers. Survivors’ concerns about shared decision-making and support for ongoing remediation of ULPSSI identified in a prior study (Chapter 8) also informed the intervention content. Furthermore, therapists were provided with information on managing CDM in areas of uncertainty and evaluating their practice and well as resources for keeping up to date with their knowledge base.

Chapter 9: Summary, clinical implications, strengths and limitations, and future directions.

This Chapter synthesises the thesis findings incorporating the outcomes of the five research studies outlined in Chapters 3 to 8. The Chapter summarises the findings in relationship to the thesis aims and discusses their significance and the difficulties of addressing ULPSSI. The primary focus of the discussion will be on the clinical
implications of the five studies included in the thesis and recommendations for clinical practice change and further research. A review of the strengths and limitations of the research projects forming the basis of the thesis will also be included in Chapter 9.
CHAPTER 2: BACKGROUND TO THE THESIS: UPPER LIMB POST STROKE SENSORY IMPAIRMENTS

The hand and upper limb are intimately tied to many valued occupations and activities. What appears to be a relatively simple task, such as holding a newspaper while you read or squeezing toothpaste onto the toothbrush, all rely heavily on intact upper limb sensation. Exploration of the environment and mastery and participation in occupation are intimately associated with both movement and sensation (Carey, Oke, & Matyas, 1997; Connell, 2007; Yekutiel, 2000).

Although sensory impairments are evident in the trunk, upper and lower limb after stroke, Yekutiel (2000) argues that upper limb post stroke sensory impairments (ULPSSI) warrant close attention given the importance of the hand as a sensory tool and its subsequent importance for dexterity, its vulnerability to non-use due to ULPSSI, and the slow hand and upper limb recovery compared with the lower limb. While it may appear obvious that somatosensation is an important component of upper limb function, ULPSSI has received little attention in the literature especially when compared to motor impairments or functional deficits (Acerra, 2007; Blennerhassett et al., 2007; Kim, 2001). Understanding sensation, how it may be impaired by stroke and what the evidence shows regarding ULPSSI management is key information to support therapists’ clinical decision-making (CDM) when working with stroke survivors.

Chapter 2 provides a general background to understanding ULPSSI and then considers the implications and rationale for the first two studies in this thesis. Three aspects of somatosensation and ULPSSI are reviewed including: 1) understanding somatosensation and ULPSSI; 2) the impact of ULPSSI; and 3) ULPSSI management relevant to occupational therapy practice.
2.1. Understanding Somatosensation and ULPSSI

Central nervous system impairments, including those resulting from stroke, do not have well-defined patterns of sensory loss and may impact not only detection of sensation but also discrimination and perceptual components depending on where the interruption to the pathway occurred. While sensory threshold changes and altered nature of the sensation have been reported, anaesthesia or total loss of specific or multiple sensory modalities can be experienced, generally in broad areas of distribution e.g. hemi-body rather than specific peripheral nerve distribution. A therapist’s understanding of the key functions of sensation, the neurological basis underlying these functions, and the sensory impairments resulting from neurological damage due to stroke forms the basis for CDM regarding ULPSSI management.

2.1.1. Sensation.

DeJong’s Neurological Examination (Campbell, DeJong, & Haerer, 2005) describes the sensory system as comprising interoceptive, exteroceptive, and proprioceptive systems (see figure 2.1). The interoceptive system carries information about the internal systems and organs (Campbell et al., 2005). The exteroceptive system provides information about the external environment, including somatosensation and the special senses (vision, hearing, taste and vestibular inputs) (Campbell et al., 2005). Somatosensation incorporates the sensory modalities of pain, temperature, light touch/pressure, vibrations, and itch (Campbell et al., 2005; Carey, 2006). Proprioception incorporates kinaesthesia myaesthesia, bathyaeesthesia and is frequently considered separately from the primary cutaneous senses (Connell, 2007; Jones, 1999; Shepherd, 1994). (See Figure 2.1.)

This thesis will focus on somatosensation and proprioception. Throughout this thesis the terms sensation and sensory will refer to somatosensation and proprioception as defined in this section of the thesis.
Dannenbaum, Michaelsen, Desrosiers, and Levin (2002) described two main functional goals for the somatosensory system in the hand: 1) to provide environmental information during exploratory tasks, and 2) to provide sensory feedback to allow for control and refinement of grasp and manipulation tasks.

There are three key functions of the sensory system: detection, discrimination, and perception. These are described below.

2.1.1. Detection.

The basic or initial somatosensory function is the detection of cutaneous sensation and includes mechanical, thermal, pain, touch pressure, and vibration detection (Acerra, 2007; Carey, 1993; Carey, 1995). Detection is defined as an awareness of the sensation in the specific modality under consideration (Acerra, 2007; Carey, 1993 & 1995; Dannenbaum et al., 2002; Schabrun & Hillier, 2009; Tyson et al., 2008; Williams et al., 2006). Bohannan (2003), based on DeJong’s Neurological Examination, describes the detection or basic level for proprioception as the awareness of muscle contraction and movement, termed kinaesthesia (movement detection) and myaesthesia (muscle contraction awareness). These sensations
correspond to the primary sensory endings, receptors, and the neural pathways required to process detection information.

2.1.1.2. Discrimination.

Sensory discrimination is the ability to identify the stimulus location, discrimination of intensity, awareness of spatial relations, and a basic analysis of differences and similarities (Campbell et al., 2005; Carey, 1995; Blennerhassett et al., 2007; Bly et al., 2003; Gilroy, 2000; Kim & Choi-Kwon, 1996; Yekutiel, 2000). Discriminatory proprioceptive function includes identification of movement direction, degree or extent of movement, and some degree of discrimination of weight or force involved in the movement. Neistadt (2000) categorised proprioception and kinaesthesia as separate forms of discriminative sensation, defining proprioception as position in space and kinaesthesia as movement awareness. Carey (1995) refers to discrimination of limb position, direction and extent of limb movement and weight discrimination in the discussion of proprioceptive discriminatory sensation.

Sensory discrimination relies on cortical involvement and information from the broad associations areas of the cerebral cortex. Yekutiel (2000) proposed dividing sensory discrimination into three levels of complexity. The simplest level is localisation of the point where one was touched. The next level was slightly more complex and involved two-point discrimination. The most complex level was that of three-dimensional spatial awareness during passive movement and positioning. These discriminatory functions also closely related to functional use of the upper extremity such as grading the force used to hold a paper coffee cup and sustaining that pressure or squeezing toothpaste onto the toothbrush (Dannenbaum et al., 2002). Certainly the discriminatory functions are more complex than the mere detection of the sensation.

2.1.1.3. Perception.

The highest level of sensory processing is the integration of somatosensory information and memory to form a body image or perception and the awareness of
relationships with objects and the body or body parts. Both somatosensory and proprioceptive information is further refined and integrated in the cerebral cortex and results in tactual perception (Dijkerman & de Haan, 2007; Hsiao, 2008; Lederman & Klatzky, 2009; Loomis & Lederman, 1986).

Three types of perceptual functions arise from the processing of somatosensory and proprioceptive information: tactile perception, kinaesthetic perception, and haptic perception (Loomis and Lederman, 1986). Tactile perception is mediated solely by cutaneous sensory information while kinaesthetic perception is mediated solely by kinaesthetic/proprioceptive information. Haptic perception relies on information from both the somatosensory and proprioceptive systems and most tactual perception and tactually guided performance falls into this category (Dahiya & Valle, 2013; Loomis & Lederman, 1986).

Lederman and Klatzky (2009) describe two subsystems, the “what” and “where” channels, of tactual perception. The haptic perceptual “what” system (object recognition or stereo gnosis) integrates information about object temperature, texture, weight, and contour as well as proprioceptive information to form a mental picture and then match that with mental pictures of familiar objects (Fagot, Lacreuse, & Vauclair, 1997; Hsiao & Gomez-Ramirez, 2013; Loomis & Lederman, 1986; Zoltan, 1996).

The haptic perceptual “where” system is focused on the perception of spatial awareness of self and objects around one’s self and deals with perceptual guidance of action (Lederman & Klatzky, 2009). This system results in two functional types of haptic spatial localisation: 1) localisation of a stimulus applied to the body, and 2) localisation in the space external to the body (peri-personal space) of where a stimulus is being touched (Lederman & Klatzky, 2009). Considerable interactions and modulation occur between the visual processing systems and the
somatosensory processing systems that impact tactual perception, including both the “what” and “where” subsystems (Lederman & Klatzky, 2009).

2.1.2. Neurological systems underlying sensation.

Three distinct neurological systems (anterolateral system, dorsal column system and proprioceptive system) are responsible for sensory information being registered and transmitted and have been described by multiple authors (e.g. Bear, Connors, & Paradiso, 2001; Heimer, 1995; Jacobs & Lowe, 1999; Jones, 1999; Juliano & McLaughlin, 1999; Shepherd, 1994; Swenson, 2006). Each system carries information to the thalamus for basic detection and is then projected to the cerebral cortex for processing. A brief overview of these systems will be provided below to provide a framework for an appreciation of the mechanism of ULPSSI.

2.1.2.1. The Anterolateral System.

The anterolateral system is the main route for pain and temperature information transmission and involves two major pathways: the spinothalamic and spinoreticular pathways. The spinothalamic tract is illustrated in Figure 2.2. This system makes a secondary contribution to the dorsal column system for the transmission of light touch information though this is poorly localised (Jacobs & Lowe, 1999; Swenson, 2006). The redundancy of transmission of touch information allows for some appreciation of tactile information if the dorsal column system has been damaged.
2.1.2.2. The Dorsal Column System.

Information about touch, vibration, or joint position sense takes a distinctly different pathway to the cortex from that of pain and temperature (Juliano & McLaughlin, 1999; Swenson, 2006). This pathway is called the dorsal column medial lemniscal pathway, with the fasciculus gracilis carrying information from the lower extremities and fasciculus cuneatus carrying information from the upper extremities (See Figure 2.3). The information in dorsal column is ipsilateral until it reaches the dorsal column nuclei that lie at the spinal cord medulla junction and from there moves up through the pons to the thalamus and then projected through to the post-central gyrus of the cortex (Bear et al., 2001).
2.1.2.3. Proprioceptive System.

Proprioceptive information comes from receptors found within the muscles, joints and skin (Jones, 1999) and proprioception is perceived at both a conscious and unconscious level (Johnson, Babis, Soultanis, & Soucacos, 2008). Both conscious and unconscious proprioception are used for planning and executing complex movements while unconscious proprioception is used to maintain posture during sitting, standing and gait once these skills have been mastered (Johnson & Soucacos, 2012). Generally, impairments in the conscious proprioceptive system manifests as movement impairments, while impairments in the unconscious proprioceptive system manifests as postural deficits and ataxia (Johnson & Soucacos, 2012).
There are parallel pathways that serve conscious and unconscious proprioception. The conscious proprioception is mainly conveyed in the dorsal column medial lemniscus system. See Figure 2.3. The unconscious proprioception pathways carry sensory information from receptors in the limbs and trunk via peripheral nerves to the spinocerebellar tracts and then terminate on the ipsilateral cerebellum (Johnson & Soucacos, 2012). Afferent nerve fibres from muscle spindles and GTOs of the upper limb follow the path of the fibres in the dorsal column system and terminate on the lateral cuneate nucleus in the medulla. The cuneocerebellar tract is formed when collateral axons from the lateral cuneate nucleus pass through the ipsilateral inferior cerebellum peduncle to terminate in the spinocerebellum (Swenson, 2006). Animal studies have demonstrated this pathway contains limb position sense, weight discrimination and thresholds for detecting tactile information for the upper limb (Jones, 1999). See Figure 2.4.

Figure 2.4. The proprioception cerebellar pathways. (Used with permission © Swenson 2006).
2.1.2.4. Cortical structures and somatosensory processing.

The parietal lobe is the area of the cortex most responsible for somatosensory processing. The primary somatosensory cortex (S-I) occupies the post central gyrus and structurally has four distinct areas from the central sulcus back that are known as Brodmann’s areas 3a, 3b, 1 and 2. Area 3b in S-I appears to be primarily responsible for information related to texture, size and shape of an object. Projections from Area 3b to Area 1 involve texture information and to Area 2 size and shape. S-I is somatotopically organised as shown in Figure 2.5 and is very responsive to somatosensory stimuli but no other stimuli (Bear et al., 2001). Looking at the somatotopic map (Figure 2.5.), one observes large representations for the hand and mouth areas based on the density of sensory input received from that body part and demonstrates the relative importance of sensory input from each body part (Bear et al., 2001). The relative density and size of the area devoted to specific digits in the somatotopic map can be increased with training, revealing that cortical maps are plastic and dynamic, adjusting to the amount of sensory input (Bear et al., 2001; Swenson, 2006).

The secondary somatosensory cortex (S-II), positioned at the lower part of the parietal lobe under the temporal lobe and the posterior parietal cortex, sits just posterior to S-I also processes sensory information received from S-I and other thalamic nuclei (Bear et al., 2001). S-II. This information allows for the discrimination of stimulus properties such as locality and intensity which is further integrated to provide perceptual information related to size, shape, and spatial relations.
2.1.2.5. Cerebellar involvement in sensory processing.

The cerebellum has a significant role in voluntary movement coordination, balance and equilibrium, posture and muscle tone particularly due to sensory afferent information from the spinocerebellar and cuneocerebellar pathways (unconscious proprioception) (Bear et al., 2001; Johnson & Soucacos, 2012). The cerebellum also has an influence on inhibitory circuits in the S-I and may modulate receptive fields and hence optimise cutaneous discrimination (Restuccia et al., 2007). Restuccia et al. (2007) concluded the cerebellum plays a role in pre-attentive detection of novel or deviant somatosensory stimuli, though consistent sensory impairment has not demonstrated with cerebellar impairments. Restuccia et al. (2007) found reports of weight discrimination and kinaesthesia impairments as well as sensory dysgraphia resulting from cerebellar impairments. Further studies to understand the role the cerebellum plays and the impact of cerebellar lesions on somatosensory processing are needed.
2.1.3. Upper limb post-stroke sensory impairments.

This section focuses on the neurological impairments that underlie somatosensory impairments, and the most frequently observed ULPSSI starting first with impairments of the upper limb contralateral to the lesion and then discussing sensory impairments in the ipsilateral limb. This information provides the basic scientific knowledge that helps inform decisions regarding the management of ULPSSI.

2.1.3.1. Neurological lesions underlying sensory impairments.

Sensory impairments after stroke result from lesions anywhere from the brainstem to the cortical areas and are dependent on the extent of the damage and the area impacted (Yekutiel, 2000). Up to 20% of all strokes involve generally small lesions in the brainstem, thalamus, basal ganglia, pons, and internal capsule (Zorowitz, Baerga, & Cuccurullo, 2004). The results of a brainstem area stroke depends on the pathways that are disrupted but generally results in the loss of pain and temperature sensory information from the ipsilateral face and contralateral loss from the trunk and limbs. A lesion in the thalamus, basal ganglia or pons, generally termed a lacunar stroke, impairs all forms of sensation with particular emphasis on position sense and can also result in detection losses (Yekutiel, 2000). Pure sensory strokes result from thalamic lesions with lateral thalamic lesions being the most common cause of pure sensory strokes (Kim, 1992). Central post stroke pain syndrome (CPSPS) has been associated with thalamic lesions, where all incoming sensory information is interpreted as pain (Yekutiel, 2000). Further research has determined that CPSPS also results from lesions at any level of the pain pathway including lower brainstem, capsular, and subcortical levels (MacGowan et al., 1997). The perception of innocuous stimuli as pain is called allodynia and several forms have been described after stroke based on the type of stimulus that triggers pain e.g. tactile, movement or thermal allodynia (Bowsher, 2005). When surveying 122 survivors with Central Post-stroke Pain syndrome (CPSPS) Bowsher (2005) found that up to 71% had some type of allodynia.
The thalamo-cortical tract is formed by the final neuron in the pathways, passing through the narrow posterior limb of the internal capsule. Stroke survivors may experience loss of detection of sensory modalities such as the loss of pain, temperature, proprioception, and touch sensation especially if the primary sensory pathways are impaired as they pass through the internal capsule (Carey, 1995; Yekutiel, 2000). As the fibres head further up to the cortex they fan out so that lesions here are less focused and are more cortical in the nature of their impairment (Yekutiel, 2000).

The most frequent impairments following a somatosensory cortex lesion are sensory discrimination impairments (Yekutiel, 2000). Discrimination loss presents as impairments in one or more of the following areas: tactile localisation, two point discrimination, texture discrimination, size, shape and form appreciation, limb position discrimination, limb movement direction and extent discrimination, and weight discrimination (Carey, 1995). Tactual perception impairments, resulting from cortex lesions, can exist when the primary sensory abilities are intact. While stroke survivors may detect crude sensations of touch, hot and cold, and pain sufficiently to pass "standard neurological testing", the discriminatory and perceptual sensory functions needed for functional performance are inadequate. The somatosensory association cortex is located directly posterior to the somatosensory cortex in the superior parietal lobe and is essential for spatial relationships, body image and coordinating the body in space (Bear et al., 2001). Damage to the somatosensory association cortex results in difficulties such as tactile agnosia (difficulty with stereognosis), anosognosia (unawareness of deficits), tactile neglect, and limb apraxias (Carey, 1995; Swenson, 2006; Yekutiel, 2000). These tasks involve a complex integration of not only somatosensory information but also of information from the special senses.

Somatic sensitivity in each lateral half-body involves both cerebral hemispheres resulting in some residual ability following unilateral lesions (Carey, 1995). The lesions most commonly associated with sensory impairments in the contralateral
upper limb include: postcentral gyrus, postparietal cortex, prefrontal cortex, communication pathways between the prefrontal cortex and the postcentral gyrus. There appears to be a secondary somatosensory area in the cortex that is associated with ipsilateral processes and may be responsible for the ipsilateral impairments (Carey, 1995). Our current understanding of lesion location associated with post stroke sensory impairment is summarised in Table 2.1.

Tactile agnosia is a disorder of higher level integration and has been associated with loss of communication between the parietal areas. Anosognosia is found in 21% of stroke patients, particularly those with right sided lesions. Tactile neglect has been found to be not as common as visual neglect and defined by Gainotti (2010) as a failure to report, respond or orient to tactile stimuli in the contralesional half space. Additional changes to sensation may include dysesthesia (distortion of a sensation that is unpleasant when it normally would not be), paraesthesia (sensation of pricking, tingling or numbness with no apparent cause) or causalgia (intense burning pain or sensitivity to the slightest vibration or touch).

Another disorder that occurs after stroke is tactile extinction. Tactile extinction occurs when a stimulus on the affected side is detected less strongly or not detected at all when another stimulus is applied simultaneously to the least affected side. The stimulus may be either tactile or visual on either side to produce the effect (Yekutiel, 2000). Incidence has been reported at 50% of stroke patients at one month post stroke, with higher incidence in right-sided lesions versus left (Rose, Bakal, Fung, Farn & Weaver, 1994). This may be complicated by primary sensory detection deficits. Beversdorf, Hughes, and Heilman (2008) describe tactile extinction as resulting from errors in processing (possibly in SII) that occurred after afferent tactile stimuli were processed in SI in patients with right temporal lobe lesions. It is thought attentional impairments also play a significant role in tactile extinction (Beversdorf et al., 2008). Further research into tactile neglect and extinction is needed to fully understand these impairments and they will not be addressed in this thesis due to
the significant attentional components and complex nature of the disorder beyond somatosensory processing.

2.1.3.2. *Contralateral upper limb post stroke sensory impairments.*

While contralateral ULPPSI appear common, incidence reported in the literature varies (See Table 2.2). Sullivan and Hedman (2008), after reviewing multiple studies, reported the incidence of ULPSSI varying from 11 – 85%. Sullivan and Hedman (2008) reported that incidence was 25% if using a unimodal sensory assessment but multimodal assessment (Kim & Choi-Kwon, 1996) increased the incidence to 60%. Variability could be attributed to generally poorly defined terminology, interchangeable use of terminology, and methodological variability (variable body part testing, variety of assessment tools used, time since stroke etc.) (Kim & Choi-Kwon, 1996; Sullivan & Hedman, 2008; Yekutiel, 2000).

Not all of the sensory modalities or body surfaces are impacted equally by stroke and Connell et al. (2008) argue that each sensory modality is independent of the other and impacted at different frequencies. The following researchers measured sensory impairments in stroke survivors within the first 6 weeks after stroke. Tyson et al. (2008) noted that tactile discrimination impairments were more common than proprioceptive impairment when testing with the RASP on the upper and lower limbs of stroke survivors. Tactile impairments were more severe in the lower limbs than the upper limbs but no difference were found in the levels of proprioception impairment between the upper and lower limbs or between the levels of proprioception impairment between distal and proximal joints in the limbs (Tyson et al., 2008). Kim and Choi-Kwon (1996) also found that discriminatory impairments were more common than position sense impairments in the hands regardless of stroke location. Connell et al. (2008) found that proprioception and stereo gnosis impairments were more common than tactile impairments using the Nottingham Sensory Assessment to test several areas throughout the body. While it is argued that the predominant impairment after stroke is the “higher cortical” tactual perceptual and discriminatory sensory skills and these occur more frequently as described above, considerable
levels of upper limb detection impairments are observed (5-47%) (Connell, 2008; Rand et al., 2001; Tyson et al., 2008; Winward et al., 2007). Connell (2008) also found a significant relationship between stroke severity and severity of sensory impairment though with low variance suggesting that other factors were also involved. Tyson et al. (2008) found that stroke severity and weakness were significant factors influencing total sensation and tactile sensation impairments while weakness was a significant factor influencing proprioception impairments. Acerra (2007) found that although only 16% of stroke survivors reported sensory impairment the actual incidence identified by formal testing (von Frey filaments) was between 53 – 89% indicating that self-report of impairment is not accurate.

2.1.3.3. Ipsilateral ULPSSI.

While ULPSSI contra-lateral to the lesion are generally accepted, several researchers documented ULPSSI in the ipsilateral or “unimpaired” upper limb. The incidence of tactile sensory loss in the “unimpaired” side was found to be around 17% in 70 stroke survivors studied by Connell (2007), with 8 – 11% impairment of tactile localisation and 0 – 8% impairment in detection of light touch, pinprick, pressure, and temperature in the “unimpaired” shoulder, elbow, wrist and hand in acute stroke survivors. Desrosiers et al. (1996), in a study of 43 stroke survivors six months or more post stroke and 43 healthy matched adults, found significantly impaired kinaesthesia in the ipsilateral limb but did not find significantly impaired moving or static two point discrimination or touch pressure threshold. Kim & Choi-Kwon (1996), when studying a prospective cohort of 67 acute stroke survivors, found 44% impairment of point localisation and 18% impairment of stereo gnosis in the ipsilateral arm using modality specific measures. In a study of 25 chronic stroke patients with 25 healthy matched controls, Brasil-Neto and de Lima (2008) found that there was a significant impairment of moving light touch detection in the ipsilateral upper limb that may contribute to previously described clumsiness in that upper limb.

Carey (1995) suggests that due to the level of ipsilateral ULPSSI, this limb should not be used as the normal comparison in clinical evaluations. Stroke survivors may
also experience significant frustration trying to use their so called “unimpaired” limb for tasks due to the ULPSSI. This information would be important when planning interventions which may include compensatory use of the ipsilateral upper limb. It is unclear if occupational therapists are aware of the level of ipsilateral ULPSSI and the resulting clinical implications.

In summary the incidence of ULPSSI (either contralateral or ipsilateral) reported in the literature varies, and this is dependent on the type of modality being tested, body part tested, type of assessment used, and the methods of the study and difference in terminology. However, while there is variation regarding the incidence of ULPSSI in the literature, the levels reported still indicate that a significant proportion of stroke survivors experience ULPSSI and for this reason it is important to understand the impact of these impairments.

2.1.4. Impact of ULPSSI.

The somatosensory and proprioceptive systems are the means by which we adapt and relate to our environment and are essential for performing everyday occupations. ULPSSI have been associated with decreased hand function, rehabilitation outcomes and participation.

2.1.4.1. Impact on motor control and hand function.

Proprioceptive information is important when learning new motor tasks, performing fine, accurate movements, lifting heavy weights, reaching, and tracking movements (Carey, 1995). Several studies have addressed the impact of ULPSSI on motor control and hand function. Rand, Gottlieb, and Weiss (2001), in a study of 20 stroke survivors assessed every two weeks for the first six weeks after stroke, found negative relationships between proprioceptive abilities and upper extremity motor ability. Spontaneous hand use significantly decreases when cutaneous sensory input is impaired (Rand et al., 2001). Nowak et al., 2007 studied 16 stroke survivors at least one month after stroke and eight healthy controls as they completed grasping, lifting and reaching tasks. Impaired sensation, as measured by a composite of cutaneous and proprioceptive modalities in the hand, was found to be strongly
correlated with deficits related to timing, coordination and movement efficiency. In a correlational study of 10 stroke survivors and 14 healthy controls, Robertson and Jones (1994) reported elevated pressure thresholds on the thumb and index finger were associated with slower object recognition and stroke survivors had difficulty controlling the forces needed to grasp an object. Blennerhassett et al. (2007), when they studied 45 stroke survivors (36 – 182 days post-stroke) and 45 healthy controls, concluded that impaired surface friction discrimination contributes to altered timing and force adjustment in grip during pinch grip lift and hold tests.

In a prospective observational study of 66 stroke survivors for 18 months after stroke, Welmer et al. (2008) found that initially fine motor function in the impaired upper limb was strongly negatively associated with ULPSSI (proprioception and light touch) but over time this association decreased. They proposed that this may be due to increasing reliance on compensatory strategies such as vision and this may explain some of the conflicting findings. Welmer et al. (2008) also concluded that compensation for proprioception is more difficult than light touch and found a stronger negative association between proprioception and fine motor control.

While the relationship between motor control and sensation may appear clear, Wagner, Lang, Sahrmann ,Edwards, and Dromerick, (2007), in a correlational study of 39 stroke survivors at both acute (mean=8.7 days) and subacute (mean=108 days) phases and 10 healthy controls, found no significant relationship between light touch (monofilaments) and speed, accuracy and efficiency of upper limb movement as well as between joint position sense (using the standard neurological assessment) and speed, accuracy and efficiency of upper limb movements. Strength was the strongest, most consistent predictor of reaching performance variance. In this study, initially 59% and 33% of the subjects had sensory impairments, in light touch and joint position sense respectively.

Differences in study designs, measurement tools, and time since stroke of participants all possibly contribute to the different outcomes. However one of the
greatest difficulties with the research summarised here is that it only indicates whether or not an association is present, but cannot provide clear information about causality. That is, it is unclear if an association between sensation and motor control is found, whether and to what extent sensation is actually impacting on motor control, or whether there might be some other explanation. However, it appears that ULPSSI are associated with decreased hand function and use in acute stroke, though some compensatory strategies may be acquired that reduce this relationship in the subacute phase. Sensory impairments that are difficult to compensate for, such as proprioception and surface friction detection, continue to impact the timing and speed of movement and the ability to sustain appropriate forces while gripping an object.

2.1.4.2. Impact on activity, participation and functional outcomes.

Everyday tasks such as retrieving a coin from a pocket, maintaining grip on an object without crushing or dropping it, using cutlery, fastening buttons, and writing become difficult and often frustrating for stroke survivors due to ULPSSI (Carey, 1995). Desrosiers et al. (2003) studied 102 stroke survivors and found a significant small correlation \( r = .24 \) between ULPSSI (Fugl Meyer subtest) and participation restrictions or handicap (LIFE-H scale) and a significant medium correlation \( r = .31 \) between lower extremity sensory impairment scores and participation restrictions. (The strength of the correlations was based on the scale provided by Kielhofner (2006).) Tyson et al. (2008) studied 102 stroke survivors and found a significant moderate correlation \( r = .515 \) between sensation (RASP which measures detection and discrimination of proprioception and touch in both the upper and lower limbs) and functional mobility (Rivermead Mobility Index) and a significant moderate correlation \( r = .541 \) between sensation (overall RASP score) and independence in self-care tasks (Barthel Index). Proprioception (RASP subscale) independently significantly correlated to functional mobility \( r = .416 \) and to independence in self-care tasks \( r = .456 \) while tactile sensation (RASP subscale) was significantly moderately correlated to functional mobility \( r = .500 \) and independence in self-care tasks \( r = .518 \) (Tyson et al., 2008). In this study, the higher the scores on the RASP (which represented better overall sensory skills) were associated with better
functional mobility and greater independence in self-care tasks. Harris and Eng (2007) in a study stroke survivors found a significant moderate negative correlation between sensation (measured by using monofilaments on the back of the index finger throughout this study) and upper limb activity (Chedoke Arm and Hand Activity Inventory) \( r = -0.42 \), sensation and upper limb activity (Motor Activity Log) \( r = -0.43 \) and a very small significant negative correlation \( r = -0.09 \) between sensation and participation (Reintegration into Normal Living Index). In this study lower scores for sensation indicated higher levels of pressure detection and hence the negative correlation indicated that as sensation scores increased (lower levels of sensory pressure detection) scores on the other measures decreased. These studies demonstrate the importance of ULPSSI based on the impact on stroke survivors’ activity and participation.

Co-occurrence of sensory deficits with motor deficits after stroke has been shown to predict poor functional outcomes after stroke (Reding & Potes, 1988). A critical literature review by Carey (1995) identified seventeen studies that concluded stroke survivors with sensory as well as motor impairments have increased length of hospitalisation, lower levels of discharge home and increased mortality rates. While sensory impairments have been associated with decreased functional outcomes not all research has supported this finding. Carey (1995) also cited six studies that showed no association between functional status on discharge and sensory impairment. Rand et al. (2001) in a small study of stroke survivors found no significant association between proprioception and functional use of the upper limb, ADLs, or participation. Many factors may have contributed to the contrasting outcomes of these studies including: evaluating different sensory modality impairments (e.g. detection versus discrimination), pre-existing conditions, inclusion of participants with acute versus chronic impairments, and use of varying research designs. Carey (1995) concludes that several reviews support the association of somatosensory impairments with poorer rehabilitation outcomes and as a negative predictor of outcomes. Carey (1995), after an analysis of the literature, concluded that somatosensory discrimination impairments were more likely to be associated with poorer rehabilitation outcomes than somatosensory detection impairments. The
more recent studies cited above used both multimodal measures of sensory impairment (Fugl Meyer, RASP) and unimodal (measures of proprioception and monofilaments) and incorporated both detection and discriminatory somatosensation. Sullivan and Hedman (2008) reviewed a further eight studies and concluded that they supported the negative predictive influence of sensory impairments on hospital length of stay, discharge placement, recovery, and functional outcomes. These studies evaluated the impact of detection and discrimination as well as unimodal and multimodal sensory impairments.

Overall the majority of studies which have investigated the relationship between sensory impairments and outcomes related to function, activity, participation and other outcomes such as length of hospitalisation and discharge home, have demonstrated that sensory impairments are associated with poorer outcomes, although there are some exceptions to this. However this data comes largely from cross-sectional studies and therefore it is unclear whether there is some other explanation for these findings. It is therefore not possible to make conclusions about causality. While further research is needed to clarify the relationship between ULPSSI and their impact on activity participation and functional outcomes, what is currently known about the association between ULPSSI and activity, participation and functional outcomes can inform therapists’ CDM.

2.1.5. Recovery of ULPSSI.

Our understanding of stroke recovery has changed considerably over the last 10 years. This thesis section reviews our current knowledge related to general recovery after stroke, factors influencing stroke recovery, and finally ULPSSI recovery.

2.1.5.1. Defining recovery after stroke.

When discussing the recovery process from stroke one needs to define what is meant by recovery. Stroke causes significant impairments in many body functions for
example hemiparesis, ULPSSI, or visual field deficits. The resulting body function impairments impact the individual’s ability to complete valued or necessary activities and participate in previous roles hence resulting in disability. Recovery may be conceptualised at different levels. For example recovery may be defined as a reduction of impairment resulting from general neurological recovery (Teasall, Bayona, & Bitensky, 2008). Recovery may also be defined as an increased ability to perform activities and participate in valued roles and this functional or adaptive recovery is not necessarily dependent on impairment reduction. Functional recovery results from neurological recovery as well as compensation and may occur in the absence of neurological recovery, continuing for months after neurological recovery is complete (Teasall et al., 2008). While neurological recovery is dependent on the processes that result in brain repair and reorganisation, functional recovery is multifunctional and has the greatest potential to be impacted by rehabilitation (Teasall et al., 2008).

2.1.5.2. General course of recovery from stroke.

Neurological recovery after stroke is thought to be curvilinear. Time post stroke is the basic parameter. Neurologically, there is an apparent initial decline in function (over 22 – 30 % demonstrating an actual deterioration) and then a period of rapid improvement with most improvement noted in the initial 48 hours (Summers et al., 2009; Turton & Pomeroy, 2002). The first two weeks post-stroke demonstrates a significant and rapid period of neurological recovery often accounting for more than 50% of the total recovery experienced (Aichner, Adelwohrer, & Haring, 2002; Turton & Pomperoy, 2002). Most recovery, up to 90% of neurological return, occurs within the first three months after a stroke though continuing after this time at a slower rate, particularly for those with severe impairments (Johnston et al., 2002; Teasall et al., 2008; Turton & Pomperoy, 2002). A review by Teasall et al. (2008) concluded that most spontaneous recovery occurs in the first three to six months after stroke with up to five per cent continuing to recover for up to one year. There is significant survivor variability in this pattern. Recovery may plateau at any stage and only 10% of those with moderate to severe stroke are thought to experience full recovery (Teasall et al.,
Teasall et al. (2008) concluded that functional recovery may continue for months after neurological recovery has ceased.

2.1.5.3. **Neurophysiological basis for recovery.**

The following section describes our current understanding of brain recovery to provide a background for understanding somatosensory recovery. This information potentially could assist therapists' CDM regarding timing of interventions, understanding how potential interventions may impact recovery, and being able to support and provide information to the stroke survivor, potentially facilitating or improving the outcomes of the recovery. Teasall et al. (2008) describe two major categories of neurological processes that support recovery: local CNS processes and CNS reorganisation. There are three major processes occurring locally within hours to a few months after stroke that support neurological recovery; reducing oedema, reperfusion of the penumbra, and resolution of diaschisis (Krakauer, 2005; Teasall et al., 2008). The initial rapid recovery is thought to be explained by improved blood supply to the penumbral area and a decrease in oedema (Teasall et al., 2008; Turton & Pomperoy, 2002). Recovery that occurs past the first week after stroke is thought to be explained through reorganisation of spared neural connections (Turton & Pomeroy, 2002). The mechanisms involved in this reorganisation include synaptic remodelling, axonal growth, facilitation of alternative networks and unmasking of latent synapses and pathways (Carey, 1995; Cramer, Nelles, Benson, & Kaplan, 1997; Johansson, 2000; Krakauer, 2005).

2.1.5.4. **Sensory recovery.**

While numerous studies describe the course of motor recovery, there have only been a few studies describing ULPSSI recovery which may potentially be different. Carey et al. (2002a) in an fMRI case study described touch discrimination as initially impaired but then recovered at three months and was maintained at six months. Good recovery was associated with return of activation of the ipsilateral S-I and contralesional thalamic activation (Carey et al., 2011). Winward et al. (2007) followed 18 stroke survivors in two groups (acute and subacute) for six months and found
marked individual variations. Winward et al. (2007) observed that while stroke survivors recovered proprioception the most, no stroke survivor in their study achieved full somatosensory recovery. Connell et al. (2008) followed 70 stroke survivors for six months and described significant recovery of upper limb tactile sensation and stereo gnosis four months after stroke and significant recovery of proprioception between four and six months after stroke. Recovery may have continued beyond six months especially for proprioception but this is unknown as the study ended at six months. Julkenan et al. (2005) followed five stroke survivors’ recovery using somatosensory evoked potentials and quantitative sensory testing of tactile, vibratory, and thermal sensory modalities and reported most recovery occurred within the first three months but warmth, two-point discrimination, and vibration continued to demonstrate clinically significant improvement up to 12 months after stroke when the study concluded. There are some methodological concerns with this study including varying times for testing that may impact comparing the results between subjects and studies as well as use of convenience sample of consecutive patients at one centre. When describing the return of hand function in the 18 months after stroke in a prospective observational study of 66 consecutive patients, Welmer et al (2008) also recorded somatosensory functions of light touch and proprioception (Thumb Localising Test). They noted improvements in these sensory modalities in the first three months, with the numbers with normal sensory testing results increasing, and then a slight deterioration from the 3 month numbers in the number with normal sensation at the 18 months reassessment. In summary, the potential for recovery in ULPSSI has been demonstrated in the first six months post stroke but there may be the potential to see further ULPSSI recovery after six months but this is unclear and further studies are needed to support this.

Connell et al. (2008) found that stroke severity accounted for 21 to 41% of the variance in severity of initial sensory impairment and that initial sensory impairment was significantly related to sensory ability at six months post stroke (46 to 71% of variance). Upper limb motor performance was negatively associated with stereo gnosis scores (even though the examiner may move the impaired hand over the object surface in the NSA) (Connell et al., 2008). Connell et al. (2008) also reported
that initial proprioception and initial upper limb tactile impairment were associated with proprioception impairment at six months. Tyson et al. (2008), in a study of 102 stroke survivors, concluded that the degree of upper limb weakness and degree of stroke severity significantly influenced ULPSSI. Tyson et al. (2008) did not find any association with sensory loss and demographic factors and Connell (2007) did not find a relationship between age and somatosensory impairment. Connell (2007) did find a significant relationship between total ULPSSI, proprioception and stereo gnosis impairment scores and stroke type, urinary incontinence and inattention but not between swallowing problems, visual field deficits (except stereo gnosis), ataxia, aphasia, and dysarthria.

In summary, there is evidence that ULPSSI demonstrates significant recovery in the first three months after stroke, especially tactile impairments, while there is also evidence that potentially this recovery, especially in areas of proprioception, two-point discrimination, and vibration, may continue up to or beyond 12 months. Recovery after this may be possible but further studies are needed. The severity of the stroke and initial impairments were the strongest factors associated with sensory recovery. Given the impact of ULPSSI and the potential for recovery it is important to understand how these impairments are managed and if and how the understanding of ULPSSI recovery impacts clinical decision-making regarding ULPSSI management.

2.2. Management of ULPSSI

This thesis focuses specifically on the management of ULPSSI by occupational therapists. Occupational therapists are key members of the team providing rehabilitation services to stroke survivors and often focus on increasing participation through encouraging independence in basic self-care tasks and improving upper limb functional use (Richards et al., 2005). Given the relatively common occurrence of ULPSSI (Sullivan & Hedman, 2008) and the impact on upper limb motor control (Blennerhassett et al., 2007; Carey, 1995) and functional outcomes after stroke (Tyson et al., 2008), effective ULPSSI management is essential. This section briefly
describes ULPSSI measurement and treatment and considers the status of research and clinical guidelines regarding ULPSSI interventions relevant to occupational therapy practice. The studies considered in this Chapter are limited to those which were available prior to 2010, when the procedures for the systematic review, qualitative studies and survey for this thesis were undertaken. Further relevant studies published since that time were considered in preparation for the final study (Chapter 8) and in the overall thesis discussion.

### 2.2.1. Measuring sensory impairments.

The initial steps of CDM involve gathering data from multiple sources and interpreting that data (Smith et al., 2008). One key source of data utilised by therapists is data obtained from assessment tools. Assessment tools can also be used to monitor or determine the effectiveness of the intervention being used. This again provides essential information for CDM. The reliability and validity of the assessment tools used impacts the accuracy of the data obtained which in turn impacts the outcomes of CDM. To improve the quality of data available for CDM, therapists should adopt the most reliable and valid assessment tools available.

The tools or techniques used to identify and measure a variable such as upper limb sensation are generally referred to as assessments (Kucukdeveci, Tennant, Grimby, & Franchignoni, 2011). When associated with measurement of a change or outcome as a result of an intervention or process the assessment has the potential to become an outcome measure (Kucukdeveci, Tennant, Grimby, & Franchignoni, 2011). Outcome measures also evaluate the functional outcomes of the intervention and may be broader in scope than just measurement of the specific client factor initially identified, for example also measuring participation and function (Agency for Healthcare Research, 2000). Having reliable and valid measures is important both for CDM and evidence based practice, where one evaluates the outcomes of the intervention. This section will review the current measures available that focus on upper limb sensation.
Four primary detection modalities of skin sensation are generally tested in the “standard neurological evaluation”: touch, pain, heat and cold. To these original tests are often added vibration sense, position sense, movement sense, and stereo gnosis (Carey, 1995; Yekutiel, 2000). While this is the most frequently utilised sensory assessment, light touch and proprioception are the most commonly used components (Dannenbaum et al., 2002; Sullivan & Hedman, 2008). These tests lack reliability and validity, are largely subjective and lack standardised protocols (Carey, 1995; Lincoln et al., 1991; Winward et al., 1999; Yekutiel, 2000; Sullivan & Hedman, 2008) and have been noted to be particularly unreliable when used with stroke survivors (Lincoln et al., 1991; Moberg, 1964; Tomasello et al., 1982; Wade et al., 1985). For instance, Kim and Choi-Kwon (1996) found that discriminative sensation remained in only 3 of 25 stroke patients who were reported as having no sensory impairment based on the “standard neurological evaluation” sensory tests. Some of the concerns with “standard neurological evaluation” are the use gross scales such as “normal” “impaired” or “absent” which do not identify the types of impairments frequently seen after stroke (Bohannan, 2003; Wade, 1992). There are slight nuances to the methodology used in the “standard neurological evaluation” depending on the text or reference source used, but frequently no clear, structured, or standardised methodology or scoring criteria are provided. These assessments are often insensitive or inaccurate and there are no defined criterion of abnormality for the “standard neurological evaluation” (Carey et al., 2002c).

As a result there have been attempts to develop measurement tools that are objective, reliable and valid, incorporating clinician needs and clinical utility (Dannenbaum et al., 2002). Two multimodal sensory measures have been developed addressing sensation in the trunk, upper and lower limbs. The Nottingham Sensory Assessment (NSA) is a multimodal and broad sensory measure which appears to have good psychometric properties and relationship to functional hand use, though not for all tasks (Connell, 2007; Gaubert & Mockett, 2000). The first version of the NSA evaluated light touch, temperature, pin prick, pressure, two point discrimination, bilateral simultaneous touch and proprioception on face, upper limbs,
lower limbs and trunk as well as stereo gnosis (Lincoln, Crow, Jackson et al., 1991).  
A revision by Lincoln, Jackson, and Adams (1998) was undertaken due to the concerns about time to administer the test and the NSA was shortened by reducing the number of areas tested and testing of the unimpaired limbs. Lincoln et al. (1991) found excellent intra-rater reliability but poor inter-rater reliability. With the revisions, Lincoln et al. (1998) found acceptable inter-rater reliability for 12/86 items with the most reliable being light touch and pressure scales and the least reliable being pinprick and temperature scales. The 2007 revision posted on the University of Nottingham website no longer contains the two point discrimination component (University of Nottingham, 2007), and also allows for use of other terms for the flannel, glass, and biro but not alternatives for the British money. The directions are available free with adequate details for replication. Stolk-Hornsveld, Crow, Hendriks, van der Baan, and Harmeling-van del Wel (2006) published the Erasmus MC modifications of the revised NSA. This version increased standardisation and uniform scoring methods as well as removing the temperature test and adding a sharp-blunt discrimination test. Intra-rater reliability ($r = .58 - 1.0$) and inter-rater reliability ($r = .46 - 1.0$) on the tactile sensation, sharp dull discrimination, and proprioception items were found to be good to excellent. The two point discrimination had poor to good intra-rater ($r = .11 - 0.63$) and inter-rater reliability ($r = .10 - 0.66$). Due to the availability, reliability, and validity, the NSA deserves further consideration for clinical use, particularly the Erasmus MC Modifications to the revised NSA.

The Rivermead Assessment of Somatosensory Performance (RASP) is multimodal and tests sharp dull discrimination, surface pressure touch, surface localisation, joint movement and movement direction discrimination, bilateral touch discrimination and two-point discrimination in 10 different body areas (Winward et al., 1999). Good intra-rater ($r = .92$) and inter-rater ($r = .92$) reliability for all subtests and significant correlations with motor function (MOTORICITY INDEX; with proprioception movement $r = .31$ & with proprioception direction $r = .36$), independence in ADL tasks (Barthel INDEX; with proprioception movement $r = .35$ & with proprioception direction $r = .41$) and mobility (Rivermead Motor Assessment; with proprioception direction $r = .32$)
have been established but the equipment needed for the RASP is no longer commercially available (Tyson et al., 2008; Winward et al., 2002).

There are several easily available tests that evaluate elements of proprioception. The Thumb Localisation Test and Finger Shift Test evaluate awareness of thumb position and detection of finger movement and are easily replicable and have good clinical utility (Dannenbaum & Jones, 1993). The Thumb Localisation Test has both modest inter-rater reliability ($r = .54$, $p < .05$) and good predictive values for functional outcomes after stroke (Leo & Soderberg, 1981; Prescott et al., 1982; Smith et al., 1983). Validity as a test for limb localisation and clinical utility has been established by Hirayama, Fukutake, and Kawamura (1999) in a cross-sectional study of 221 persons after stroke.

The other easily available measure is the Fugl-Meyer sensory subscales. The Fugl-Meyer sensory subscale evaluates light touch and joint position sense detection. Duncan, Propst, and Nelson (1983), in a study of 19 chronic stroke patients, found excellent inter-rater reliability ($r = .95-.96$) of the sensory subscale of the Fugl-Meyer Assessment (FMA). Lin, Hsueh, Sheu, and Hsieh (2004) examined the psychometric properties of the FMA in stroke patients and found that inter-rater reliability ($r = .93$) and internal consistency ($r = .94-.98$) for the whole scale were excellent. The inter-rater reliability for the light touch was low to moderate ($r = .30 – .55$). There was also low to moderate validity ($r = .29 – .53$), and low to moderate responsiveness ($r = .27 – .67$) at various stages of stroke recovery. Lin et al. (2004) also found there was a ceiling effect for the sensory subscale and recommended not using this subscale for stroke survivors. Sullivan and Hedman (2008) conclude that the psychometric factors do not support clinical use. Given the low to moderate responsiveness, the ceiling effects, low to moderate validity and reliability for the light touch component, it would be recommended that therapists do not use the FMA-sensory subscale until further studies demonstrating improved psychometric properties with stroke survivors have been completed.
Another measure of joint position sense found in the literature is the Wrist Position Test (Carey, Matyas, & Oke, 2002). While this measure has good psychometrics and discriminatory abilities, it requires specialised equipment that is not currently available to the clinician (Carey, Matyas, & Oke, 2002; Carey, Oke, & Matyas, 1996).

Other measurement tools have been developed that evaluate components of haptic perception. The Byl-Cheney-Boczai Sensory Discriminator (BCB) was developed to evaluate stereo gnosis and has promising psychometrics and clinical utility in stroke survivors as well as providing adequate details to allow for replication (Byl, Leano, & Cheney, 2002). The BCB involves having the participant identify patterns, with vision occluded, on 20 blocks (13 mm x 13 mm) with 6 mm pins (BCBI) and in a second version (BCBII), 2 mm pins were used and match with a picture chart. This assessment takes approximately 15 minutes to administer. While the Hand Active Sensation Test (HASTe) evaluates weight and texture discrimination using everyday surfaces and was found to have good psychometric properties there is no commercially available version or adequate details for replication (Williams, Basso, Case-Smith, & Nichols-Larsen, 2006).

Tactile acuity grids or grating orientation tasks have been proposed in the field of hand surgery as an alternative measure of sensory discriminatory function and haptic sensation (Warwick et al., 2009). These tests involve a series of ridged surfaces with each level of the test having the ridges or grates at different widths apart. Commercial development of two tests in this area has been undertaken and JVP Tactile Acuity Domes and Med-Core Tactile Acuity Cube are examples. Results from these tests have been associated with manual dexterity (Tremblay, Wong, Sanderson, & Coté, 2003) but at this time no studies in stroke populations had been undertaken. Further testing of the reliability and validity of these assessments in the stroke population is warranted. The AsTex is a similar tool developed as a quick screen for ULPSSI and evaluates texture discrimination which was found to be associated with prehension and grasp (Miller et al., 2009). Miller et al. (2009) concluded the AsTex was a responsive, reliable and clinically useful tool for
measuring ULPSSI, demonstrating excellent intra-rater reliability in both normal and stroke populations. This measurement tool is only available in prototype at this time. Carey, Oke, and Matyas (1997) and Carey, Matyas, and Oke (2002) used a similar test in stroke patients called the Tactile Discrimination Test. This tool was developed based on therapists input and the subject matches eight surfaces with comparison set using their preferred finger and vision occluded. Carey, Oke, and Matyas (1997) found high intra-rater reliability and good discrimination between impairment and no impairment. This study also established normative data for the Tactile Discrimination Test. This test is currently under commercial development but not available at this time. These tools may provide future measurement options for therapist working with patients with ULPSSI.

While the use of monofilaments, which measure touch threshold, have been found reliable in other diagnostic groups and identified impairments in stroke survivors (Bell-Krotoski, Fess, Figarola, & Hiltz, 1995; Mawdsley et al., 2004), Carey (1995) concluded that there was poor association between the results and functional hand use. Further research is recommended before the use of the monofilaments for testing in stroke survivors. Addressing the concern that stroke survivors experience multiple impairments including attention, memory and language communication impairments, Korner-Bitensky, Kehayia et al. (2006) successfully evaluated the efficacy of using a Visual Analogue Scale (VAS) to differentiate between two different temperature stimuli in stroke survivors with and without aphasia. While further research is indicated, the VAS and monofilaments may provide future measurement options for therapists working with stroke survivors with ULPSSI.

While there are many different ULPSSI measurement tools available or in development, each with varying psychometric properties and level of clinical utility, no standardisation or “gold standard” in ULPSSI testing has emerged (Dannenbaum et al., 2002; Tyson et al., 2008). This potentially creates difficulty for therapists identifying impairments and outcomes, when interpreting the results of studies, and communicating with other professionals. There is a need to develop measures that
focus on the key ULPSSI impacting upper extremity functional use. For example, there are few tests that address discriminatory and higher level ULPSSI yet it appears that these deficits directly impact grip and functional control (Blennerhassett et al., 2007). Clinicians should carefully consider not only the psychometric properties of the measures and their clinical utility but also the likelihood that they will provide clinically useful information.

Completing a valid and reliable ULPSSI assessment is essential for developing an effective management plan as well as evaluating the outcomes of therapy and hence is important for occupational therapists’ CDM. Based on the psychometric information summarised above, availability and clinical utility, the NSA is recommended when a comprehensive measure is required. The Thumb Localisation Test also has good clinical utility, validity, reliability and predictive values, however it is limited in its focus though would provide some information on tactual perception not offered with the NSA (Hirayama, Fukutake, & Kawamura, 1999; Leo & Soderberg, 1981; Prescott et al., 1982; Smith et al., 1983). These measures, used together, cover a range of somatosensory modalities but have limited ability to evaluate the skills of grading force and grip as well as surface friction which have been associated with higher functional hand use impairments after stroke.

2.2.2. Interventions for ULPSSI.

The Occupational Therapy Practice Framework defines the intervention process as the skilled actions taken by the therapist “in collaboration with the client to facilitate engagement in occupation related to health and participation” (AOTA, 2008, p652). The Occupational Therapy Practice framework outlines the occupational therapy intervention plan as including objective, measurable goals, defining the intervention approach or approaches, and the service delivery mechanisms (AOTA, 2008). The intervention approaches listed include remediation and compensatory approaches, specifically “create or promote, establish or restore, maintain, modify, and prevent” (AOTA, 2008, p656). Many interventions utilised with stroke survivors are complex
and more than one approach may be employed either concurrently or consecutively. When providing rehabilitation for people with ULPSSI, occupational therapists need to decide the intervention approach or approaches to use.

This thesis section describes approaches to ULPSSI intervention, that are not necessarily limited to those provided by occupational therapists, and then summarises the recommendations from systematic reviews published up to 2010 (when this thesis work was being undertaken) to inform the need for future systematic reviews and further research.

### 2.2.2.1. Intervention approaches for ULPSSI.

Bentzel (2008), in the classic occupational therapy text “Occupational Therapy for Physical Dysfunction”, recommended that therapists focus on remedial and educational interventions for ULPSSI while concluding that the evidence was limited and the techniques less well defined for interventions for ULPSSI when compared to interventions for sensory impairments following peripheral nerve injury. In “Occupational Therapy Practice Skills for Physical Dysfunction”, a text commonly used in American occupational therapy programs, Cooper and Pressman Abrams (2006) recommended both compensatory and remedial approaches, as well as education, when addressing ULPSSI in a case study they provided. Hence it appears that remediation, compensation, and education are commonly recommended intervention approaches for ULPSSI management provided by occupational therapists. These approaches will be first described and then the evidence to supporting specific interventions strategies and approaches will be reviewed.

#### 2.2.2.1.1. Remediation.

The Occupational Therapy Practice Framework (AOTA, 2014) describes remediation as an intervention approach designed to restore or improve an impaired skill or ability. Generally, two strategies have been described in the literature for ULPSSI
remediation. The first is a sensory bombardment/exposure and the other is a graded sensory retraining strategy. Both are explained below.

2.2.2.1.1. Non-specific repeated sensory exposure

Sensory bombardment/exposure strategies deliberately provides sensory stimulation using multiple forms of sensory input graded from coarse to fine, with the aim of activating the senses. Current articles investigating this strategy explain that the rationale is to encourage plasticity processes in the brain (Dinse, 2012). Although it may actively involve the client, it is also possible for this strategy to be used without attention from the client or without use of reinforcement by the therapist (Dinse, 2012; Hodzic, Veit, Karim, Erb, & Godde, 2004). De Jersey (1979) proposed a strategy focused on sensory bombardment involving stimulation of touch, pressure, temperature, joint receptors and muscle spindles in bursts one after each other for six minutes using icing, vibration, pounding and rubbing with towelling. Other modalities have included electrical stimulation (Smith, Dinse, Kalisch, Johnson, & Walker-Batson, 2009), pneumatic compression (Cambier, de Corte, Danneels, & Witvrouw, 2003) and thermal stimulation (Bohls & McIntyre, 2005). Sensory bombardment has been recommended in occupational therapy textbooks. For example, Iyer and Pedretti (2001) discussed remedial treatments including the use of sensory bombardment involving as many senses as possible as well as weight bearing, which is thought to increase proprioceptive input. In Radomski’s and Latham Trombly’s classic text “Occupational Therapy for Physical Dysfunction”, Woodson (2008) recommended providing stimulation to encourage the patient to use the involved hand. It was suggested that this be provided by the use of different textures on weight bearing surfaces and contact surfaces with objects to increase the sensory input (Woodson, 2008).

Another form of sensory exposure is to provide sensory input through movement. The Neuro-Developmental Treatment/Bobath model has been the most common intervention frame of reference used to treat stroke patients (Natarajan et al., 2008). In the Bobath based text “Occupational Therapy in the Treatment of Adult
Hemiplegia”, Eggers (1983) recommended that sensory impairments should not be treated separately from motor impairments, rather that sensory treatments be integrated with neurodevelopmental treatment techniques. Based on this frame of reference, treating sensory impairments should not be given priority until certain arm and hand functions are possible and never at the expense of treating motor impairments (Eggers, 1983). In her text “Steps to Follow: A Guide for the Treatment of Adult Hemiplegia”, Davies (1993) proposed that abnormal sensation leads to abnormal movement patterns and tone, perpetuating this pattern by providing further abnormal sensory input. Treatment recommendations focused on providing and facilitating “normal” movement to provide “normal” sensory input, which they titled “sensory education”. Ryerson and Levit’s (1997) “Functional Movement Re-education” expanded further on this concept proposing this form of “sensory education” is the first stage of movement re-education. Passive movements are used to provide sensory information and teach the stroke survivor about the movement, establish kinaesthetic perception and muscle memory. Passive movement through the “normal” movement is then thought to provide “normal” sensory input providing cues to the somatosensory system so that normal sensory input for muscle movement is learnt (Ryerson & Levit, 1997).

2.2.2.1.2. Sensory retraining.

Carey (1995) critiqued the sensory bombardment/exposure approaches suggesting they were based on weak study methodologies, utilising a passive approach, excessive stimuli, and lack of meaningful stimuli, and contrasted these approaches with current perceptual learning models that propose that active attention and meaningful tasks result in improved learning. These more active approaches focus on sensory retraining and incorporated principles of neuroplasticity and learning into their methods. Historically, Vinograd, Taylor and Grossman (1962) proposed retraining of the post stroke hand that involved placing objects of different weight, shapes and texture in the hand and retraining the stroke survivor with and without the use of vision. Carey, Matyas, and Oke (1993) and Carey (1995) proposed a method of sensory re-education that focused on tactile discrimination and proprioception due to their common impairment after stroke. The sensory re-
education approach included principles of repeated presentation of targeted discrimination tasks, graded stimuli, active exploration of the stimuli with vision occluded, and use of anticipation and feedback. Generalisation tasks were then added to the program to improve generalisation of the skills (Carey, 1995).

Dannenbaum and Dykes (1998) proposed an approach to sensory retraining based on four principles: firstly that cortical representation of the body can be modified by sensory input on important sensory surfaces, secondly that there are modality specific cortical maps, thirdly that there is an unmasking of previously suppressed input after trauma or injury, and finally that reorganisation of the cortex is affected by attention and motivation. Dannenbaum and Dykes (1998) then devised a graded, targeted, functional program of sensory re-education based on these principles. Similarly, Yekutiel (2000) offered clinical guidelines for post-stroke sensory re-education of the hand that included a sequential sensory re-education approach focused on specific graded sensory retraining tasks, active learning and participation by the stroke survivor.

Sensory re-education is also proposed as a means to reduce learned non-use of the impaired upper limb. Bentzel (2008) called for incorporating meaningful sensory and motor experiences into early stroke rehabilitation especially incorporating the impaired limb in bimanual tasks based on the work of Carr and Shepherd (2000). Bentzel (2008) also recommend a prerequisite level of tactile detection and basic motor skills for sensory re-education based on the work by Dannenbaum and Jones (1993). Where the patient did not have sensory detection skills early training with electrical stimulation was recommended initially with vision, then with vision occluded, and then progressing to textured moving stimuli. As the survivor progressed Bentzel (2008) suggested incorporating activities used by Yekutiel and Guttmann (1993) and Yekutiel (2000) such as graph aesthesia training, thumb localisation training, weight, shape and texture discrimination tasks.
2.2.2.1.2. Compensation.

The Occupational Therapy Practice Framework (AOTA, 2014) describes a compensatory approach as one that focuses on supporting performance by altering the activity demands or environmental context so that the client can perform the tasks when they have specific impairments without directly focusing on changing the level of impairment. When addressing sensory impairments in general (not specific to, but including stroke) Bentzel (2008) recommended utilising compensatory techniques to prevent injury acknowledging that there is only anecdotal evidence and widespread acceptance to support use of compensatory strategies. These compensatory strategies included reliance on other senses, frequent position changes, avoiding high pressure tasks, increased awareness of sources of danger such as hot coffee cups, avoidance of repetitive motions and friction, and good skin care (Bentzel, 2008). Compensatory techniques emphasised safety and positioning of the upper limb focused on increasing independence in self-care tasks (Edmans et al. 2001). Iyer and Pedretti (2001) also recommended a compensatory intervention approach focused on safety and increasing independence by use of the unimpaired arm, use of adaptive equipment or techniques, and positioning as well as education of the survivor and caregivers.

2.2.2.1.3. Education.

Education has an important role to play in the management of all health conditions. For people who have ULPSSI the literature indicates that education should be focused on helping the survivor understand what has happened to them, making the survivor aware of the sensory impairment and encouraging use of the impaired limb to provide sensory feedback (Edmans et al., 2001). Education has also been focused on stroke survivor and caregiver training for safety and positioning (Iyer & Pedretti, 2001). Bentzel (2008) recommended education for sensory impairments that covered safety, protection and regular skin inspection as well as the sources of injury for skin with loss of protective sensation. However Bentzel (2008) extrapolated evidence supporting the effectiveness of education about sensory impairments in stroke survivors from its use with diabetic patients.
Although there is no evidence available specifically guiding the use of education for ULPSSI, evidence clearly exists for the use of education in general for people post stroke. A Cochrane systematic review of 11 RCTs by Smith, Forster and Young (2009) concluded that in general, education was effective in increasing stroke survivors' and their caregivers' knowledge and patient satisfaction and improving depression, with more active educational strategies resulting in greater positive effect on patient anxiety and depression than passive strategies. Smith et al. (2009) concluded that there was inadequate evidence to recommend specific educational strategies although strategies that actively involve stroke survivor and or caregivers are more likely to be effective.

2.2.2.2. Status of research about the effectiveness of interventions for ULPSSI.

When deciding on interventions to use, evidence based practice (EBP) encourages clinicians to base that decision on the best available evidence as well as the client preference and clinician expertise (Sackett et al., 2000). There is increasing research being undertaken regarding ULPSSI and developing a sense of the current status of research regarding the effectiveness of interventions for ULPSSI will help support therapists' CDM. Typically, the status of research is reviewed through clinical practice guidelines, literature reviews and systematic reviews, each of which will be considered here.

Clinical practice guidelines can provide a summary of the status of research related to specific clinical problems or populations. They have been defined as “systematically developed statements to assist health professionals and patient decisions about appropriate health care for specific circumstances” (Field & Lohr, 1992, pp 2). The recommendations of the clinical practice guidelines available at the time of the commencement of data collection for this thesis (2008 – 2009) are summarised below. While the American Heart Association and American Stroke
Association endorsed guidelines (Duncan, Zorowitz, Bates, Choi, Glasberg, Graham, Katz, Lamberty, & Reker, 2005) acknowledged the presence of ULPSSI and recommended therapists use standardised measurement tools when evaluating stroke patients, there was no comment on evidence for interventions for ULPSSI or specific recommendations for ULPSSI measures. Similarly, the Canadian Best Practice Recommendations for Stroke Care (Canadian Stroke Network and Heart and Stroke Foundation of Canada, 2006) recommended therapists utilise standardised measurement tools, focused on motor impairments and shoulder pain when addressing the upper limb impairments and provided no recommendations for addressing ULPSSI.

Sensory specific training (Carey, Matyas, & Oke, 1993; Yekutiel & Gutta, 1993; Byl et al., 2003) sensory-related training (Carey & Matyas, 2000), and cutaneous electrical stimulation (Peurala, Pitkanen, Sivenius, & Tarkka, 2002) were recommended by the Australian National Stroke Foundation (2005) Clinical Guidelines for Stroke Rehabilitation and Recovery based on five studies identified as Level III and IV evidence. The Royal College of Physician's (2004) clinical guidelines focused on pain in the sensory impairment recommendations although acknowledging that there is ongoing research on the impact of electrical stimulation on ULPSSI. The next edition of clinical guidelines from the Royal College of Physician's (2008) recommended that all stroke survivors should be asked about ULPSSI, and where necessary a formal sensory assessment should be undertaken, with the NSA specifically recommended. Where ULPSSI are present, the Royal College of Physicians (2008) recommended that the stroke survivor be educated regarding safety concerns and techniques to avoid injury to the upper limb. Intense sensory re-education was recommended only in the context of research trials.

Literature reviews are another source of information therapists may draw on for CDM. Therefore a brief summary of literature reviews examining interventions for ULPSSI is presented here. A literature review by Carey (1995) that included seven studies of varying types (though no RCTs), but very few incorporated a control group
and most had potentially a high risk of bias. The interventions covered were sensory exposure or bombardment and graded sensory retraining programs. The theoretical rationale guiding the earlier intervention studies using sensory exposure or bombardment often was not supported by the current understanding of neurological recovery and retraining (Carey, 1995). However Carey (1995) concluded that there is emerging evidence for a graded sensory retraining program. Several RCTs demonstrating some effectiveness for widely ranging interventions such as thermal stimulation (Chen et al., 2005), sensory re-education (Byl et al., 2003), sensorimotor training (Feys et al., 1998), and intermittent pneumatic stimulation (Cambier et al., 2003) were reviewed by Connell (2007) who found that most of the studies have small sample sizes, and were methodologically flawed. Consequently the author noted that it was difficult to reach conclusions on their effectiveness and further research was needed. In their literature review, Sullivan and Hedman (2008) included similar RCTs (Byl et al., 2003; Cambier et al., 2003) addressing ULPSSI as Connell (2007) but also several that addressed impairments in the lower limb and looked at outcomes that incorporated motor recovery after sensory stimulation. Sullivan and Hedman (2008) determined that there was emerging evidence for interventions that deliver sensory input. However the overall picture about the effects of interventions is unclear due to the variation in the interventions tested and the poor quality of the prior studies (Carey, 1995; Connell, 2007; Sullivan & Hedman, 2008).

Although literature reviews provide a good introduction to the topic, they are not necessarily comprehensive and may not provide a clear picture of the state of evidence for ULPSSI interventions. Instead, systematic reviews incorporating comprehensive and reproducible methods provide a concise summary of the available research evidence (Bennett, Leicht Doyle, & O’Connor, 2010). Systematic reviews use clearly structured methods to find, select, and appraise the methodological quality of individual studies, and then synthesise their results in order to provide an understanding of the status of existing research (Crowther & Cook, 2007; South African Cochrane Centre, 2011). A brief summary of systematic reviews
addressing post stroke sensory impairments existing at the time this thesis commenced is provided here.

Only one systematic review (Schabrun & Hiller, 2009) specifically addressed sensory impairments while two reviews (Ma & Trombly, 2002; Steultjens et al., 2003) broadly focusing on interventions for stroke survivors mention interventions for somatosensory impairments. Ma and Trombly (2002) completed a systematic review of the remediation of stroke related impairments and while they titled a subsection of the review sensorimotor impairments, the topics addressed were focused on motor impairments (endurance, range of motion and strength, organization of movement, and tone) with no mention of somatosensory impairments. In a systematic review of occupational therapy interventions for stroke, Steultjens et al. (2003) reviewed interventions for sensory-motor impairments and identified two RCTs that addressed ULPSSI (Feys et al., 1998; Jongbled, Stacey & Brighton, 1989). No details were provided about the interventions within the review and only outcome measures related to ADL performance and arm function were considered.

A systematic review by Schabrun and Hillier (2009) focused specifically on upper and lower limb sensory impairments after stroke and concluded there was some limited evidence for passive interventions, such as electrical stimulation. The systematic review included 14 studies with outcome measures that addressed motor function, spasticity and gait as well as sensory impairments. The study designs included in this review ranged from five RCTs to lower level pseudo randomised trials, comparative studies and case series designs. While this systematic review had nine studies (only one RCT) that addressed the upper limb, the studies did not primarily address sensory changes, and included non-randomised studies that the authors indicated had methodological concerns. One of the difficulties faced by systematic reviews which include non-RCTs is that the conclusions may be influenced by, or even rely on data from non-RCTs. Although including both RCTs and non-RCTs provides a useful overview, the conclusions do not necessarily stem from the strongest evidence available (Sackett et al., 2000).
In summary, one systematic review, two literature reviews, and a clinical practice guideline have identified five RCTs (Byl et al., 2003; Cambier et al., 2003; Chen et al., 2005; Feys et al., 1998; Jongbled, Stacey & Brighton, 1989) testing the effects of ULPSSI interventions but no comprehensive systematic review of RCTs has been undertaken on this issue. A rigorous systematic review identifying the number of RCTs available, such as Cochrane Systematic Review, which synthesises the effects of interventions for ULPSSI is needed to provide clinicians with a clear statement about the status of the evidence from rigorous research, and inform future clinical guidelines.

2.3. Conclusion and Implications for the Thesis
Understanding ULPSSI and how those impairments impact upper limb use, participation, and functional outcomes, and how recovery after stroke occurs forms the basis of scientific knowledge supporting therapists’ CDM when working with persons who have had a stroke. It is unclear whether therapists use this information in CDM and how it impacts their decision-making. Identifying and understanding the nature of ULPSSI provides essential information for CDM regarding its management. It is therefore important that appropriate measurement tools are selected for this purpose with clinical practice guidelines recommending the use of standardised measures with good psychometric properties. Based on a summary of the evidence provided and balancing clinical utility and psychometric properties, two sensory measures are recommended for clinicians to use: the Erasmus MC modifications of the Nottingham Sensory Assessment, and the Thumb Localisation Test. From the literature it appears therapists have not been using these standardised measures but no recent studies of therapists in America has been undertaken. Further studies are needed to ascertain whether or not these standardised measures are being used in clinical practice by occupational therapists.

This Chapter also summarised the intervention approaches and strategies for ULPSSI and the evidence supporting those interventions. Prior reviews and guidelines have relied on largely non-randomised studies with few RCTs to support
their conclusions about the use of utilise sensory specific training strategies. While systematic reviews, literature reviews and clinical practice guidelines identified five RCTs testing the effects of ULPSSI interventions, there appears to be no comprehensive, well designed systematic review that summarises what is known about the effects of interventions on ULPSSI to inform CDM. A Cochrane systematic review of the effectiveness of interventions for ULPSSI is warranted to address the current situation. Furthermore, it would also be important to actually see which sensory measures and interventions therapists are using to address ULPSSI and to understand their CDM as they choose how to address ULPSSI.

2.4. Tables

Table 2.1. Lesion location and post stroke sensory impairment

<table>
<thead>
<tr>
<th>Area</th>
<th>Sensory impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anterior SI hand area</td>
<td>Contralateral size discrimination loss, no shape discrimination loss</td>
</tr>
<tr>
<td>Anterior deep SI</td>
<td>Contralateral impaired detection of passive movement, kinaesthesia, detection of size and shape</td>
</tr>
<tr>
<td>Small lesions result in paraesthesia</td>
<td></td>
</tr>
<tr>
<td>Somatosensory association areas</td>
<td>Contralateral discrimination loss</td>
</tr>
<tr>
<td>(cortex lining postcentral sulcus,</td>
<td>Loss of primitive or detection sensation</td>
</tr>
<tr>
<td>supplemental sensory area, retro</td>
<td></td>
</tr>
<tr>
<td>insular cortex-parietal operculum</td>
<td></td>
</tr>
<tr>
<td>Lateral anterior part of superior parietal lobe area 5L</td>
<td>Kinaesthetic discrimination</td>
</tr>
<tr>
<td>Superior and middle frontal gyrus</td>
<td>Increased discrimination thresholds</td>
</tr>
</tbody>
</table>
Inconsistent reports of somatosensory discrimination loss, deficits seem to be modest compared with those of primary cortex area. Impaired modulation of pain and thermal stimulation.

Tactile Extinction

Angular gyrus, supramarginal gyrus

Finger agnosia

Cerebellar lesions

Difficulty with weight discrimination

Kinaesthesia

Sensory dysgraphia

Thalamic nuclei

Ventral Caudal Nucleus – impaired cold sensation, pain syndromes, tactile sensation impairment

Lateral nuclei - sensory strokes

(Compiled from: Beversdorf, Hughes, & Hielman, 2008; Carey, 1995; Jacobs & Lowe, 1999; Kim, 2007; Restuccia, Marca, Valeriani, Leggio, & Molinari, 2007; Swenson, 2006; Yekutiel, 2000)

Table 2.2. Incidence of Contralateral ULPSSI.

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Population (Body part tested)</th>
<th>Modality (sensory measure used)</th>
<th>Incidence of impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accerra, (2007)</td>
<td>Observational cohort study</td>
<td>70 Ischemic Stroke survivors m=6 days post stroke (range 2 – 14 days)</td>
<td>Light Touch (von Frey monofilaments) Punctate Touch (von Frey monofilaments)</td>
<td>89% 71%</td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Measures</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>3 sites tested (Deltoid, hand, Tibialis anterior; Data provided for the hand)</td>
<td>Cold Touch (Numeric Rating Scale (NRS))</td>
<td>56%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hot Touch (NRS)</td>
<td>67%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Connell, Lincoln, and Radford (2008), Prospective observational study</td>
<td>Light touch absent</td>
<td>15 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Temperature absent</td>
<td>20 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pinprick absent</td>
<td>16 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pressure absent</td>
<td>29 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tactile localization Absent</td>
<td>19 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Nottingham Sensory Assessment)</td>
<td>28 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rand, Gottlieb, and Weiss 2001 prospective observational study</td>
<td>proprioception (Thumb Localisation Test and Finger Shift Test)</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kim and Choi-Kwon 1996 prospective observational study</td>
<td>Bilateral impairments</td>
<td>85 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discriminative sensation stereo gnosis point localisation</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tyson et al. (2008)</td>
<td>Proprioception</td>
<td>Impaired 3.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prospective cross-sectional survey survivors (2-4 wks. post stroke) (Elbow, wrist, thumb, ankle, big toe; Composite Upper limb data provided)</td>
<td>detection</td>
<td>Proprioception discrimination</td>
<td>Absent 12.7%</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tactile detection</td>
<td>Absent 13.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tactile discrimination</td>
<td>Impaired 7.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Rivermead Assessment of Somatosensory Perception (RASP))</td>
<td>Absent 23.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Impaired 8.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Absent 35.3%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 3: INTERVENTIONS FOR SENSORY IMPAIRMENT OF THE UPPER LIMB AFTER STROKE

This Chapter presents the results of a systematic review that addresses the first aim of this thesis, to synthesise studies testing the effects of interventions for ULPSSI. Chapter 2 outlined the current clinical practice recommendations and summary of the evidence to support ULPSSI interventions from clinical practice guidelines, literature reviews, and systematic reviews. The recommendations made were based on RCTs as well as non-RCTs of varying quality and designs. One of the difficulties faced by systematic reviews which include non-RCTs is that the conclusions may be influenced by, or even rely on data from non-RCTs. Although including both RCTs and non-RCTs provides a useful overview, the conclusions do not necessarily stem from the strongest evidence available (Sackett et al., 2000). RCTs are the preferred source of evidence to support the effectiveness of an intervention as they are less prone to bias (Reeves, Deeks, Higgins, & Wells, 2008). While a number of RCTs evaluating the effects of interventions for ULPSSI have been identified in the previous literature summary, there were significant limitations in the methodology, aims and thoroughness of the prior reviews (See Chapter 2 for more details). These studies were also not summarised in one review to provide a concise statement of the evidence available to support practice. A rigorous systematic review identifying the number of RCTs available, such as a Cochrane Systematic Review, which synthesises the effects of interventions for ULPSSI is needed to provide clinicians with a clear statement about the status of the evidence from rigorous research, and to inform future clinical guidelines.

The following Chapter is based on the peer-reviewed manuscript titled “Interventions for sensory impairment of the upper limb after stroke” which was published in the Cochrane Database of Systematic Review. This manuscript aims to synthesise RCTS testing the effects of interventions for ULPSSI. The results of this study also inform the discussion of the results from the next two studies (about CDM and practice patterns of occupational therapists with regard ULPSSI) as the systematic review was completed but not yet published at the time these studies were
Interventions for sensory impairment in the upper limb after stroke

Accepted: August 8th, 2009


3.1. Abstract

3.1.1. Background.

Sensory impairments significantly limit the ability to use the upper limb after stroke. However, little is known about the effects of interventions used to address such impairments.

3.1.2. Objectives.

To determine the effects of interventions that target upper limb sensory impairment after stroke.

3.1.3. Search strategy.

We searched the Cochrane Stroke Group Trials Register (last searched 8 October 2009), the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library 2009, Issue 1), MEDLINE (1966 to January 2009), EMBASE (1980 to January 2009), and six further electronic databases to January 2009. We also hand searched relevant journals, contacted authors in the field, searched doctoral dissertation databases, checked reference lists, and completed citation tracking.
3.1.4. Selection criteria.

Randomised controlled trials and controlled trials comparing interventions for sensory impairment after stroke with no treatment, conventional treatment, attention placebo or with other interventions for sensory impairment.

3.1.5. Data collection and analysis.

Two review authors selected studies, assessed quality and extracted data. We analysed study data using mean differences and odds ratios as appropriate. The primary outcome we considered was sensory function and secondary outcomes examined included upper limb function, activities of daily living, impact of stroke and quality of life as well as adverse events.

3.1.6. Main results.

We included 13 studies, with a total 467 participants, testing a range of different interventions. Outcome measures included 36 measures of sensory impairment and 13 measures of upper limb function. All but two studies had unclear or high risk of bias. While there is insufficient evidence to reach conclusions about the effects of interventions included in this review, three studies provided preliminary evidence for the effects of some specific interventions, including mirror therapy for improving detection of light touch, pressure and temperature pain; a thermal stimulation intervention for improving rate of recovery of sensation; and intermittent pneumatic compression intervention for improving tactile and kinaesthetic sensation. We could not perform meta-analysis due to a high degree of clinical heterogeneity in both interventions and outcomes.

3.1.7. Authors’ conclusions.

Multiple interventions for upper limb sensory impairment after stroke are described but there is insufficient evidence to support or refute their effectiveness in improving sensory impairment, upper limb function, or participants' functional status and participation. There is a need for more, well-designed, better reported studies of sensory rehabilitation.
3.1.8. Plain language summary.

Up to 80% of people who have a stroke experience sensory loss in their affected arm. This sensory loss puts the arm at risk for injury and impacts functional use of the arm and the survivors' level of independence during daily activities. We found 13 studies involving 467 participants that tested different treatments for sensory loss. There is limited evidence that these treatments may be effective. Not more than one study examined each particular intervention; frequently the studies were of poor quality and lacked sufficient information. Further research is needed before clear recommendations can be made.

3.2. Background

Stroke is the leading cause of disability and the third or fourth leading cause of death both in the USA and many developed countries around the world (Eaves, 2000; Heart and Stroke Association of Ontario, 2001; Heart and Stroke Foundation of Canada, 2005; National Stroke Foundation, 2005). Pendlebury et al. (2004) concluded that approximately one million strokes occur each year in Europe, making it the most common neurological disorder. There are three million permanently disabled stroke survivors in the USA. In the USA in 2006 the American Stroke Association estimated the costs of stroke (both direct and indirect) to be USD 57.9 billion (American Stroke Association, 2006). In the United Kingdom, stroke accounts for approximately 6% of total National Health Service and social services expenditure, with most of the cost associated with the resulting chronic disability (Pendlebury et al., 2004). Approximately 25% of chronic disability in Australia is due to stroke, costing the Australian economy over AUD 1.3 billion annually (Aboriginal Stroke Project Steering Committee, 2004). There are 300,000 Canadians living with the effects of stroke costing the Canadian economy about CAD 2.7 billion per year (Heart and Stroke Foundation of Canada, 2005). Recognition of the importance of rehabilitation services in the management of conditions that affect people's functional abilities is growing. In Canada and the USA, those who require rehabilitation after stroke make up the largest category of rehabilitation patients and have the third longest length of inpatient stay (Hopman & Verner, 2003). The cost of stroke is
expected to continue to grow worldwide over the next two decades due to the increasing age of the population (Pendlebury et al., 2004).

The most common deficit after stroke is hemiparesis of the contralateral upper limb, with more than 80% of those with stroke experiencing it acutely and more than 40% chronically (Cramer et al., 1997). Upper limb impairments continue to limit the functional independence and satisfaction for 50% to 70% of stroke survivors, and only 5% of survivors who initially experienced complete paralysis achieve functional use of their arm (Heart and Stroke Association of Ontario, 2001). Exploration of the environment and mastery and participation in daily occupations are intimately associated with both movement and sensation. Deficits in somatic sensations (body senses such as touch, temperature, pain and proprioception) after stroke are common with prevalence rates variously reported to be 11% to 85% (Yekutiil, 2000), 65% (Carey et al., 1993), 60% to 74% (Hunter & Crome, 2002), and 100% (Rand et al., 2001). This variability among the studies is thought to be related to differences in assessment and definition of sensory impairment, and study design (Yekutiil, 2000). The sensory deficits do not appear to be confined to the contralateral upper limb, with several studies noting significant impairment in the ipsilateral upper limb after stroke (Carey, 1995; Kim & Choi-Kwon, 1996; Nowak et al., 2007). While the level of impairment in the ipsilateral upper limb is generally considered less than that of the contralateral upper limb, in some cases moderate to severe deficits have been reported and deficits have also been noted to persist for a period of years after stroke. The incidence of ipsilateral impairment generally cited Interventions for sensory impairment in the upper limb after stroke varies from 12% to 26% (Carey, 1995).

There are many different sensory modalities affected by stroke. The loss of detection of touch sensation has been noted in up to 65% to 94% of all stroke survivors (Acerra, 2007; Carey et al., 1993). Impairment in proprioception (ability to sense the position and orientation of parts of the body) (17% to 52%), vibration (44%), light touch (32% to 89%), and loss of pinprick sensation (35% to 71%) have also been
noted (Acerra, 2007; Hunter & Crome, 2002; Tyson et al., 2008). Disturbance of other sensory modalities including two-point discrimination, stereo gnosis (recognition or identification of objects by use of touch), kinaesthesia (detection of bodily position, weight, or movement of the muscles, tendons, and joints), graph aesthesia (recognition of writing on the skin by the sensation of touch) and pain are found (Connell et al., 2008; Kim & Choi-Kwon, 1996). Tactile extinction (where people with unilateral damage do not detect touch given to the contralateral side when a symmetrical touch stimulus is given to the ipsilateral side) has been considered to be attentional in nature (tactile neglect) by some authors but is described by other authors as a higher order or cortical tactile sensation along with two point discrimination, stereo gnosis and graph aesthesia and as such is often reported with sensory modalities in medical texts (Blumenfeld, 2002; Bohannan, 2003; Campbell et al., 2005; Gilroy, 2000). It is therefore included in this review but considered separately. The quality of sensory deficits experienced after stroke include delayed perception, uncertainty of responses, changes in sensory thresholds, fatigue, altered time for sensory adaptation, sensory persistence, and altered nature of the sensation (Hunter & Crome, 2002; Robertson & Jones, 1994).

Functionally, the problems resulting from sensory deficits after stroke can be summarised as (1) impaired detection of sensory information, (2) disturbed performance of motor tasks that require somatosensory information, and (3) diminished rehabilitation outcomes for the upper limb (Hunter & Crome, 2002). Sensation is essential for safety even if there is adequate motor recovery (Yekutiel, 2000). The development of secondary complications such as sores, abrasions, and shoulder-hand syndrome has been associated with the impairment of sensation (Rand et al., 2001). Sensory impairment has also been found to be directly associated with the development of shoulder pain and subluxation (Chang et al., 1995; Gamble, Barberan, Bowsher, Tyrrell, & Jones, 2000; Suethanapornkul et al., 2008).
When impairment in the ability to detect and process sensory data occurs, the stroke survivor will have difficulty exploring and relating to his environment (Dannenbaum & Jones, 1993; Yekutiel, 2000). It was postulated by van der Lee et al. (1999) that stroke survivors who have sensory impairments do not use the affected limb to their fullest motor potential. The spontaneous use of the upper limb has been noted to significantly decrease when cutaneous sensory processing is impaired (Carey et al., 1993; Rand et al., 2001). This continued disuse of the affected extremity leads to a further decrease in skilled movement, particularly for functional skills that require a constant sustained muscle contraction (Dannenbaum & Jones, 1993). This further contributes to the pattern of learned non-use. The quality of upper limb movements is also impaired in the presence of sensory impairments (Nowak et al., 2007; Rand et al., 2001). Stroke survivors were found to have impairments in force control, fine motor manipulation of objects, sensory ataxia, decreased grasp, and changes in prehension patterns, all of which have been found to be associated with sensory impairment (Aruin, 2005; Blennerhassett et al., 2007; Carey, 1995; Nowak et al., 2007; Robertson & Jones, 1994; Welmer et al., 2008; Yekutiel, 2000).

Sensory deficits have been shown to predict poor functional outcome after stroke, including increased length of hospitalisation, lower levels of discharge home, lower numbers of home discharges, and increased mortality rates (Carey, 1995; Rand et al., 2001; Yekutiel, 2000). Tyson et al. found that impairment of sensation was significantly associated with mobility, independence in activities of daily living and recovery (Tyson et al., 2008) while Desrosiers et al. (2006) found a significant association with long-term participation. While proprioceptive status soon after stroke has been reported to be a reliable predictor of long-term motor recovery, other studies have shown no association between functional status at discharge and somatosensory impairment (Carey, 1995). For example, Rand, Weiss and Gottlieb (1999) found no significant difference in functional outcomes six weeks post-stroke between individuals with both motor and proprioceptive deficits and those with pure motor deficits. Tactile extinction on the left side of the body (of double simultaneous stimulation) was shown to be the single most important predictor of functional outcome (Rose et al., 1994). Many factors contribute to the varied outcomes among
these studies, including how sensory impairment is defined and measured, and the time post-stroke and stage of recovery (Carey, 1995).

Although sensory impairments significantly limit the ability to use the upper limb after stroke and increase the risk of secondary complications, to date little is known about the effectiveness of interventions that address this issue. This systematic review examines the effectiveness of interventions for sensory impairment after stroke.

3.3. Objectives

The objectives of this review were to determine if interventions for upper limb sensory impairment are more effective at improving:

1. sensory function than no treatment, control or placebo interventions;
2. upper limb function than no treatment, control or placebo interventions;
3. activity limitations than no treatment, control or placebo interventions; and
4. participation than no treatment, control or placebo interventions.

3.4. Methods

3.4.1. Criteria for considering studies for this review.

3.4.1.1. Types of studies.

We included controlled trials of sensory interventions to improve function or remediate sensory impairments of the upper limb following stroke where participants were randomly or quasi-randomly assigned to one of two or more treatment groups. We also included trials with or without blinding of the participants, therapists, or evaluators. We also included randomised cross-over trials that met the above criteria.
3.4.1.2. Types of participants.
We included adults (18 years and over) with a clinical diagnosis of stroke, either haemorrhagic or ischemic, that did not necessarily need to be confirmed using imaging studies. The stroke resulted in the participants initially experiencing a disturbance in sensory function of the upper limb. We defined a disturbance in sensory function as any impairment that impacted on sensory registration, perception, or discrimination, resulting from a cerebral vascular accident and where the primary sensory receptors are intact. We included studies with mixed aetiology groups if at least 50% of participants were diagnosed with stroke.

3.4.1.3. Types of interventions.
Included studies addressed the recovery of function or remediation of sensory impairments in the upper limb by specifically focusing on interventions hypothesised to remediate sensory impairments after stroke, or both. These interventions included: sensory re-education, tactile kinaesthetic guiding, repetitive sensory practice, or desensitisation. We also examined studies that explored novel intervention strategies if they were relevant to upper limb functional use and included an outcome measure for sensory function or impairment. These interventions were delivered as stand-alone or as an adjunct to conventional therapy.

3.4.1.4. Types of outcome measures.
The primary outcome of interest was sensation. There are many distinct sensory modalities identified in the literature and defined in the Background above. We considered measures of the following sensory modalities in this review (and will consider these in review updates):

1. light touch;
2. mechanical sensation;
3. temperature detection;
4. two-point discrimination;
5. depth sense;
6. vibration sense;
7. sustained pressure;
8. kinaesthesia;
9. position sense;
10. stereo gnosis;
11. graph aesthesia;
12. pain (pressure pain, temperature pain, pain intensity);
13. combined sensory modality assessment.

Some controversy surrounds the inclusion of tactile/proprioceptive extinction as a sensory modality. We have included it in this review and will look at the data separately. In addition, we considered somatosensory evoked potentials. Measurement of these modalities may be from modality specific measures, global sensory measures, or sensory subscales of larger scales such as the Motor Assessment Scale and the Fugl-Meyer, which are impairment-based measures and address sensation. We also included the perceived level of impairment or discomfort by the stroke survivor.

The secondary outcomes of interest were upper limb functional use, activity limitations, and participation. Each of these is explained in more detail below.

1. Functional use of the upper limb. This outcome included:
   a. specific components of upper limb function such as dexterity or hand function (using measures such as the Jebsen Taylor Hand Function Test);
   b. upper limb motor functioning (using measures such as the Fugl Meyer, Modified Motor Assessment scale);
   c. upper limb functioning (using measures such as Chedoke or the Motor Activity Log);
   d. scales that identified the survivors' perceived level of use and satisfaction with level and quality of upper limb use.
2. Activity limitations measures focus on performance of activities of daily living. This outcome included:
   a. basic activities of daily living (using measures such as the Barthel Index or the Functional Independence Measure);
   b. instrumental activities of daily living (using measures such as the Frenchay Activities Index);
   c. global dependency scales.
3. Participation measures focus the level of participation in life roles and satisfaction levels with that participation. This outcome included:
   a. measures of the impact of a stroke on participation (using measures such as the Stroke Impact Scale);
   b. quality of life measures.
   We also included death from any cause during the treatment, adverse effects and economic data, if available. We recorded outcome measures based on these categories, extracted the appropriate data from the studies, and came to a consensus as to which to include in the final analysis.

3.4.2. Search methods for identification of studies.

See the 'Specialised register' section in the Cochrane Stroke Group module.

We searched the Cochrane Stroke Group Trials Register, which was last searched by the Managing Editor on 8 October 2009. In addition, we searched the following electronic bibliographic databases; the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library 2009, Issue 1), MEDLINE (1966 to January 2009), EMBASE (1980 to January 2009), CINAHL (1982 to January 2009), AMED (1985 to January 2009), PsycLIT (1974 to January 2009), Science Citation Index (1945 to January 2009), Social Science Citation Index (1956 to January 2009) and LILACS (Latin American and Caribbean Health Sciences Literature) (1982 to January 2009). The MEDLINE Search strategy (Section 3.12), developed with assistance from the Cochrane Stroke Group Trials Search Co-ordinator, was used as the basis for the above literature searches (with the last updated search
completed 19 January 2009). We also searched the following specialist occupational therapy and physiotherapy databases: PEDro (http://www.pedro.org.au/) and OTseeker (www.otseeker.com) (last searched January 2009).

3.4.2.1. Current awareness.

We searched the Excerpta Medica abstract journal Rehabilitation and Physical Medicine (Section 19 EMBASE) and the Index Medicus monthly bibliographic index.

3.4.2.2. Citation tracking and reference lists.

Using key references, we used the cited reference search in Science Citation Index to identify further studies. We also searched the reference lists of all relevant articles identified.

3.4.2.3. Hand searching.

We hand searched the following journals (the years selected represent the timeframe of increased interest and research publications in this topic area and accessibility to the journals):

American Journal of Occupational Therapy (1980 to 2008);
American Journal of Physical Medicine & Rehabilitation (1988 to 2009);
Archives of Physical Medicine and Rehabilitation (1995 to 2008);
Australian Journal of Physiotherapy (1980 to 2008);
Australian Occupational Therapy Journal (1999 to 2008);
British Journal of Occupational Therapy (1998 to 2008);
Canadian Journal of Occupational Therapy (1997 to 2008);
Head Trauma Rehabilitation (1986 to 2008);
International Journal of Therapy and Rehabilitation (1996 to 2009);
NeuroRehabilitation (1999 to 2009);
Occupational Therapy in Health Care (1984 to 2008);
OTJR: Occupation, Participation and Health (2002 to 2009);
Physical and Occupational therapy in Geriatrics (1982 to 2008);
Physical Therapy (1980 to 2008);
Physiotherapy (1995 to 2008);
Physiotherapy Canada (1997 to 2009);
Stroke (1980 to 2008).

To avoid duplication, we checked the Cochrane Master List of journals hand searched on behalf of The Cochrane Collaboration (http://apps1.jhsph.edu/cochrane/masterlist.asp) to identify hand searching already completed.

In an effort to identify further published, unpublished and ongoing trials we have:

1. searched for Doctoral and Masters' theses on the OT Search bibliographic database, the AOTA website, Dissertation Abstracts and Physical Therapy theses indexes;
2. contacted research and professional associations or foundations (such as the Medicine and Stroke Foundations in USA, UK, Canada, and Australia) to identify any other research that they know of;
3. identified key researchers in the area and contacted them with regard to unpublished research;
4. searched the following international clinical trials and research registers: the National Research Register Archive (https://portal.nihr.ac.uk/Pages/NRRArchive.aspx), Current Controlled Trials (http://www.controlledtrials.com/), and REHABDATA (http://www.naric.com/research/rehab/).

We did not impose any language or date restrictions on the electronic searches for trials.
3.4.3. Data collection and analysis.

3.4.3.1. Selection of studies.

The primary review author reviewed the titles identified and eliminated obviously irrelevant studies; we then obtained the abstracts for the remaining studies. Using the titles and abstracts obtained from the searches, two review authors independently completed the study selection form to determine if a study should be included or excluded or to state that they were unsure of this decision. We resolved disagreements by discussion based on the inclusion criteria.

3.4.3.2. Data extraction and management.

Two review authors then reviewed the articles that were considered appropriate for inclusion in the review and completed the data extraction form with the following information.

1. Retrieval characteristics: source and date of publication, and authors.
2. Sample characteristics: sex, age, sample size, diagnosis (right or left cerebrovascular accident areas specified), and other reported clinical variables listed as inclusion or exclusion characteristics.
3. Time since stroke
4. Intervention: specific intervention technique: detail the specific intervention technique used in the study.
5. Frequency (dosage): detail the specific intervention frequency.
6. Follow-up time period stated.
7. Outcome measures.
8. Adverse effects or side effects.
9. Results: means, standard deviations, significance test, t, f, P values and directions of findings.

3.4.3.3. Assessment of risk of bias in included studies.

Two review authors rated the risk of bias of the studies using the Cochrane Risk of Bias Assessment as outlined in the Cochrane Handbook for Systematic Reviews of
Interventions (Higgins & Green, 2008) and in the Review Manager software RevMan 5 (Cochrane Collaboration, 2008). If there was disagreement, we asked the third review author to rate the study and used the rating that two of the three review authors selected. Where this did not occur all three review authors discussed the decision further until we reached agreement. Where there were items that were unclear, we attempted to contact the study authors by email or telephone to obtain the information needed.

3.4.3.4. Data analysis.

We entered data into RevMan 5 (Cochrane Collaboration, 2008) using the double data entry facility to allow for error checking. We used RevMan 5 for data entry, analysis, and display.

We undertook the following analyses:

1. specific treatment for sensory impairment versus no treatment (or with conventional treatment in both study arms);
2. specific treatment for sensory impairment versus conventional upper limb therapy;
3. specific treatment for sensory impairment versus placebo sensory treatment or attention placebo;
4. comparisons between different types of treatments for sensory impairment.

We placed studies in which both the treatment and control group received conventional therapy and the only difference was that the treatment group also received specific treatment for sensory impairment in the first group above. We defined attention placebo as a type of comparison group in which the participants met with the clinician for the similar duration and frequency as those in the experimental group but did not receive the intervention (Nock, Janis, & Wedig, 2007), or received some input designed to provide attention.
3.4.3.5. Assessment of heterogeneity and subgroup analysis.

We planned to undertake a meta-analysis for this review and to examine heterogeneity prior to completing a meta-analysis. However, due to significant clinical diversity amongst the studies found in terms of both interventions and outcomes, and in many instances, lack of available data, it was not possible to undertake a meta-analysis or sensitivity analyses for this review.

We have expressed dichotomous outcomes as odds ratios (OR) with 95% confidence intervals (CI). We have expressed continuous outcomes, if possible, as mean differences (MD) with 95% CIs.

3.5. Results

3.5.1. Description of studies.

We identified 1554 references in initial searches. Initial screening by one of the review authors reduced this to 662 references whose abstracts were then screened by two review authors to see if they met the inclusion criteria. Two review authors reviewed full copies of the references to 48 studies. At the end of this process 13 studies met the inclusion criteria and study design requirements (randomised controlled trial or controlled clinical trial) (Acerra 2007; Burridge 2002; Byl 2003; Cambier 2003; Chen 2005; Feys 1998; Heldman 2000; Jongbloed 1989; Miller 2004; Poole 1990; Posteraro 2001; Wolny 2003; Yozbatiran 2006). We limited excluded studies listed in the review in accordance with section 7.2.5 of the Cochrane Handbook for Systematic Reviews of Interventions (Higgins & Green, 2008) and 32 studies that met all the inclusion criteria except study design were not included. We included five studies as excluded studies (Brogardh 2006; Carey et al., 1993; Liu 2002; Van Vliet 2005; Yekutiel 1993) and three as ongoing studies (Ben-Shabat 2005; Carey 2004; Carey 2005).
Sample sizes in the included studies ranged from 10 (Posteraro 2001) to 100 (Feys 1998) for a total of 467 participants. The participants ranged in age from 22 to 87 years. The sample included 173 females and 184 males. Four studies (Miller 2004; Poole 1990; Posteraro 2001; Wolny 2003) did not provide information on the gender of their participants. All studies required that the participants had had one stroke that impacted their upper limb with the exception of Byl 2003, which included three participants with more than one stroke. Each study varied in the specific definition of sensory impairments, how they were measured, and the level of impairments experienced by their participants. Not all the studies consistently reported if the upper limb impaired was right or left, or dominant or non-dominant. Time since stroke varied between participants and between studies, with eight studies including participants within three months of their stroke (Acerra 2007; Cambier 2003; Chen 2005; Feys 1998; Jongbloed 1989; Miller 2004; Posteraro 2001; Yozbatiran 2006), three studies including participants from four to 20 months (Heldman 2000), one to 12 months (Burridge 2002), and one with a mean of 5.1 years post-stroke (Byl 2003). Two studies (Poole 1990; Wolny 2003) did not provide any data related to the time post stroke. The exact setting of included studies was only described for six of the studies: inpatient rehabilitation (Acerra 2007; Cambier 2003; Chen 2005), combined inpatient and outpatient rehabilitation (Burridge 2002; Cambier 2003), and acute care (Jongbloed 1989; Yozbatiran 2006). The 13 studies were completed in 11 different countries as outlined in the Characteristics of included studies table.

In general interventions could be considered as taking either a sensory retraining approach or sensory stimulation approach. Only three studies had a sensory retraining focus (Acerra 2007; Byl 2003; Posteraro 2001). The remaining studies provided some sort of stimulation intervention including compression, electrical stimulation, thermal stimulation, sensory integrative treatment, magnetic stimulation, or tensive mobilisations. Many different intervention techniques were examined by the studies with most providing clear descriptions of the interventions. Two studies (Miller 2004; Wolny 2003) provided few details of the intervention even when we contacted the authors.
A sensory retraining program was used by three studies (Acerra 2007; Byl 2003; Posteraro 2001). Acerra 2007 used mirror therapy in addition to therapy as normal, asking participants to complete sensory motor tasks inside a mirror box that provided visual feedback of bilateral simultaneous hand movements. Byl 2003 compared two different sequences for fine motor and sensory retraining programs. They had clear guidelines for a fine motor program that included stress free hand activities, practising repetitive specific fine motor tasks, general aerobic, strengthening and flexibility training, and reinforcement with mental rehearsal. The sensory component involved using stress free hand strategies, graded and repetitive sensory discrimination activities, nervous and sensory system quieting activities, and reinforcement with mental imagery. Posteraro 2001 used a graded program that focused on tactile recognition starting with simple recognition and progressing through simultaneous stimuli recognition and progressing to complex stimuli recognition.

Electrical stimulation was used by two studies (Burridge 2002; Yozbatiran 2006). Burridge 2002 used a two channel neuromuscular electrical stimulation unit to stimulate the triceps brachialis and the second channel to stimulate extensor digitorum communis, extensor carpi radialis, and if possible extensor pollicis longus. This was a synchronised contraction with a duty cycle of eight seconds on and eight seconds rest and a ramp up and down time of two seconds. The pulse width was set at 300 μs and had a frequency of 40 Hz. Yozbatiran 2006 used a transcutaneous electrical nerve stimulator (TENS) machine and 2.5 cm electrodes placed on the extensor digitorum communis and extensor carpi radialis muscles at 2 HZ, pulse width 260 μs symmetrical biphasic square pulse, with the amplitude adjusted to elicit wrist and finger extension.

Cambier 2003 used intermittent pneumatic compression with an automatic intermittent pattern over three minutes, with a 90-second inflation and 90-second deflation cycle at 40 mmHg pressure while the patient was positioned in supine with 45 degrees shoulder vertical abduction and forearm, wrist and fingers extended. The
sham treatment consisted of the same positioning with a shortwave machine positioned over the hemiplegic shoulder but not turned on. Chen 2005 used thermal stimulation via monitored hot and cold packs. After 15 and 30 seconds application, respectively, the participants were encouraged to actively withdraw from the stimulus. This was repeated 10 times per cycle with at least a 30-second pause between applications and two alternating cycles of hot and cold for each session.

Feys 1998 used sensory motor stimulation that involved pushing a rocking chair with the affected arm in an inflatable splint, designed to provide motor, proprioceptive and exteroceptive (pressure) stimulation. Heldman 2000 used repetitive peripheral magnetic stimulation produced by a figure of eight coil placed over the innervation zone for forearm and finger movement. The stimulator was able to generate instantaneous intensity of 1500 J and at a rate of 40/s. Miller 2004 used early intensive task training emphasising unimanual and bimanual functional activities, while Poole 1990 used an inflatable pressure splint with positioning at 90 degrees shoulder flexion, full elbow extension and as much external rotation as possible. Wolny 2003 examined tensive mobilisations of the peripheral nerves of the affected upper limb. Jongbloed 1989 compared sensory motor integrative treatment with functional treatment. The sensory motor integrative treatment focused on patient preparation, tone normalisation, functional activity, giving verbal and visual cues and following a developmental sequence while the functional treatment emphasised compensation and adaptation.

The duration of the studies ranged from one treatment (Heldman 2000) to 12 weeks, though five studies used a six to eight-week intervention period (Byl 2003; Chen 2005; Feys 1998; Jongbloed 1989; Posteraro 2001) and the others less. Only two studies had long-term follow-up time periods, Feys 1998 with six and 12-month follow-ups and Miller 2004 with a three-month follow-up. The dose frequency varied considerably with Heldman 2000 providing a single dose. The most common dose frequency was 30 to 40 minutes five days per week (Cambier 2003; Chen 2005; Feys 1998; Jongbloed 1989; Poole 1990) while Yozbatiran 2006 was 60 minutes and
Bryl 2003 was 90 minutes daily. Burridge 2002 was the only study to use a dose frequency of 30 minutes two times daily. Miller 2004, Posteraro 2001, and Wolny 2003 did not provide details of their dose frequency, though Miller 2004 did state daily.

Sensory impairment modalities tested in the studies included: light touch, mechanical sensation, two-point discrimination, sustained pressure, kinaesthesia, position sense, form perception, stereo gnosia, graph aesthesia, pain (pressure pain, temperature pain, pain intensity) and combined sensory modality assessment. Tactile/proprorceptive extinction was also tested. The 13 studies in this review used 36 different outcome measures for sensory impairment. Two-point discrimination and the Nottingham Sensory Assessment two-point discrimination subtest were used the most frequently (Burridge 2002; Cambier 2003; Wolny 2003). Kinaesthesia was measured by Bryl 2003 and Yozbatiran 2006. Cambier 2003 used the Nottingham Sensory Assessment Kinaesthesia subtest. Other standardised outcome measures for sensory impairment included the Nottingham Sensory Assessment (Cambier 2003), Semmes Weinstein Monofilaments (Chen 2005), Bickerstaff Sensory Protocol (Feys 1998), Sensory Motor Integration Tests (Jongbloed 1989), the QST (Acerra 2007), Bryl-Cheney Boczai Stereo gnosia Test (Bryl 2003), and components of the Brunnstrom Fugl Meyer Assessment (Cambier 2003; Feys 1998; Poole 1990). Two forms of extinction tests were also employed: the Quality Extinction Test used by Heldman 2000, and the Tactile Extinction Test that included both tactile and proprioceptive extinction used by Posteraro 2001.

Eleven of the 13 studies addressed functional use of the upper limb, using 13 different outcome measures. The most frequently used measures were components of the Brunnstrom Fugl Meyer Assessment (Cambier 2003; Feys 1998; Poole 1990) and the Action Research Arm Test (Burridge 2002; Feys 1998). Other tests used included the Hand Function Test (Yozbatiran 2006), Hand Movement Scale (Yozbatiran 2006), Motricity Scale (Posteraro 2001), Modified Motor Assessment Scale (Chen 2005), Brunnstrom Stage Score (Chen 2005), Manual Dexterity (Miller...
Functional performance and participation outcomes were addressed in only 50% of the studies. The Barthel Index was the most frequently used outcome measure at this level (Feys 1998; Jongbloed 1989; Posteraro 2001). Other outcome measures at this level were the Katz Index of Independence in Activities of Daily Living (KATZ ADL) and Instrumental Activities of Daily Living (IADL) scales (Posteraro 2001), Stroke Adapted 30 Item Sickness Impact Profile (Miller 2004), Meal Preparation (Jongbloed 1989), and the California Functional Evaluation (Byl 2003).

Given the significant clinical and methodological diversity in the studies and the incomplete data for some of the studies, we did not attempt a meta-analysis.

3.5.2. Risk of bias in included studies.

Of the 13 included studies only three (Acerra 2007; Burridge 2002; Chen 2005) had adequate random sequence generation and concealment. Yozbatiran 2006 used 'controlled clinical trial with alternate allocation' for the allocation to groups and the other studies did not provide enough information to make a judgement though they did say that participants were randomly allocated to the control and experimental groups. Fifty per cent of the studies (Acerra 2007; Byl 2003; Cambier 2003; Chen 2005; Feys 1998; Jongbloed 1989; Poole 1990) included in the review reported blinding of at least outcome assessment personnel and key personnel where possible, while some reported blinding of participants as well. Burridge 2002, Posteraro 2001, and Yozbatiran 2006 did not blind any study personnel or participants and Heldman 2000, Miller 2004, and Wolny 2003 did not provide adequate information to know if blinding occurred. All participants were accounted for in all of the studies except for Byl 2003, Feys 1998, Miller 2004, and Wolny 2003 who did not provide adequate information, with only one study (Yozbatiran 2006)
providing the CONSORT flow chart. All of the studies were free from selective reporting of the outcomes except for Wolny 2003 where some outcomes were not mentioned in the abstracts provided, and Miller 2004 who did not provide adequate information. All of the studies appeared free of other biases except for Byl 2003, Miller 2004, and Wolny 2003 who did not provide adequate information to allow judgement on these criteria. See Figure 1 and Figure 2.

In summary, most of the information in this review is from studies that have unclear or high risk of bias. The following studies were classified as having unclear risk of bias for one or more domains: Byl 2003, Cambier 2003, Feys 1998, Heldman 2000, Jongbloed 1989, Miller 2004, and Poole 1990. The following studies were classified as having high risk of bias for one or more domains: Burridge 2002, Posteraro 2001, Wolny 2003, and Yozbatiran 2006. Only two studies (Acerra 2007; Chen 2005) had a low risk of bias.

3.5.3. Effects of interventions.

3.5.3.1. Comparison 1: Specific treatment for sensory impairment versus no treatment (or with conventional treatment in both study arms):
sensory impairment measures.

Seven studies (Chen 2005; Heldman 2000; Miller 2004; Poole 1990; Posteraro 2001; Wolny 2003; Yozbatiran 2006) compared a specific treatment for sensory impairment with either no treatment, or compared a specific treatment in conjunction with conventional treatment with conventional treatment alone, and used sensory impairment outcomes with a total of 162 participants. Three studies (Chen 2005; Poole 1990; Yozbatiran 2006) provided adequate data to allow for calculations of effect size. They were as follows.

1. A trial of electrical stimulation of wrist and fingers in addition to neurodevelopment exercise compared with neurodevelopment exercise alone (Yozbatiran 2006) used clinical assessment of kinaesthesia and position
sense of wrist and fingers but found no differences between experimental and control groups (Analysis 1.1; Analysis 1.2; Analysis 1.3).

2. In a comparison of inflatable pressure splinting intervention and no splinting, Poole 1990 reported upper limb sensation (combined light touch and position sense) and pain at the end of scheduled follow-up using subscales of the Fugl-Meyer upper limb assessment as an outcome measure. An individual analysis of 18 participants from this study found no difference in scores between the intervention and control group. A difference between control and experimental group was found for pain with the experimental group having lower pain scores (MD -2.40, 95% CI -4.65 to -0.15) (Analysis 1.4).

3. One trial compared repetitive thermal stimulation (heating alternating with cooling) of the hand (with participants being encouraged to move their hand away from the stimulus on discomfort), in addition to standard therapy with standard therapy alone (Chen 2005). This study tested mechanical sensation using the Semmes-Weinstein monofilament and reported a greater rate of recovery of sensation over six weeks in favour of the experimental group (MD 0.21, 95% CI 0.10 to 0.32) (Analysis 1.5).

The remaining four studies (Heldman 2000; Miller 2004; Posteraro 2001; Wolny 2003) did not provide adequate data to calculate an effect size. Wolny 2003 measured two-point discrimination and thermaesthesia to test the effect of tensive mobilisations of the peripheral nerves. Although the authors reported a significant improvement in discrimination sense for the treatment group, between-group results were not reported. Miller 2004 reported a significant difference in hand sensation in favour of the early, intensive task-oriented training over the control group that had postural and concentration exercises but did not provide adequate data to calculate effect size.

Two trials focused on tactile extinction (Heldman 2000; Posteraro 2001). Heldman 2000 compared a single dose of repetitive peripheral magnetic stimulation with no intervention. Using the Quality Extinction Test as the outcome measure they reported significant reduction in left-side tactile extinctions but no impact on
ipsilateral extinctions. Attentional cueing did not impact left-side extinction errors but
did increase ipsilateral errors. However, this study did not provide adequate data to
calculate effect size. A trial of a graded sensory rehabilitation program (Posteraro
2001) reported significant differences for their outcome measures of tactile and
proprioceptive sensation in favour of the treatment condition but did not provide
adequate data to calculate effect size.

3.5.3.2. Comparison 2: Specific treatment for sensory impairment versus
no treatment (or with conventional treatment in both study arms): upper
limb functional use outcome measures.

Five studies (Chen 2005; Miller 2004; Poole 1990; Posteraro 2001; Yozbatiran 2006)
compared a specific treatment for sensory impairment with either no treatment, or
compared a specific treatment in conjunction with conventional treatment with
conventional treatment alone, and utilised upper limb function outcome measures
with a total of 108 participants. Three studies (Chen 2005; Poole 1990; Yozbatiran
2006) provided adequate data to allow for calculations of effect size. They were as
follows.

1. The trial of thermal stimulation (Chen 2005) demonstrated a greater rate of
recovery of arm function over a six-week period in the experimental group
than the control group using the Modified Motor Assessment Scale (MD 1.58,
95% CI 0.98 to 2.18) (Analysis 2.4) and a greater recovery rate using the
Brunstrom Stage Score over six weeks (MD 0.19, 95% CI 0.09 to 0.29)
(Analysis 2.5).

2. Poole 1990 used the Fugl-Meyer Assessment upper arm and hand and wrist
outcome measures to assess the effect of using an air splint on upper limb
function. No between-group differences were demonstrated for Fugl-Meyer
Assessment upper limb function (MD -6.00, 95% CI -16.58 to 4.58) (Analysis
2.1) or for Fugl-Meyer Assessment hand and wrist function (MD -0.12, 95% CI
-9.06 to 8.82) (Analysis 2.2).

3. Yozbatiran 2006 used the Hand Function Test to measure the effectiveness of
electrical stimulation on upper limb function and found a significant difference
in favour of the control group (MD -1.16, 95% CI -2.10 to -0.22) (Analysis 2.3).
There were insufficient data to calculate effect sizes for the study of an early, intensive task-related training program (Miller 2004) although the authors reported significantly greater gains in motor recovery of the arm for the experimental group compared with control on the Chedoke McMaster Stroke Assessment ($P < 0.001$), but not for dexterity.

A trial of tactile extinction (Posteraro 2001) with only 10 participants had no data reported but the authors stated there was no difference between groups for the outcome of motricity.

### 3.5.3.3. Activities limitations and participation outcome measures.

Two studies considered effects of their interventions on functional performance or participation. Miller 2004 used the Barthel Index and Stroke-Adapted Sickness Impact Profile and Posteraro 2001 used the Katz Index of Activities of Daily Living, Katz Index of Instrumental Activities of Daily Living, and Barthel Index. Neither study presented sufficient data to determine effect sizes but reported between-group differences in favour of the experimental groups.

### 3.5.3.4. Specific treatment for sensory impairment versus conventional upper limb therapy.

No studies met this categorisation.

### 3.5.3.5. Comparison 3: Specific treatment for sensory impairment versus placebo/attention placebo: sensory impairment outcome measures.

Four studies (Acerra 2007; Burridge 2002; Cambier 2003; Feys 1998) compared a specific treatment for sensory impairment with either a placebo or attention control and used sensory impairment outcomes with a total of 144 participants. Three of
these studies provided enough data to calculate effect sizes for the individual studies. They were as follows.

1. A study of mirror therapy compared with sham treatment measured light touch, thermal (hot pain) and pressure pain thresholds using the Quantitative Sensory Test and shoulder and arm pain intensity at rest using a 0 to 10 Visual Analogue Scale (Acerra 2007). Between-group differences in favour of the experimental group were found for light touch on the volar side of the hand (dorsal side had similar results) (MD -2.05, 95% CI -2.42 to -1.68) (Analysis 3.1), thermal (hot) pain measured on the hand (MD -1.20, 95% CI -1.42 to -0.98) (Analysis 3.9), and pressure pain (MD -41.30, 95% CI -56.57 to -26.03) (Analysis 3.10). No between-group differences were found for pain intensity at rest (Analysis 3.8).

2. A trial of neuromuscular electrical stimulation compared with passive stretching (Burridge 2002) found no differences between groups in mean change of two point discrimination at the end of treatment (MD 5.18, 95% CI -1.50 to 11.86) (Analysis 3.3).

3. A study of intermittent pneumatic compression of the hemiplegic upper limb compared with sham short-wave therapy (Cambier 2003) demonstrated between-group differences in favour of the experimental group on the Nottingham Sensory Assessment overall (MD 37.10, 95% CI 8.16 to 66.04) (Analysis 3.11) and for the subscales of tactile sensation (MD 26.20, 95% CI 6.99 to 45.41) (Analysis 3.2) and kinaesthetic sensation (MD 5.00, 95% CI 0.05 to 9.95) (Analysis 3.5), but not for two-point discrimination (MD 0.31, 95% CI -0.43 to 1.05) (Analysis 3.4) or stereo gnosis (MD 5.60, 95% CI -0.54 to 11.74) (Analysis 3.6). No difference between groups was found for pain (MD -5.00, 95% CI -31.82 to 21.82) (Analysis 3.7).

A novel intervention required participants to push themselves in a rocking chair with the hemiplegic limb in an inflatable splint compared with sham short-wave therapy while in a rocking chair (Feys 1998). It tested exteroceptive and proprioceptive sensory function but did not provide data sufficient for calculating an effect size. The authors reported no significant differences between the groups.
3.5.3.6. Comparison 4: Specific treatments for sensory impairments versus placebo/attention placebo: upper limb function outcome measures.

Four studies compared a specific treatment for sensory versus placebo or attentional control and measured upper limb functional outcomes (Acerra 2007; Burridge 2002; Cambier 2003; Feys 1998).

1. The study of mirror therapy compared with sham treatment measured grip strength. Post-intervention between-group differences were found in favour of the experimental group for grip strength (MD 4.10, 95% CI 1.06 to 7.14) (Acerra 2007).

2. The trial of neuromuscular electrical stimulation compared with passive stretching (Burridge 2002) measured upper limb function using the Action Research Arm Test (ARAT) and found a between-group difference in favour of the experimental group (MD 12.90, 95% CI 5.65 to 20.15) (Analysis 4.2).

3. The study of intermittent pneumatic compression of the hemiplegic upper limb compared with sham shortwave therapy (Cambier 2003) found no difference using the Brunnstrom Fugl-Meyer assessment of motor recovery (MD 11.50, 95% CI -5.45 to 28.45) (Analysis 4.3).

4. Feys 1998 study of participants with their hemiplegic arm in an inflatable splint while in a rocking chair compared with sham short-wave therapy demonstrated a higher proportion of participants achieving a greater than 10% gain on the Brunnstrom Fugl-Meyer assessment in the experimental group compared with controls (OR 6.05, 95% CI 2.00 to 18.31) but did not provide adequate data to calculate an effect size for the use of the ARAT.

3.5.3.7. Activities limitations and participation outcome measures.

Only the study by Feys 1998 measured the effects of the intervention on functional performance using the Barthel Index but it did not provide adequate data to calculate an effect size. The authors reported no significant differences between the groups.
3.5.3.8. Comparisons between different types of treatments for sensory impairment.

3.5.3.8.1. Sensory impairment outcome measures.

Two studies (Byl 2003; Jongbloed 1989) compared different types of treatments for sensory impairment using sensory impairment outcomes with a total of 108 participants. In a cross-over trial of sensory discrimination retraining followed by fine motor retraining Byl 2003 measured graphesthesia, kinaesthesia and stereognosis but only means were presented so that effect sizes could not be calculated. The authors concluded that both groups made significant gains in sensory discrimination. The study by Jongbloed 1989 compared the effects of an occupational therapy sensorimotor integrative treatment with a functional approach using the Sensorimotor Integration Test Battery (including finger identification, form perception, wire shape recognition, imitation and sequencing of postures) but did not provide sufficient data to calculate an effect size. The authors reported significant between-group differences for finger identification and posture imitation in favour of the functional approach group.

3.5.3.8.2. Upper limb function outcome measures.

Byl 2003 used Digit reaction, the Purdue Pegboard, and Wolf Motor Function Test to measure upper limb function but provided insufficient data to determine effect sizes. The authors reported significant improvements in both groups with no significant differences between them except the group that had motor then sensory retraining had significantly higher fine motor outcomes at the end of the follow-up period than the other group (sensory followed by motor retraining).

3.5.3.8.3. Activities limitations and participation outcome measures.

Jongbloed 1989 measured functional performance using the Barthel Index and assessment of meal preparation but did not provide sufficient data to calculate an effect size. The authors reported no significant between-group differences. Byl 2003
used the California Functional Evaluation to measure functional performance and participation but provided insufficient data to determine effect sizes.

Two of the 13 studies addressed adverse effects (Chen 2005; Feys 1998). Chen 2005 reported no physical damage or adverse effects although their observations were limited to increased muscle tone, which showed no difference between the groups and the fact that assessment took place during and after thermal stimulation. Feys 1998 assessed participants for soft tissue lesions, shoulder-hand syndrome, subluxation, and shoulder pain before and after the intervention and at follow-up. They concluded that there were no significant differences between the two groups at the end of the study.

3.6. Discussion

3.6.1. Summary of results.

The aim of this review was to examine the effects of interventions for sensory impairment on upper limb sensation, upper limb function, activities limitations and participation in participants who have experienced a stroke. We included 13 studies. Meta-analyses were not possible due to considerable clinical and methodological diversity and lack of data. Lack of data also limited the calculation of individual study effect size for a large number of the studies.

In summary there is insufficient evidence to reach conclusions on the effectiveness of any interventions for sensory impairment of the upper limb. Only preliminary evidence exists from individual studies for the effectiveness of some specific interventions for sensory impairment in the upper limb. With respect to the primary outcome of interest, upper limb sensation, there was some limited evidence for:

- the effects of mirror therapy for improving detection of light touch, pressure and temperature pain;
• a thermal stimulation intervention for improving rate of recovery of sensation; and
• intermittent pneumatic compression for improving tactile and kinaesthetic sensation.

It is possible that other interventions reporting statistically significant results may be beneficial (repetitive peripheral magnetic stimulation, early intensive task-orientated training and graded sensory rehabilitation) but data were not available to determine effect sizes. Similarly there is insufficient evidence to reach conclusions on the effectiveness of any interventions for sensory impairment to make a difference to upper limb function, activity limitations, and participation.

Overall there were limited studies on each of the interventions, inadequate data available in many instances to determine effect sizes, and unclear or high risk of bias for most of the studies, limiting the ability to draw significant conclusions.

3.6.2. Overall completeness and availability of the evidence.

Most studies did not provide adequate descriptions of the study design to allow for accurate assessment of risk of bias. It was difficult to obtain adequate data to complete statistical analysis of the results. It was difficult to track down several of the authors to try to obtain adequate data. Several authors did assist with providing further data when contacted though one set did state they were going to publish the study and did not want to release any of the data.

3.6.3. Quality of the evidence.

Overall the sample size for the studies was small, with no mention of power calculations for sample size in most of the studies. There were some exceptions with a larger sample size of 100 and 90 used by Feys 1998 and Jongbloed 1989; otherwise, all other samples sizes were under 40 with some as low as 10
participants. The considerable clinical and methodological diversity impacted on the study conclusions. The risk of bias was unclear or high for all but two studies.

### 3.6.4. Potential biases in the review process.

When designing this review, we made the decision to include only studies that were directly aimed at improving sensory impairments. We found several studies that were focused on motor outcomes but used sensory motor stimulation and had some sensory outcome measures. These were not included. It is possible that these studies may have added to the evidence available. Tactile extinction was included in this review as it remains contentious in the literature as to how to separate sensation from the attention (Yekutieli 1993) and is included as a disorder of sensation in a number of medical texts.

### 3.6.5. Agreements or disagreements with other studies or reviews.

There was one other review of sensory retraining after stroke found in the literature search during completion of this review, carried out by Schabrun and Hillier (2009) titled Evidence for the retraining of sensation after stroke: a systematic review. Our review is different from Schabrun and Hillier's review in several ways. Schabrun and Hillier (2009) included both sensory retraining for the upper and lower limb in the review. They also included non-randomised studies. Schabrun and Hillier (2009) also included some studies where the stated aim was not to improve sensory function but to improve motor function although sensory outcome measures were used. Our review focused clearly on studies that were aimed specifically at improving sensory function.

Schabrun and Hillier (2009, p. 36) concluded that “the results of this meta-analysis suggest that there is some evidence to support the use of passive sensory training to improve hand function and dexterity in those with stroke.” Schabrun and Hillier’s term passive sensory training referred to electrical stimulation interventions. Our results for the effectiveness of studies that involved electrical stimulation are mixed. Yozbatiran 2006 compared electrical stimulation with NDT-Bobath therapy with NDT-
Bobath therapy alone and found no differences on the sensory impairment outcome measures of kinaesthesia and position sense though they did find an effect in favour of the control group on the Hand Function Test. Burridge 2002 compared electrical stimulation with a placebo of passive stretching. In this study no effect was found on the sensory impairment outcome of two-point discrimination but upper limb function as measure by the Action Research Arm Test demonstrated an effect in favour of the treatment group. In Schabrun and Hillier’s (2009) review the electrical stimulation was compared to sham or low current electrical stimulation. This may explain the differences in the results from the Yozbatiran 2006 study in which the comparison was with a more active and dynamic treatment that espoused to incorporate active and guided movement that incorporates sensory input.

Schabrun and Hillier (2009, p.36) also reported the following finding: "A number of single studies report positive effects on function, sensation and proprioception following active sensory training. However, the lack of sufficient data to perform meta-analysis and insignificant effect sizes mean it is not yet possible to determine the effectiveness of active sensory training in stroke rehabilitation". Schabrun and Hillier’s definition of "active sensory retraining" included interventions that were generally a graded sensory re-education program. This review found similar findings in that there was a lack of sufficient data to perform a meta-analysis. In our review we identified three studies that used a sensory retraining program. Acerra 2007 used mirror therapy and found improvements in detection of light touch and pain. Byl 2003 compared a graded sensory re-education program for four weeks followed by a graded fine motor program for four weeks with the reverse order for the other treatment group and found no significant differences between the groups for graph aesthesia, kinaesthesia, and stereo gnosis. Significant gains were reported for upper limb function outcome measures (digit reaction time, Purdue pegboard, Wolf Motor function test) but there were insufficient data available to calculate effect sizes. Posteraro 2001 used a graded sensory re-education program to address tactile and proprioceptive extinction. Posteraro 2001 found no difference in the tactile and proprioceptive extinction scores of the Motricity score for upper limb function between the control and the intervention group. The authors reported significant
differences in favour of the intervention group on the functional performance outcomes of Katz ADL & IADL, and Barthel Scales although inadequate data were provided for effect sizes to be calculated. These findings tend to support the findings found by Schabrun and Hillier.

Our review also found some single studies that reported positive effects on sensory impairment, upper limb function and functional performance and participation for interventions not addressed by Schabrun and Hillier’s review such as intermittent pneumatic compression, repetitive peripheral magnetic stimulation, early, intensive task oriented training, and thermal stimulation.

Overall, our review was specifically directed at the sensory rehabilitation of the upper limb after stroke versus the more general approach of the Schabrun and Hillier (2009) review. While the results were generally consistent with the findings of the Schabrun and Hillier (2009) review, this review found a larger number of randomised controlled trials relevant to the upper limb that addressed a wider range of interventions and outcomes. Similar issues related to the number and quality of the studies remain and similar conclusions related to single studies that may support specific interventions were found but there were inadequate data to allow effective analysis.

3.7. Authors’ conclusions

3.7.1. Implications for practice.

There are a large number of techniques that show promise for addressing sensory impairments in the upper limb after stroke but we do not at this stage have adequate high quality trials to be able to make recommendations that support or refute the use of specific interventions. Since few studies mentioned adverse effects, the clinician should be conscious of monitoring adverse effects when using any interventions for sensory impairment.
3.7.2. Implications for research.

This review was based on a small number of trials, generally only one, for each of the types of interventions. Most of the trials included a small number of participants and had high to unclear levels of bias. Addressing these issues should be priorities in research design in the stroke rehabilitation area. Some interventions identified in this review have potential to prove beneficial to those with sensory impairment of the upper limb after stroke but need further high quality studies to assess their effectiveness. When searching for studies for this review it was evident there are also many non-randomised studies that addressed these and other interventions that could be investigated with randomised controlled trials to ascertain the value of these treatment techniques in this field.

The large number of outcome measures used was another significant factor that contributed to the clinical diversity of this review. Diagnostic test accuracy reviews to look at the effectiveness of these outcome measures for measuring sensory impairments, upper limb function and functional performance and participation after stroke would also be a priority.

Improved reporting of trials of rehabilitation interventions would assist with the ability to determine risk of bias and contributions of these trials. Compliance with the CONSORT guidelines is recommended. Researchers should include outcome measures that address participants’ functional performance and quality of life and any possible adverse reactions should be actively screened for in both experimental and control groups. Improved descriptions of the intervention would assist with reviewing the study and with replicating the study. The description of usual care in the studies contained within this review provided very little detail about what this involved. Therefore it is not possible to determine whether some amount of sensory treatment was also a component of usual care which could impact the results of the study.
There were inadequate descriptions of the settings in which the interventions occurred and no studies addressed cost effectiveness of the different delivery options, dosages available, or the timing of the intervention after stroke. These would be factors to address in further studies.

3.8. References to studies

3.8.1. Included studies.

**Acerra 2007**


**Burridge 2002**

* Burridge JH, Mann GE, Malone L, Taylor PN. A randomized controlled pilot study to investigate the effects of neuromuscular electrical stimulation on upper limb function following stroke. Neurorehabilitation and Neural Repair 2002;16(1):11.


Byl 2003

Cambier 2003

Chen 2005

Feys 1998

Heldman 2000

Jongbloed 1989

**Miller 2004**

Published data only (unpublished sought but not used)


Poole 1990

Posteraro 2001
Published and unpublished data

Wolny 2003

Yozbatiran 2006

3.8.2. Excluded studies.

Brogardh 2006

Carey 1993
Liu 2002

Van Vliet 2005

Yekutiel 1993

3.8.3. Ongoing studies.

Ben-Shabat 2005
Published and unpublished data
* Ben-Shabat E, Carey L, Brotchie PR. A brain activation study of limb position sense in stroke affected individuals with and without sensory training and in healthy aged. Royal Australian College of Physicians 2006.


Carey 2004
Published data only (unpublished sought but not used)
Carey 2005
Published data only (unpublished sought but not used)
Carey L. Effectiveness of training somatosensation in the hand after stroke: a randomized controlled trial. Australian New Zealand Clinical Trials Registry 2002.


3.9. Data and analyses
Table 3.1. Analysis 1: Specific Treatment for Sensory Impairment VS No Treatment (or with conventional treatment in both study arms)- Sensory impairment outcome measures

<table>
<thead>
<tr>
<th>Outcome or Subgroup</th>
<th>Studies</th>
<th>Participants</th>
<th>Statistical Method</th>
<th>Effect Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Kinaesthesia - Thumb opposition (post intervention)</td>
<td>1</td>
<td></td>
<td>Odds Ratio (M-H, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>1.2 Kinaesthesia - Digit flexion (post intervention)</td>
<td>1</td>
<td></td>
<td>Odds Ratio (M-H, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>1.3 Position sense - Digit flexion (post intervention)</td>
<td>1</td>
<td></td>
<td>Odds Ratio (M-H, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>1.4 Pain (FMA) (post intervention)</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>1.5 Mean recovery rate of sensation over 6 weeks</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
</tbody>
</table>
1.6 Combined sensory modalities (FMA Sensation= light touch plus position sense) (post intervention)

<table>
<thead>
<tr>
<th>Outcome or Subgroup</th>
<th>Studies</th>
<th>Participants</th>
<th>Statistical Method</th>
<th>Effect Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 FMA - Upper Limb Function</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>2.2 FMA - Wrist and Hand function</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>2.3 Hand Function Test</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>2.5 Recovery rate on Modified Motor Assessment Scale over 6 weeks</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>2.6 Recovery rate of Brunstrom Stage Score over 6 weeks</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
</tbody>
</table>

Table 3.2. Analysis 2: Specific Treatment for Sensory Impairment VS No Treatment (or with conventional treatment in both study arms)- Upper Limb Functional Use Outcome Measures

Table 3.3. Analysis 3: Specific Treatment for Sensory impairment VS Placebo/Attention Placebo - Sensory Impairment Outcome Measures
<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Light touch (hand)</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.2 NSA - Tactile Sensation, Post intervention</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.3 Two point discrimination</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.4 NSA - Two point discrimination, Post intervention</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.5 NSA Kinaesthetic Sensation, Post intervention</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.6 NSA - Stereognosis, Post intervention</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.7 Visual Analogue Scale Pain, Post intervention</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.8 Shoulder Pain intensity at rest (0-10)</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.9 Temperature -hot pain (hand) 0-10 scale</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.10 Pressure pain (difference in hand pain between affected and unaffected arm)</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
<tr>
<td>3.11 Nottingham Sensory Assessment</td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
</tr>
</tbody>
</table>
Table 3.4. Analysis 4: Specific Treatments for Sensory Impairments VS Placebo/Attention Placebo - Upper Limb Function Outcome Measures

<table>
<thead>
<tr>
<th>Outcome or Subgroup</th>
<th>Studies</th>
<th>Participants</th>
<th>Statistical Method</th>
<th>Effect Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Grip strength</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>4.2 Action Research Arm Test</td>
<td>2</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>4.3 Brunnstrom-Fugl-Meyer Assessment</td>
<td>1</td>
<td></td>
<td>Mean Difference (IV, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
<tr>
<td>4.4 Percentage achieving &gt;10% improvement on Brunnstrom-Fugl-Meyer Assessment at 12 months</td>
<td>1</td>
<td></td>
<td>Odds Ratio (M-H, Fixed, 95% CI)</td>
<td>No totals</td>
</tr>
</tbody>
</table>
3.10. Figures

Figure 3.1. Methodological quality summary: review authors’ judgements about each methodological quality item for each included study.
3.11. MEDLINE search strategy

We used the following search strategy, developed with assistance from the Cochrane Stroke Group Trials Search Coordinator, to search MEDLINE (Ovid) and we adapted it for the other databases.

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or cerebrovascular accident/ or exp brain infarction/ or exp cerebrovascular trauma/ or exp hypoxia-ischemia, brain/ or exp intracranial arterial diseases/ or intracranial arteriovenous malformations/ or exp "Intracranial Embolism and Thrombosis"/ or exp intracranial haemorrhages/ or vasospasm, intracranial/ or vertebral artery dissection/

2. (stroke or post stroke or post-stroke or cerebrovasc$ or brain vasc$ or cerebral vasc$ or cva$ or apoplex$ or SAH).tw.

3. ((brain$ or cerebr$ or cerebell$ or intracran$ or intracerebral) adj5 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$)).tw.
4. ((brain$ or cerebr$ or cerebell$ or intracerebral or intracranial or subarachnoid) adj5 (haemorrhage$ or haemorrhage$ or haematoma$ or hematoma$ or bleed$)).tw.

5. hemiplegia/ or exp paresis/

6. (hemipleg$ or hemipar$ or paresis or paretic).tw.

7. 1 or 2 or 3 or 4 or 5 or 6

8. exp Upper Extremity/

9. (upper adj3 (limb$ or extremity)).tw.

10. (arm or shoulder or elbow or forearm or hand or wrist or finger or fingers).tw.

11. 8 or 9 or 10

12. sensation/ or proprioception/ or kinesthesis/ or touch/

13. sensation disorders/ or exp somatosensory disorders/

14. stereo gnosis/ or agnosia/

15. Psychomotor Disorders/

16. (sensation or sensory or somatosensory or propriocept$ or kinesthesi$ or touch or stereo gnosis or tactile).tw.

17. two point discrimination.tw.

18. position sense.tw.
19. 12 or 13 or 14 or 15 or 16 or 17 or 18

20. 7 and 11 and 19
ULPSSI management is complex and requires therapists to access, interpret, and weigh up different types of information from multiple sources to make decisions about the best care for their clients. Such decisions might include which sensory measures to use, whether or not to provide interventions, determining the most effective interventions to use, or when to try alternative intervention strategies. Making choices about a course of action in clinical practice is known as clinical decision making (CDM) (Smith, Higgs, & Ellis, 2008).

This Chapter presents a peer-reviewed, published manuscript, describing a qualitative research study that sought to explore how occupational therapists make and manage decisions for the management of ULPSSI. This manuscript addresses aims 2 and 3 of this thesis and has been formatted to maintain consistency throughout the thesis. However, prior to providing the methods, results and discussion from this study, an expanded background is presented to describe key aspects of clinical decision-making (CDM) that is a key concept in this thesis. Evidence-based practice (EBP) is first considered as a CDM framework, and the theoretical underpinnings of CDM are then described, followed by discussion about how this occurs in situations of limited information or uncertainty.

The literature reviewed in this section is consistent with the timeframe of the study it supports, that is, prior to 2010. The results of this study were used to design the questionnaire for the survey reported in the Chapters 5 and 6, and informed the content of the educational intervention for the final study reported in Chapter 8.

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Decision for revisions received: February 14th, 2014

Resubmitted: March 28th, 2014

Accepted: May 04, 2014
4.1. Abstract

4.1.1. Background.

Stroke survivors experience sensory impairments that significantly limit upper limb functional use. Lack of clear research-based guidelines about their management exacerbates the uncertainty in occupational therapists’ decision-making to support these clients.

4.1.2. Purpose.

This study explores occupational therapists’ clinical decision-making regarding ULPSSI that can ultimately inform approaches to support therapists working with such clients.

4.1.3. Methods.

Twelve therapists participated in a qualitative descriptive study. Transcripts of semi-structured interviews were analysed using content analysis.

4.1.4. Findings.

Three overarching categories were identified: *Deciding on the focus of interventions* (describing intervention choices), *It all depends* (outlining factors considered when choosing interventions), and *Managing uncertainty in decision making* (describing uncertainty and actions taken to resolve it).

4.1.5. Implications.

Providing training about ULPSSI and decision-making may improve therapists’
decision-making and ultimately improve client outcomes. Further research is needed to understand the impact of uncertainty on occupational therapy decision-making and resulting care practices.

4.1.6. Key words

clinical reasoning, uncertainty, evidence based practice, sensation, stroke

4.2. Background

Manipulating small objects such as coins or buttons, holding a cup without it slipping, and eating with a fork require adequate motor and sensory abilities for skilled performance. These are frequent challenges that stroke survivors with upper limb sensory impairments face even if they have adequate motor recovery. The management of upper limb post stroke sensory impairments (ULPSSI) is also challenging for occupational therapists as there is limited research addressing this area. This qualitative study explores occupational therapists’ decision-making when addressing ULPSSI.

4.2.1. Upper limb post-stroke sensory impairment.

Stroke is a leading cause of adult disability, affecting 15 million people worldwide each year (American Heart Association, 2007). ULPSSI affect the majority of stroke survivors, substantially impacting their recovery and functional independence (Tyson, Hanley, Chillala, Selley, & Tallis, 2008; Yekutieli, 2000). Sensory deficits result in impaired detection and discrimination of sensory information, disturbed motor performance, diminished upper limb functional use, and poor functional outcomes (Harris & Eng, 2007; Tyson et al., 2008). There are also increased economic costs due to the increased length of hospital stays and assistance needed at discharge (Sullivan & Hedman, 2008; Tyson et al., 2008).

Research about the effects of interventions for ULPSSI is an area of growing interest. At time of data collection for the current study (2008-2010), 13 randomised
controlled trials (RCTs) about the effects of interventions for ULPSSI had been published. Amongst these, six trials found significant benefits including studies testing graded mirror therapy (Acerra, 2007), thermal stimulation (Chen, Liang, & Shaw, 2005), intermittent pneumatic compression (Cambier, De Corte, Danneels, & Witvrouw, 2003), graded sensory re-education (Bly et al., 2001, Yekutiel et al., 1993) and early intensive task oriented training (Miller, 2004) for improving aspects of sensation. However this evidence wasn’t available in a synthesised format until the publication of two systematic reviews (Schabrun and Hillier 2009; Doyle et al. 2010) with some of the most recent clinical guidelines (National Stroke Foundation, 2010; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) only having captured some of this evidence. Staying up to date with increasing research evidence is difficult and it is unclear if therapists participating in this study were aware of this growing evidence base, or if so, how they may have incorporated it into their practice.

4.2.2. Evidence-based practice and decision-making.

Evidence-based practice (EBP) is essentially a clinical decision-making (CDM) framework encouraging therapists to integrate information from the best available research with information about clients’ preferences and circumstances, clinical experience (Sackett, Rosenberg, Muir-Gray, Haynes, & Richardson, 1996). One of the original definitions of EBP indicates that its purpose is to guide CDM. “Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al., 1996, p71) and involves integrating clinical expertise and client’s values with high quality research evidence. Other authors (Hoffman, Bennett, & Del Mar, 2010) have since highlighted the need to also consider information from the clinical context.

The process of EBP, is commonly described as consisting of formulating a clinical question, searching for the best evidence, critically appraising the evidence, integrating the evidence with clinical expertise and client preferences and values, and evaluating the outcomes (Sackett, Strauss, Richardson, Rosenberg, & Hayes, 2000). One of the difficulties with the EBP framework, however, is that it is unclear
how health professionals actually integrate these different pieces of information (Bennett et al., 2003; Tonelli, 2006). Bennett et al. (2003) suggest the clinical reasoning process is used to integrate information from research, with clinical experience and the client's preferences. Bannigan and Moores (2009) described integrating scientific knowledge, practice knowledge and the therapist’s internal frame of reference (Chapparo & Rankin, 2008) into CDM as a challenge for occupational therapists and concluded that reflective practice is an integral component of professional reasoning that will assist with this integration.

The use of the EBP framework in practice has been problematic. In a survey of 649 Australian occupational therapists by Bennett et al. (2003) 96% of the respondents indicated that they thought EBP was important to the profession. In this study, respondents most frequently reported lack of time, the limited evidence available and their lack of skills as barriers to EBP (Bennett et al., 2003). Other surveys about the use of EBP amongst occupational therapists have also identified similar barriers to the use of evidence in practice (Cameron, Ballantyne, Kulbitsky, Margolis-Gal, Daugherty, & Ludwig, 2005; Dysart & Tomlin, 2002; McCluskey, 2003; Salls, Dohli, Silverman & Hansen, 2009). McCluskey (2003), in a survey of 67 Australian occupational therapists, found six common barriers to EBP: lack of time, a large caseload, limited searching skills, limited appraisal skills, difficulty accessing journals and a perceived lack of evidence to support occupational therapy intervention. Similarly, Salls et al. (2009), when sampling 930 occupational therapists in Pennsylvania who were and were not members of AOTA, found that the majority (96%) of therapists agreed or strongly agreed on the importance of EBP to occupational therapy but only one fourth (24.2%) reported using research evidence for CDM. Time was found to be the single most important factor that limited the use of EBP, with more than 71.5% of the therapists citing it as the most limiting factor and 87.1% citing lack of time in the top three factors (Salls et al., 2009). The other barriers to EBP found by Sall et al. (2009) included lack of information resources, lack of work site support and difficulty understand the statistical information. Therapists also requested information on how to incorporate research evidence into their daily practice and a majority reported a desire to improve their EBP skills (Salls et al., 2009). Salls et al. (2009) reported a low return rate of 15% which may impact
their results and conclusions though the sample size was very large comparative to other studies in this field. A recent systematic review by Upton, Stephens, Williams, & Scurlock-Evans (2014) found that while occupational therapists view evidence based practice favourably they demonstrated limited utilisation of research in practice, instead relying more frequently on clinical experience and that of their colleagues for decision-making information.

Lopez, Vanner, Cowan, Samuel and Shepherd (2008) surveyed 142 occupational therapists who worked in short term rehabilitation in five north-eastern states of America regarding their perceptions of four facets of intervention planning, one of which was EBP. Lopez et al (2008) found that therapists had negative perceptions about the ability to implement EBP, with more than 26% of the sample reporting difficulty utilising research evidence in their CDM and 34.5% were neutral on this question. The majority of respondents still highly valued the concept of EBP and utilising research in their clinical practice. Lopez et al. (2008) reported that 57.7% of therapists in their survey agreed that not enough research is available that is relevant to occupational therapists and provided a significant barrier to the use of EBP in CDM. Bennett and Bennett (2000) argue however that a lack of research evidence should not limit therapists using EBP as the important factor is to search for and utilise the best available evidence. This is supported in the Sicily statement on evidence-based practice, where Dawes, Summerskill, Glasziou Cartabellotta, Martin, Hopayian et al. (2005) contend that EBP requires clinical decisions to be based on the systematic retrieval of the “best available, current, valid and relevant evidence” (p.1) and incorporates research evidence and non-research based evidence such as tacit and experiential knowledge that is informed by evidence and outcomes.

Regardless of these challenges, therapists generally value research and see research as playing an important part in validating occupational therapy services and informing practice (Bennett, et al., 2003; Cameron et al., 2005; Salls et al., 2009). However, while therapists acknowledge the importance of incorporating research into their CDM, multiple studies have found that therapists continue to predominantly rely on prior experience, colleagues, and continuing education programs as sources of information for decision making (Bennett et al., 2003; Copley & Allen 2009; Dysart
& Tomlin, 2002; Sweetland & Craik 2001; Salls et al., 2009). Generally therapists have expressed an interest in further training in EBP and having more research, especially summaries and appraised research, available that supports clinical practice (Bennett et al., 2003; Salls et al., 2009).

In the previous Chapters research-based recommendations regarding the use of two specific sensory measures for identifying ULPSSI were identified, and 13 RCTs testing various interventions for ULPSSI were located in the searches carried out for the systematic review. While there are some limitations to this evidence and the systematic review concluded there was insufficient evidence to support or refute specific interventions at the time it was undertaken, this is currently the best available evidence and can still be used to inform therapists’ CDM. It is unknown if this evidence is currently being incorporated into therapists’ CDM with regards to the management of ULPSSI.

It is thought that therapist perceptions of an intervention’s effectiveness is a strong motivating factor in selecting interventions, however therapists do not necessarily rely on research to determine what might be effective or to make decisions (Vogt, Armstrong, & Marteau, 2010). If therapists do choose to access research evidence to inform practice, deciding whether or how to use research information is complex. For example, the best available evidence that demonstrates the effectiveness of interventions for ULPSSI comes from single RCTs. Understanding and judgment are then required to interpret this evidence, determine whether it warrants translation to practice, and if so, for which clients. Understanding therapists’ reasoning and CDM (regardless of whether or not they use research evidence) is therefore of particular interest.

### 4.2.3. Clinical decision-making.

Clinical reasoning is the overarching thinking process utilised throughout practice (Higgs & Jones, 2008). As part of this reasoning, therapists make choices about a course of action, a process termed clinical decision-making (CDM) (Smith, Higgs, & Ellis, 2008). CDM is both a component of clinical reasoning and an expected
outcome of the reasoning process with CDM being the point of clinical judgment or choice between alternatives and clinical reasoning being the cognitive process used to arrive at clinical decisions (Smith et al., 2008).

Clinical reasoning and therefore CDM has both process and content dimensions which are contextually situated and influenced by the nature of the decision and decision maker (Atkins & Ersser, 2008; Chapparo & Ranka, 2008; Higgs & Jones, 2008; Leicht & Dickerson, 2001). Just as Mattingly and Fleming (1994a) described clinical reasoning as how therapists think and what therapists think about, this Chapter considers the process of decision making as how decisions are made, and content as the ‘what’ of decision making. CDM content refers to the knowledge, information and motivations that influence the decision, whereas the process of decision-making refers to how therapists integrate and process this knowledge in order to make a choice. Although the focus of this thesis is on CDM, both CDM and clinical reasoning are strongly intertwined and will therefore be discussed together.

4.2.3.1. The process of clinical decision-making.
The CDM process is dynamic and fluid, involving gathering data from multiple sources, interpreting the data, collaborating with both the client and other professionals, choosing a course of action, and evaluating the outcomes of that choice (Smith et al., 2008). Descriptions in occupational therapy literature of the clinical reasoning processes have either focused on describing the reasoning style or track based on the content of the reasoning task or the different cognitive reasoning processes being used (Harries & Harries, 2001).

4.2.3.1.1. Clinical reasoning tracks.
Occupational therapy literature describes different modes or tracks of reasoning used in response to the problems raised by the client, context, or therapist. These include procedural, narrative, interactive, conditional, pragmatic and ethical reasoning tracks (Mattingly & Fleming, 1994a; Schell & Schell, 2008). Each track emphasizes one form of knowledge or content over others in the reasoning process (Leicht & Dickerson, 2001; Harries & Harries, 2001). Given that the emphasis in the occupational therapy literature has been on different styles or tracks of clinical
reasoning, these warrant discussion. Each of the reasoning tracks are summarised briefly here with the content or focus of the reasoning track identified.

Rogers (1983) explored the concepts of “what could be done” and “what should be done” stimulating the discussion on ethical reasoning. Ethical reasoning within occupational therapy involves the principles of autonomy, beneficence, non-maleficence, and justice as well as incorporating veracity, fidelity, privacy and confidentiality (Kanny & Slatter, 2008; Kyler-Hutchinson, 1988; Neuhaus, 1988). Ethical reasoning results from consideration of not only the client’s and therapist’s values but those of the culture and organisation and must result in action (Kanny & Slatter, 2008).

Mattingly and Fleming (1994a) identified a further four reasoning tracks (procedural, interactive, conditional and narrative reasoning). Procedural reasoning focused on problem definition and selection of treatments (procedures) to use (Mattingly & Fleming, 1994a; Tomlin, 2008). Identifying the problem has also been described as diagnostic reasoning (Rogers & Holm, 1991). However, when undertaking these tasks, Fleming (1991) noted that occupational therapists used many of the same thinking processes used in medical problem solving (Coughlin & Patel, 1987; Elstein & Bordage, 1979; Elstein, Shulman, & Sprafka, 1978).

Interactive reasoning is reasoning about how to interact with clients, collaborate with them, and have them engage in the therapeutic process (Mattingly & Fleming, 1994b). Interactive reasoning is used to make and sustain the human interactions key to the therapeutic process (Schell, 2008a). Interactive reasoning involves an extension of the therapist’s personal and professional personas, frames the therapeutic process and addresses the issues of power within the clinical relationship (Shell, 2008a).

Fleming (1994b) described conditional reasoning as a form of inquiry that seeks to understand the client in their social context, and the impact of their disability on their prognosis. After considering how their condition might change, the therapist then helps the client interpret therapy in relation to a possible future (Fleming, 1994b).
This process of imagining the future trajectory of the therapeutic process and clients outcomes provides a hypothetical frame within which decisions can be made.

Narrative reasoning focuses on the client’s life story, their individual experience and imagined future setting the context for therapeutic intervention (Mattingly & Fleming, 1994a). Narrative reasoning is involved with the individual lived experience from the client’s perspective as well as the experience of the clinician within the specific context and has a chronological or temporal sequence (Hamilton, 2008). Narrative reasoning can focus on either the illness or occupational perspective or narrative of the client’s story (Hamilton, 2008).

Schell and Cervero (1993) described the effects of context on therapy as pragmatic reasoning and viewed this as consistent with the emerging sociological concept of situated cognition. This form of reasoning focuses on the practical realities and considers the possibilities related to the practice context and the client and therapist’s personal contexts (Barris, 1987; Schell, 2008b).

Although the literature describing different tracks of reasoning is important, a number of authors have emphasised that these different clinical reasoning tracks actually describe what occupational therapists think about as they practice rather than the actual process involved in thinking (Carrier, Levasseur, Bedard, & Desrosiers, 2010; Roberts, 1996). Roberts (1996) argued that the literature at times confuses the ‘process’ with the ‘content’ of reasoning and that ‘there is a universal underlying process of problem solving based on acquiring cues, processing these and proposing a solution’ (p. 236). Hence describing the cognitive processes involved in problem solving may improve understanding of the clinical reasoning or CDM process.

4.2.3.1.2. Cognitive processes of reasoning and decision-making.
On close inspection of Fleming’s article about the ‘three-track mind’ (1991), we can see that procedural reasoning was named for what therapists were thinking about. However, in her Chapter that further elaborates on procedural reasoning, Fleming (1994a) notes that “procedural reasoning is similar to hypothetical or propositional
reasoning described in the medical problem-solving literature" (p137). Here she described two phases: problem identification and problem solving. Fleming (1994a) describes the processes involved as answer or pattern recognition, 'generate and test' or heuristic search strategies. Pattern recognition is dependent on immediately recognising the problem and the answer if not then the clinician has to think about it (Fleming, 1994a). The two processes Fleming (1994a) describes therapists utilising when thinking about an answer are ‘generate and test’ and heuristic search. Both involve generating possible sets of solutions and testing those in application, while ‘generate and test’ methods have less steps heuristic search involves more detailed searching for cues prior to generating the hypothesis and set of solutions (Fleming, 1994a). The second phase involves formulating the goals and intervention plan collaboratively with the client.

Chapparo and Ranka (2008) proposed that diagnostic and procedural reasoning are forms of scientific reasoning in occupational therapy, though these problem solving processes are evident in most tracks of reasoning described in occupational therapy literature (Robertson & Griffiths, 2012). For example, cue acquisition is evident when using each of the procedural, interactive and conditional reasoning tracks but what differs between these tracks is the type of cues occupational therapists attend to, therefore providing some evidence of a common underlying problem solving process. Thus these cognitive operations of problem solving; cue acquisition, hypothesis generation, refinement and verification (Carrier et al., 2010, Chapparo & Ranka, 2008, Leicht & Dickerson, 2001), also described by several occupational therapy authors as scientific reasoning (Chapparo & Ranka, 2008; Schell & Cervero 1993; Tomlin, 2008), may deserve greater attention than they have to date.

Experience appears to impact the use of scientific or problem solving reasoning processes. Experienced therapists generate two to four hypotheses, while newer therapists generate fewer hypotheses, regarding the cause and nature of the occupational diagnosis and possible intervention strategies (Chapparo & Ranka, 2008). Critical reflection is then used to evaluate the hypotheses. Newer therapists are prone to formulating fewer hypotheses sooner (jumping to conclusions) while experienced therapists are prone to depend exclusively on experience that has not
been subjected to critical reflection (Chapparo & Ranka, 2008). Thompson (2012) proposed that scientific reasoning is used by inexperienced therapists or when experienced therapists face an unfamiliar or complex situation.

While scientific reasoning appears to explain some of the reasoning therapists use in CDM, especially related to formulating an occupational therapy diagnosis, it does not explain all of the reasoning seen in occupational therapy practice. Less commonly considered in the occupational therapy literature is the dual processing theory from cognitive science which has been applied to decision making and health care decision making (Evans, 2003; Sladek, Phillips, & Bond, 2006). Dual processing theory postulates that there are two distinct cognitive processes, the first of which is intuitive and automatic, drawing on past experience to allow decisions to be made quickly (Type 1 processing), and the second (Type 2 processing), a slower, more deliberate and logical cognitive process, utilising a system of weighing information, analysis and reflection to reach decisions, particularly when dealing with uncertainty (Evans, 2003; Stanovich & Toplack, 2012).

There are several types of processes considered Type 1 processing that are able to act in parallel, including emotional regulation, unconscious implicit learning and conditioning, and overlearned associations, with their defining characteristic being autonomy (Croskerry, 2009a; Evans, 2003). Deciding on an action based on our past experience, using what has worked well in the past, or that is intuitive, requires little reflection, and is the basis of Type 1 decision making processes (Croskerry, 2009a; Evans, 2003). Type 1 processing is formed by associated learning processes and is hence domain specific i.e. specific to the topic or task associated with the learning (Evans, 2003). Intuitive reasoning is a largely unconscious and rapid process, and with only the final product of the reasoning process being conscious (Croskerry, 2009a; Evans, 2003). This form of reasoning is frequently used particularly by experts (Leicht & Dickerson, 2001) and relies on pattern recognition and heuristics (Croskerry, 2009a; Harries & Harries, 2001). Pattern recognition involves the identification of cues linked to known patterns. Routine thinking tasks that are repetitive can become largely unconscious and intuitive in nature (Evans, 2003; Harries & Harries, 2001). Utilising automatic decision making can be particularly
efficient in familiar situations when time is of the essence and immediate action is required, however can also be prone to bias (Stanovich & West, 2000). In situations where Type1 processing may produce a suboptimal response, there is a need to be able to override this process using Type 2 processing (Croskerry, 2009).

In contrast, Type 2 processing is non-autonomous. A defining feature of Type 2 processing is cognitive decoupling, the ability to maintain separate imagined and real representations of the world or problem, and the ability to override Type 1 processing (Stanovick & Toplack, 2012). Cognitive decoupling allows the decision maker to carry out cognitive simulations without losing the representation of the real problem or situation (Stanovick & Toplack, 2012). Hence, Type 2 thinking permits the construction of mental models and simulations which allow for future planning or hypothesis testing (Evans, 2003). Type 2 processing uses cues to generate hypothesis which are then tested (Harries & Harries, 2001). Type 2 thinking, a slower, more deliberate and logical cognitive process often performed in series, utilises a system of weighing information, analysis and reflection to reach decisions, and is commonly used when dealing with uncertainty (Croskerry, 2009a; Evans, 2003). Despite the slower processing and limited capacity, Type 2 processes allow for abstract thinking and more conscious awareness (Croskerry, 2009a; Evans, 2003; Harries & Harries, 2001).

Multiple factors, related to both the individual and environment, have been shown to influence the relationship between Type 1 and Type 2 reasoning processes (Croskerry, 2009a). The corrective operation of the Type 2 reasoning mode has been shown to be influenced by time pressures, concurrent involvement in other cognitive tasks, mood and even time of day (Sladek et al., 2006). The level of expertise of the decision maker also impacts the use of Type 1 or Type 2 reasoning strategies. As expertise increases the reasoning task and information become more familiar and there is increasing use of intuitive reasoning (Harries & Harries, 2001). Croskerry (2009a) proposes that pattern recognition is the basis for Type 1 decision making and if the pattern is easily recognized then Type 1 processes are used but if this is not the case the more effortful Type 2 processes will be utilised.
Well practiced clinical decisions that are based on years of experience are almost automatic, often unconscious and fast, while incorporating new evidence into practice would require a conscious override by Type 2 processes of the routine Type 1 decision making (Harries & Harries, 2001; Sladek et al., 2006). While therapists utilise pattern recognition (as in Type 1 processes) and deductive reasoning or scientific problem solving methods (as in Type 2 processes), these strategies appear to be embedded in complex reasoning processes that individualise the intervention process to the specific client and setting (Harries & Harries, 2001; Smith et al., 2008).

Both Type 1 and Type 2 reasoning processes are prone to errors in decision making (Croskerry, 2009a). Errors with pattern recognition, especially in conditions with poorly demarked features and limited clinician experience, components of Type 1 processing can occur resulting in faulty decision making (Croskerry, 2009b). The repeated use of Type 2 processes (overlearning) for a specific problem set can result in them becoming Type 1 processes prematurely before all the exceptions to the rule have been experienced or adequate feedback on the accuracy of the decision making has been received (Croskerry, 2009; Croskerry, 2009b). Under these circumstances experience may not necessarily lead to expertise or accuracy in CDM. Once a response has been relegated to Type 1 processing further cognitive exploration of the decision-making is limited (Croskerry, 2009b). Other errors may occur when the surveillance or monitoring role of the Type 2 processes are compromised due to cognitive overload, fatigue, and affect issues (Croskerry, 2009b). There are also instances where Type 1 processes overrule Type 2 process resulting in errors, for example where the clinician is over confident (Croskerry, 2009b). Generally more errors occur with Type 1 processing compared to Type 2 processing (Croskerry, 2009b). To what extent these are two different processes or whether intuition (Type 1) and analysis (Type 2) actually occur along a continuum as described in cognitive continuum theory is debated (Hammond, Hamm, Grassia, & Pearson, 1997; Harries & Harries, 2001). Expertise of the decision maker and task characteristics are factors that influence the position on the continuum (Harries & Harries, 2001).
CDM by experienced therapists does not appear to follow a linear progression through the occupational therapy process but rather uses a much more complex process (Harries & Harries, 2001). CDM has been described as recursive, using both deductive and inductive skills (Simmons, 2010). Smith et al. (2008) also described CDM as a dynamic and fluid process involving interaction between data gathering from multiple sources, data interpretation, collaboration with clients and other professionals, choosing an action, and reflecting on and evaluating of the outcomes of that choice. That is, CDM is a cyclic, dynamic series of reasoning processes where decision making and actions are intertwined, building on each other to tailor and fine tune the intervention plan to the specific client and situation (Smith et al., 2008). Understanding how occupational therapists make clinical decisions is important to allow for the development of methods for supporting CDM and hence improve outcomes for stroke survivors impacted by those decisions.

4.2.3.2. Content in clinical decision-making.
CDM has been considered in terms of both content and process. We have seen that the process of CDM refers to how decisions are made. CDM content however refers to the ‘what’ of decision making: what the focus of the decision is; the knowledge used for making decisions; and the motivations and influences on the decision.

4.2.3.2.1. Knowledge and information for decision-making.
Occupational therapists make many different decisions each day. These may be about assessment or intervention, or about how they interact with their clients. However looking more closely, within each of these categories there are many further decisions to be made. For instance, when considering interventions, therapists need to make decisions not just about which intervention to use, but for whom, when, for how long, at what intensity, in which location, at what cost and so on. Each of these decisions requires different types of information and knowledge from many different sources. The phrase ‘practice knowledge’ encompasses most types of knowledge underpinning clinical decisions. It includes propositional knowledge (theory, science and available research evidence) and non-propositional
knowledge (professional and personal experience) as well as knowledge about the client (Chapparo & Ranka, 2008, Copley et al., 2010; Higgs, Jones, & Tichen, 2008).

In order to manage all this information, therapists form an internal frame of reference from processing knowledge related to interventions, clients, other professionals, the context, as well as professional and personal beliefs (Chapparo & Ranka, 2008). This then enables therapists to create pictures of their client, their problems, therapy and outcomes to direct reasoning, prioritisation of information, and CDM (Chapparo & Ranka, 2008; Smith et al., 2008). Practice knowledge is highly contextualised, influenced by the setting, current societal and organisational influences, and forms an overall frame within which clinical decisions are made (Chapparo & Ranka, 2008; Copley et al., 2010; Larsen, Loftus & Higgs, 2008).

**4.2.3.2.2. Sources of knowledge and information to inform clinical decisions.** Therapists access information from a range of different sources to inform their decision-making. In a literature review (Kloda & Bartlett, 2009) of 17 studies (predominantly survey studies) of rehabilitation (occupational therapists, physiotherapists and speech language pathologists) therapists’ information seeking behaviour, the authors found rehabilitation therapists sought information focused on specific diagnostic groups and intervention strategies. Rehabilitation therapists primarily consulted their peers and journal articles for information (Kloda & Bartlett, 2009).

There has been one study specifically addressing the types and sources of information therapists seek about interventions when treating stroke survivors. Sweetland and Craik (2001), after surveying 200 British occupational therapists treating adult stroke survivors, found the majority of therapists (76%) reported that their knowledge was influenced by peers, post graduate courses (69%) and that 61% based their knowledge on their prior experiences. Experience and peers were not the only sources of information used in CDM by therapists who treat stroke survivors. In a survey of 117 occupational therapists and 126 physiotherapists across Canada who treat stroke survivors, Korner-Bitensky et al. (2007) reported that the most frequently given reason for choosing interventions was that the therapist had learnt
the intervention during their professional education even though more than half of
the survey respondents had been practicing more than ten years. There were no
specific studies that identified where therapists obtained information about
interventions addressing ULPSSI.

While practice based knowledge is important in CDM experience can also be a
double edged sword. This is because although it provides information to inform CDM
it is also subject to bias and can limit our consideration of alternative approaches
(Robertson, 1999; Thompson, 2003). Several biases or reasoning errors such as
overconfidence, distortion of hindsight, base rate of neglect, anchoring and
availability have all been discussed in the literature (Thompson, 2003). Thompson
(2003) recommended methods to strengthen the validity of knowledge developed
from practice to reduce the risk of bias and reasoning errors.

It is unclear what sources of information contribute to therapists' knowledge about
ULPSSI or what information they rely on when making decisions regarding
addressing ULPSSI. Since this is an emerging area of research it would also be
important to identify the practice knowledge therapists are using to base their clinical
decisions on. Making sound clinical decisions is dependent on the type and quality of
the knowledge utilised in the CDM process (Higgs et al., 2008) and understanding
the sources of this knowledge will allow for understanding the basis for the decision
outcome as well as providing ways to support or improve the knowledge basis for
CDM. An important type of information for informing clinical decisions that has
received much greater attention over the last few decades is research evidence.

4.2.3.3. Factors influencing CDM.

However before decisions are made, information is filtered by the therapist. In
Schell’s Ecological Model of Professional Reasoning, professional reasoning is
described as being dependent on the personal lens (beliefs, values, knowledge and
experience) of both the practitioner and client as well as the professional lens
(practice theories, knowledge, experience and skills) of the therapist (Schell &
Schell, 2008). Thus therapist’s interpretations of different pieces of information or
‘factors’ about the client, available evidence, the impairment process, the external
context or therapy environment, theoretical models, occupational needs and opportunities all impact what information is prioritised and how decisions are made (Hooper, 2008; Smith et al., 2008). Similarly, the clients’ knowledge, prior health experiences, goals, preferences and the extent to which they are involved in the CDM process impact both the direction and processes of clinical reasoning (Atkins & Ersser, 2008).

Therapists prioritise and synthesise many different factors when making decisions (Rassafiani et al., 2008). Understanding the type of factors commonly influencing CDM is useful because it can enable therapists to think more consciously about the information they need and the way in which decisions are made (Rassafiani et al., 2008). Additionally, understanding the factors influencing CDM will also allow exploration of how these factors impact quality of care or may contribute to errors in practice (Smith et al., 2008).

A number of studies have examined the factors influencing occupational therapists’ CDM including: studies of factors influencing whether or not to accept referrals in community mental health (Harries & Gilhooly, 2003); factors affecting management of upper limb hyper tonicity in children and adolescents with cerebral palsy (Rassafiani et al., 2008); factors influencing management of upper limb performance dysfunction following brain injury (Kuipers et al., 2006); and factors impacting drivers licensing decisions in elderly and functionally impaired individuals (Unsworth, 2007).

These studies identified that therapists focused on client-specific factors (Kuipers et al., 2006; Rassafiani et al., 2008; Unsworth, 2007), therapist-specific factors (Kuipers et al., 2006) as well as context (Harries & Gilhooly, 2003; Kuipers et al., 2006) when making decisions. For example, Harries and Gilhooly (2003) used social judgement theory in a quantitative study of 40 occupational therapists’ decisions to accept or decline 120 (30 were repeats) case scenarios that were referrals for mental health occupational therapy. Therapists prioritised accepting referrals based on multiple client-specific and contextual factors including: who referred the client, demographic information, diagnosis, living situation, mental health history including other services involved, reason for referral and the reported level of violence of the client.
Kuipers et al. (2006), when interviewing 11 occupational therapists who work with clients with brain injury in two focus groups, found that therapists focused on client factors such as client condition, personal attributes, and occupational performance needs. Therapists in this study also utilised factors specific to the therapist, such as their level of comfort with specific interventions, and the environment in their decision making. Rassafiani et al. (2008) studied 18 occupational therapists that worked with children with cerebral palsy and asked them to review 110 cases (20 repeats) to analyse their decision making. Researchers then calculated a Cochran–Weiss–Shanteau (CWS) index to assess their ability to discriminate and evaluated consistency in CDM. Rassafiani et al. (2008) found that high performing (greater ability to discriminate but also higher consistency in CDM) decision makers used more factors in their CDM than low performing (lower ability to discriminate and lower consistency in decisions) decision makers. The majority of factors used by the expert therapists in Rassafiani et al.’s study were focused on client factors, impairments and previous therapy intervention, while low performing decision makers focused on a lower number of client factors and the clients’ and families’ background.

The nature of the decision task such as its familiarity, certainty, level of risk, stability and congruence (Shanteau, 1992; Smith et al., 2008), as well as the personal attributes and expertise of the decision maker and the context also impact the reasoning processes (Harries & Harries, 2001; Schell & Schell, 2008, Smith Higgs & Ellis, 2007; Smith et al., 2008). Smith et al. (2008) suggest that in order to improve CDM skills clinicians need to be aware of the multiple factors contributing to their CDM, whether content-based or contextual. This may help clinicians have greater accuracy and consistency in CDM (Rassafiani et al., 2008; Smith et al., 2008). Researching factors impacting expert clinicians’ CDM will also help students and new practitioners focus on the most relevant factors or information (Rassafiani et al., 2008).

A number of qualitative studies have explored the influences on occupational therapists’ reasoning and CDM in different practice areas (Kuipers & McKenna,
Smith, Higgs, and Ellis (2007) proposed these influences include the attributes of the task, the nature of the specific decision, specific attributes of the decision maker, and context within which the decision occurs. However, Rassafiani et al. (2008) argue that information obtained from studies of decision-making with one client group is not readily transferable to another client group as expertise is domain specific. Currently no research has explored occupational therapists decision-making when addressing ULPSSI. Smith et al (2008) suggest that to improve decision-making skills clinicians need awareness of the multiple factors influencing their decision-making, especially for practice areas in which uncertainty about effects of interventions exists. Studying these factors in different fields can help therapists be more cognisant of their clinical decisions and the type of information they require. Further research regarding the factors impacting occupational therapy CDM when addressing ULPSSI could potentially improve clinicians’ CDM and ultimately outcomes for stroke survivors.

4.2.3.4. Managing uncertainty in decision-making.
While incorporating research evidence into CDM is important, there are many areas in occupational therapy practice where there is limited research to support interventions (Kuipers & McKenna, 2009; Rassafiani et al., 2008; Rassafiani, Ziviani, Rodger, & Dalgleish, 2009; Smith et al., 2008). This may lead to uncertainty in the therapists’ CDM (Beresford, 1991). Where high levels of clinical uncertainty exist there is a higher level of variation in the interventions utilised by clinicians (Jette & Jette, 1997). Uncertainty in health care decision-making is inevitable and has three proposed forms; technical, personal, and conceptual (Beresford, 1991). Technical uncertainty results from having inadequate information to predict effectiveness of the interventions and inform prognosis. For example, often occupational therapy practice has limited research to support interventions (Kuipers & McKenna, 2009; Rassafiani et al, 2008) or therapists may be unaware of the research which is available (Kielhofner, 2005; Upton et al., 2014), both of which could contributing to clinician’s technical uncertainty. Personal uncertainty is related to the client-practitioner relationship and understanding the client’s goals whereas conceptual uncertainty is linked to applying guidelines, theories and past experiences to current clients (Hall, 2002). Occupational therapists often have difficulty identifying the relevance or
applicability of research findings to their particular clients which can be characterised as a form of conceptual uncertainty (Kielhofner, 2005; Upton et al., 2014).

Only one study, published prior to the timeframe of the study forming this Chapter, was found addressing uncertainty in occupational therapists. Kuipers and McKenna (2009), in a qualitative study of 11 expert occupational therapists noted that occupational therapy neurological practice is characterised by uncertainty and lack of confidence and even expert therapists sought guidance and structure for their CDM. Lack of knowledge increases levels of technical uncertainty, placing greater demands on therapists’ clinical reasoning (Kuipers & McKenna, 2009). Kuipers and McKenna (2009) recommended using evidence-based decision aids (based on evidence and expert opinion) and training therapists in clinical reasoning skills in areas of uncertainty.

Uncertainty in CDM has been studied in other health care professionals and these studies may provide useful information for understanding occupational therapists CDM in areas of uncertainty. In a literature review of more than 60 research articles about uncertainty and intuitive reasoning in medical decision making, 19 of these studies addressed uncertainty (Hall, 2002). It concluded that physicians deal with uncertainty by denying its existence, doing what others are doing, and increasing actions such as ordering of tests or use of technical responses. In a literature review of 10 studies describing how nurses manage uncertainty, Cranley et al. (2009) observed that they use heuristics and relied on the expertise of colleagues when faced with uncertainty. In a handbook on EBP and patient safety for nurses, Benner, Hughes, and Sutphen (2008) concluded that when evidence or knowledge is missing, clinicians draw on general scientific knowledge, evaluate its relevance to the specific situation, or need access to guidelines that combine experts’ opinions and the knowledge that is available.

Another strategy utilised in situations of uncertainty is analogy. The use of analogy is fundamental to human cognition and commonly used in decision making particularly when research evidence is not available (Patel, Arocha, & Zhang, 2004). Analogy occurs when one extrapolates information from an area or condition that may have a
degree of certainty to one of less certainty and is a means for reducing uncertainty (Gray, 2010). However while there are advantages to reasoning by analogy, this form of reasoning is prone to error because of the potential that factors that are different but unknown are likely to be operating in the two areas or conditions (Gray, 2010). For this reason Roberto (2009) recommends decision makers should use strategies to recheck conclusions drawn from this approach. Indeed, being reflective, observing what works well and learning from experience is recommended in particularly complex, uncertain areas of practice (Plesk & Greenhalgh, 2001). It is likely that reasoning by analogy is a common strategy used by therapists in areas where uncertainty exists and therefore warrants further research in order to understand its advantages and limitations.

In a study of 462 physiotherapists and their intervention choices in an area of clinical uncertainty, Jette and Jette (1997) concluded that CDM was influenced by idiosyncratic factors such as the educational level of the clinician, the practice environment and context, as well as the clinical status of the client. Therapists' internal beliefs or frame of reference also impact their CDM and this may be especially true in areas of uncertainty or limited evidence (Chapparo & Ranka, 2008). A qualitative study of 64 mental health professionals (Leydon & Raine, 2006) found clinicians felt a “need to act”, despite the lack of evidence, based on a need to help and for practitioners to maintain their own self-worth. Similarly in their interviews with physiotherapists, Smith, Higgs and Ellis (2007) noted that decisions were not only made to optimize health outcomes for clients, but sometimes may be motivated by ensuring clinicians’ own emotional comfort. This further illustrates the importance of professional and personal beliefs and the highly interdependent nature of clinical, professional, personal, and contextual factors, content and context in CDM (Chapparo & Ranka, 2008).

4.3. Summary and Implications for this Thesis

In summary, so far this Chapter has described CDM and EBP, factors influencing CDM and EBP, and how clinicians may manage uncertainty. Despite the importance of ULPSSI to functional use of the upper limb and outcomes for the stroke survivor, very little is known about the CDM underpinning the management of ULPSSI by
occupational therapists. While Chapter 2 described some research evidence regarding sensory measures and interventions for ULPSSI, it is limited, and until very recently had not been appraised or synthesised. EBP requires that clinicians locate and utilise the best available evidence in their CDM but it is unclear if therapists utilise this evidence in their CDM regarding ULPSSI management and if they do not, what sources of information do they use, and how do they deal with the uncertainty that may arise. Further studies that attempt to describe CDM, including influencing factors, types and sources of information accessed by therapists, and how they include the stroke survivor into the CDM process are necessary. This will provide information to understand CDM in general, and to specifically develop methods to improve occupational therapist’s decision making for ULPSSI management.

4.4. Study Aims
This study, therefore, aimed to explore and describe how occupational therapists make and manage (direct or control) decisions, particularly regarding the use of interventions when addressing ULPSSI. Specifically the research questions were:

1. How do therapists manage the decision-making process when addressing ULPSSI?
   a. What interventions do therapists decide to use?
   b. What influences decisions about interventions for ULPSSI?
   c. What strategies do therapists utilise, or types of information do they draw on, when making decisions?

4.5. Methods
A qualitative descriptive study, as described by Sandelowski (2000) and Ritchie (2003), was undertaken to explore and describe occupational therapists’ CDM when addressing ULPSSI. Qualitative descriptive methods are ideal when straightforward descriptions and interpretations of phenomena are desired, such as exploring and describing decision-making. Sandelowski (2010) describes the qualitative descriptive method as having a theoretical location of naturalism and with key design features of maximum variation sampling, individual or focus group interviews, and analysis utilizing variants of content analysis. Qualitative descriptive methodology takes a
factist perspective that views the interview data as accurately conveying the truth out there consistent with the naturalism perspective (Sandelowski, 2010). The qualitative descriptive approach is low on inference; requiring the researcher to complete the analysis and interpretation while staying close to the data (Sandelowski, 2010).

4.5.1. Participants and setting.

Occupational therapists that treat stroke survivors were purposefully recruited using maximum variation sampling to enlist participants from a range of clinical settings and experience, enhancing the richness and variation in the data (Patton, 1990). Fliers and brochures advertising the study were distributed in occupational therapy clinical settings in the Pacific Northwest of the USA. The fliers provided the primary researcher’s contact information for those who were interested. A maximum of four participants were recruited from each of the clinical settings until a total of 12 participants were recruited. Maximal variation sampling allowed identification of a range of content and contextual elements of decision-making, consistent with the study aims to describe how therapists manage ULPSSI and the qualitative descriptive approach (Ritchie, Lewis, & Elam, 2003; Sandelowski, 2000). Common categories identified using maximum variation in sampling will reflect core experiences of occupational therapy practice across settings and experiences related to providing ULPSSI interventions (Patton, 1990).

This study utilised a sample size of 12 based on previous research suggesting that sample sizes of 12 to 20 participants enables data saturation to be achieved for studies that aim to describe shared perceptions even when utilising maximal variation sampling (Guest, Bunce & Johnson, 2006; Kuzel, 1999). Twelve occupational therapists (one male) in a large metropolitan area of the Pacific Northwest United States from the following settings participated: acute hospital (four), skilled nursing facilities (three), outpatient clinics (three), home health (one) and inpatient rehabilitation (one). Participants’ mean years of experience was 11.7 years (range 1.8 to 39) and they reported an average of 28.8 % (range 5%- 80%) of their case load as stroke survivors. Approval was obtained from a Research Ethics Board at the University of Queensland and the Institutional Review Board at
Southwest Washington Medical Center where the primary researcher was employed and informed consent by all participants was obtained prior to the interview.

4.5.2. Data collection.

A semi-structured interview guide utilising open ended questions (Arthur & Nazroo, 2003) focused on exploring therapists’ choice of interventions for varying levels of ULPSSI and time post-stroke guided data collection (See Table 4.1 for examples). The questions were developed by the initial research team that consisted of the primary researcher (an occupational therapist with over 30 years of experience in stroke rehabilitation, working in academia, and completing her doctoral studies), the primary research advisor (an experienced occupational therapist, academic, and researcher in the area of stroke and client centred practice), and a consultant (a gerontologist, researcher and academic). The questionnaire was piloted by two experienced occupational therapists who were also working in academia that not only completed the interview but provided feedback on the questions. The pilot data was not incorporated into the study data. Therapists were asked to describe the interventions they chose because these represent the actual decisions made, and provided a framework for understanding their decision-making. The interview guide asked about participants’ knowledge of ULPSSI and interventions, their perception of the chosen intervention’s effectiveness, and where they had learnt about those interventions. The probing question of “Why?” was utilised to capture reasoning, especially related to intervention choices.

Table 4.1: Examples of open ended questions

| 1. What intervention strategies do you choose to use with your clients who have sensory deficits after a stroke? |
| Probes: What kind of reasoning did you use to support that? What are you thinking here? How do you decide on you are going to do? Why? How does this choice of intervention change over time (e.g. 3 weeks post-stroke, 3 months post-stroke, and 1 year post-stroke)? How does your choice of intervention differ in relation to the severity of stroke? |
2. How effective do you think these strategies are?
Probes: What do you mean by effective? What evidence do you have that this intervention is effective? What do you mean by evidence? When there is little evidence what do you do?

3. How did you learn about this intervention approach/treatment strategy?

Due to resource limitations, the primary author conducted the interviews and techniques such as using a structured interview guide, member checking and peer-debriefing were utilised to minimise bias (Cohen & Crabtree, 2008). Individual interviews ranging from 30 minutes to 1½ hours duration were recorded and then transcribed. Data collection occurred from July 2007 to January 2010.

4.5.3. Trustworthiness.

Prior to conducting the interviews, the primary researcher answered all the open-ended questions to be used in the semi-structured interview outlining the expected findings that formed an initial reflexivity statement. This reflexivity statement, identifying the biases and perspectives of the primary researcher, was reviewed during data collection and analysis by the full research team to evaluate the impact of the primary researcher’s biases on the questions, interview probes, and analysis. The primary researcher initially believed that most therapists would utilise an NDT approach to treatment, focus on remediation of ULPSSI until six to twelve months after stroke, utilise research evidence as a means of determining effective interventions, and would search for research articles to find effective interventions for clients.

An audit trail allowed tracking of the decision-making process. The need to elicit further data regarding therapists’ decision-making and how they integrated prior experience, information from research, other therapists, and clients into this process was identified after the first few interviews. Further probing questions, specifically asking for examples and for the participants to define terms used, were incorporated.
in subsequent interviews with the hope that this would elicit richer details and further insight into the clinical decision making process.

Individual transcriptions were summarised and both the transcription and summary were emailed to each participant to review and amend or make additions allowing for member checking and confirmation of the data findings (Graneheim & Lundman, 2004). One participant added demographic data and another participant added one intervention strategy that he/she would not use and one intervention strategy that he/she would use for clients with severe ULPSSI. This participant’s comments were then incorporated into the transcripts.

**4.5.4. Data analysis.**

Using qualitative content analysis (Ritchie, Spencer & O’Connor, 2003; Sandelowski 2000) codes were derived from the interview data itself as key points from each of the transcripts were reviewed. Initially the transcripts were read and “chunked” into sections or “units of meaning” that described a single idea or thought and were each assigned a code that reflected the idea or thought (Graneheim & Lundman, 2004). Where two strong ideas were intertwined some chunks of text were assigned two codes. Ethnograph V6 was used to organise the data by highlighting areas of text, assigning codes to those text chunks, storing operational definitions, and an outline of the codes and the links to categories. The researchers reviewed the operational definitions of the codes individually and in group discussions for consistency and accuracy. Sub-categories were developed initially based on the interview questions. Nine sub-categories emerged from this process that utilised the systematic method described by Ritchie et al. (2003) and Graneheim and Lundman (2004) as well as diagraming the sub-categories and the related codes during discussions. The sub-categories were then reformulated based on the patterns that emerged from the data coding and the common elements linking them in relationship to the study aims to form the three major overarching categories. This process occurred during face to face meetings between the primary researcher and one of the research advisors and individually by the other researcher. Further email discussions between all three researchers resulted in the emergence of three categories and consensus regarding
the sub-categories and codes that were assigned to each category.

4.6. Findings.
Participants’ descriptions of choosing intervention approaches with stroke survivors that had ULPSSI are outlined in the category *Deciding on the focus of interventions*. Intervention choice utilised a combination of domain-specific content and contextual information described in the category *It all depends*. A final category of *Managing uncertainty in decision-making* reflects descriptions and experiences contributing to a sense of uncertainty when making intervention decisions and how they managed the decision-making process. The categories and exemplary data are presented below.

4.6.1. Deciding on the focus of interventions.
This category describes the choice of interventions participants made and some of the reasons they reported for making these choices. When addressing ULPSSI participants explained that they predominately focused on safety concerns and education, but also incorporated some compensatory and remedial strategies. One reason given for focusing primarily on safety was that patients with severe sensory deficits were viewed as being at increased risk for injury.

“The safety component is the biggest component that has to be addressed with any sort of sensory loss because there is such a high risk for injury to that arm.” (P5)

The predominant method participants reported using to address safety issues was education, targeting both patients and their caregivers and incorporating information on sensory deficits and related risks. Participants also provided information on visual and environmental adaptations and modifying daily routines to improve safety. While vision was used to increase safety, participants described encouraging patients to use vision to compensate for sensory loss. Similarly, using a mirror was seen as a compensatory strategy to increase visual feedback in functional tasks.

A lot of the patients seem like that they do not have that fine tuning so that you have to do a lot of visual compensation for these guys… visually knowing
Participants mainly described providing non-specific stimulation or exposure to stimuli (termed sensory bombardment (Bohls & McIntyre, 2005) to remediate ULPSSI with only a few participants describing a more directed sensory re-education approach. The goal of sensory bombardment/stimulation was described as “stimulating it and hoping that it is going to come back.” (P4) and as another participant explained: “I would just try to bombard different sensory systems to see what we could get” (P10). Stimulation methods included: passive use of rubbing (using a washcloth or lotion), brushing, electrical stimulation, vibration, exposure to textures, weight bearing, and using ice. Sensory re-education appeared to be a graded and active strategy, assessing the patients’ current level of sensory awareness and then grading sensory input to re-educate different sensory modes. “My whole plan is that it is kind of like relearning, relearning how things feel so that they can accurately say where they are feeling it.” (P7)

4.6.2. It all depends.

Decision-making regarding ULPSSI management appears to be conditional and fluid, influenced by and dependent on a number of factors, with participants describing predominately considering clinical and contextual factors. While decision-making incorporated clinical and contextual factors, participants rarely mentioned asking their patients about his or her intervention preferences.

4.6.2.1. Clinical factors.

Participants recounted choosing compensatory approaches earlier in treatment for patients with severe sensory impairments. “If somebody is a low level, you just, then, it is more focused on protecting the limb.” (P4) For patients with mild sensory impairment, there was a dual emphasis on safety education and remediation of sensation initially with increasing emphasis on functional and compensatory approaches over time.
Participants described focusing predominately on compensation for severely impaired survivors as early as three weeks post-stroke, while for patients with mild sensory impairment the transition to compensation started at three months. The rate of recovery influenced decision-making about interventions with participants reporting monitoring return of sensation in considering adjustments to interventions. As the rate of recovery slowed participants described an increased emphasis on safety and compensation.

Well it just depends. Do they continue to make weekly or monthly gains for three months? Then I would still be pretty optimistic and continue to work with them as much as I could until they kind of reach a plateau I would think. (P13)

Sensory return and motor return were described by participants as being linked. “I also think that sensory and motor does go hand in hand and probably you would see if their motor impairment has improved and their sensory has improved.” (P 11) When deciding on interventions for either motor or sensory impairments the level of return in the other system was considered and affected intervention choice and focus. “Not knowing how much motor function that they have, would be the question, it would make a difference.” (P10)

Participants made many references to complicating clinical factors such as visual impairments, visual perceptual deficits including neglect, cognitive impairments, and communication impairments. Participants also recounted considering contraindications to the interventions they were considering including: having a pacemaker, open sores, and decreased temperature awareness. Coexisting medical conditions were commonly considered in the decision-making process such as hypersensitivity, skin condition, oedema, pain, anxiety and emotional status. Coexisting conditions either altered the intervention choice, application intensity (both dose and duration) and/or the intervention timing. “If they have co-occurring things like oedema or anything like that, I am going to be a little more careful with what I am doing.” (P7) Finally, participants described a fluid process of adjusting the intervention approach they utilised throughout the rehabilitation process depending on a mix of these factors. As one participant stated: “[With] every one you are treating you are always looking and adjusting, it is the whole picture because [of] all
these things.” (P7)

4.6.2.2. Contextual factors.
Contextual and pragmatic factors were recounted by participants as important in the decision-making process. Participants reported different treatment focused expectations in different clinical settings, such as focusing more on personal ADLs and safety in the acute and inpatient rehabilitation settings, and more attention on instrumental ADLs and sensory remediation in the initial outpatient setting while continuing the focus on safety.

Three months out they are typically in an outpatient setting seeing me here and at that point living at home or in a permanent living situation. So they may want to do things like cooking, or more ADLs for themselves, like bathing where they are doing their own temperature adjustment, so you want to reemphasize the sensory awareness. (P8)

Participants also considered the patients’ living situation and the social supports available to them. Patients transitioning to home increased the urgency to utilise compensatory strategies and education. As one therapist stated:

I might [use] caregiver education with the family or the caregiver depending on the setting that the patient might be going to. Then again looking at their safety awareness is the biggest part of that. Have they learnt their strategies to make them safe in terms of being home alone? You know. Is it a caregiver issue or is it a patient issue? (P5)

4.6.3. Managing uncertainty in decision-making.
Participants reported significant uncertainty in CDM regarding management of ULPSSI and discussed strategies they used to manage decisions when uncertain. Searching for new information, reasoning by analogy, and trialling interventions were common strategies to deal with this uncertainty in clinical care.

Participants described considerable uncertainty about assessment findings and utilising them when designing an intervention plan, expressing difficulty relating results to interventions, or to functional outcomes. This was noted in the following
participant’s comments: “The thing is if I find a deficit then I am kind of like ok. (laughter) What am I going to do about it? I can make them aware of it for safety issues.” (P13) Another participant expressed it this way:

At least, what I did is just measure it as a kind of screening to get an idea to guide treatment but then to look at function after that. Then maybe I just do not know enough about it or what else to do with that information. (P4)

Although able to describe interventions for ULPSSI when questioned, participants reported lacking knowledge about interventions. This lack of knowledge led to participants frequently reporting uncertainty about intervention options available. “If I get someone who has the severe sensory problems I am at a loss.” (P3)

Participants also reported uncertainty regarding the effectiveness of the interventions they chose. Participants felt interventions for sensory impairments were not as effective as interventions for motor impairments. “And I wouldn't say that the treatments that we use for that are as effective (as motor treatments).” (P8) Participants indicated changes were related to the patients’ natural return and not necessarily facilitated by the intervention. “Doing the things that we do is more of a… It is more of a test to see if there is return versus this is going to help you.” (P13)

Participants used a number of strategies and sources of information to deal with this uncertainty. They reported using peers as the greatest source of information. Information about sensory interventions was learnt by watching other therapists, asking for advice and input, or collaborative problem-solving. Generally, participants sought out more experienced therapists but also therapists who utilised interventions they perceived as effective. A participant described it as follows:

Just watching the other therapists here. There are a lot of therapists here who have had a lot more experience; there are a lot of people here. Kind of seeing what they do and asking a lot of questions if I am kind of at a dead end and I do not know what to do. (P13)

While another participant reported: “probably my biggest amount of learning has been from actually the other therapists that I have worked with over the years.” (P3)
Participants reported searching easily accessible journals, professional papers and online for information or research related to ULPSSI, but considered it time intensive and not generally useful.

Well, I feel like there is not as much research, either that I have read or that is available, to support sensory return as compared to motor return. So I can’t say that I have as much research in my treatment for this that is supporting what I am doing. (P8)

Participants reported using strategies such as reasoning by analogy; utilising information and research from areas they were familiar with to manage uncertainty in decision-making regarding ULPSSI. For example, participants reported learning about sensory interventions for paediatric populations in their professional education and extrapolating that knowledge to the adult population.

We do the motor sensory education stuff like in school with the paediatric population. … So when I think about sensory therapy … I just kind of think about those things and apply it to this population. (P13)

Other participants described utilising information regarding motor return and applied those ideas to the sensory area.

I think that I just extrapolated that if I am going from a foundation of what can happen to improve motor function that I can exercise the sensory system too. (P10)

Participants also recounted drawing analogies to interventions for peripheral nerve injuries. One participant described reasoning about ULPSSI as being intuitive and common sense by drawing parallels to everyday experiences such as numbness and tingling. When faced with uncertainty, it appears participants reached for parallels with familiar areas in order to make inferences.

Though expressing considerable uncertainty about available interventions and their effectiveness, participants felt compelled to trial interventions. This was expressed by one participant as follows:

I am not sure. I just go on a belief system that it may make a difference and it
is worth trying and I want to have something that I can offer people with sensory loss. I have not seen any studies that tell me that there is a benefit to doing it. (P10)

4.7. Discussion.
The interventions participants reported employing focused on safety and education, non-specific sensory stimulation and compensation as the predominant intervention strategies for ULPSSI. While decision-making appeared largely influenced by clinical and contextual factors, the study participants recounted experiencing considerable uncertainty when addressing ULPSSI. They managed the uncertainty in decision-making through reasoning by analogy, trying options out, and, consistent with previous research, seeking information from their peers and relying on their experience. They did not report utilising EBP strategies such as searching for evidence to deal with this uncertainty. The following discussion will address each of the three research questions that support the main aims of this study in further detail.

4.7.1. Interventions used.
Participants reported predominantly employing interventions that focused on safety and education, non-specific sensory stimulation and compensation for ULPSSI. The most common strategies participants reported using to address safety issues was education that targeted both patients and their caregivers. When taking a remediation approach, participants mainly described providing non-specific stimulation or exposure to stimuli with only a few participants describing a more directed sensory re-education approach. Participants reported not knowing if the interventions they used were effective further reducing their confidence in decision-making. Given the relatively limited research available and lack of systematic reviews or up to date guidelines synthesising existing research at the time of the interviews this uncertainty is not surprising. Further, participants did not report using any of the interventions shown to be potentially effective for improving sensory impairments from the systematic review presented in Chapter 2 (Acerra, 2007, Chen, Liang, & Shaw, 2005, Cambier, De Corte, Danneels, & Witvrouw, 2003). Although
the systematic review (Doyle et al., 2010) has not been published when the interviews for this study were undertaken; the individual trials within the review had been published. Systematic reviews systematically locate and critically appraise the available evidence, providing a summary for clinicians and potentially hastening the assimilation of research into practice (Cook, Mulrow, & Haynes, 1997). However it is important to acknowledge that the mere publication of systematic reviews or other forms of synthesised evidence such as clinical guidelines will not inform CDM and clinicians need to be supported and encouraged to access, read and understand the research that is published.

At the time of this study, very little has been written about what interventions therapists actually use in practice for managing ULPSSI. De Wit et al. (2006) observed 15 occupational therapy and 15 physical therapy sessions with stroke survivors in each of four countries and concluded that occupational therapists address sensory impairments though the overall time was limited. There was no specific information provided regarding the interventions used. Limited time devoted to addressing ULPSI was also supported by Gustafsson et al. (2012), who observed three Australian occupational therapists conduct 22 therapy sessions with nine stroke survivors and noted only three interventions for sensory impairments during 181 observations. Again no details of the interventions observed were provided. In a survey of 78 American occupational therapists, Welters (2011) found more than 85% of therapists used awareness training with stroke survivors with sensory impairments and a high percentage also took a compensatory approach towards treatment. Surveying occupational therapists to determine practice patterns and decision-making using a larger sample would therefore be informative. A survey was completed by Doyle, Bennett, and Gustafson (2013) as a follow up to this study.

4.7.2. Influences on decision-making.

This supports research findings that indicate the interdependence of domain specific knowledge, professional, personal, and contextual factors in decision-making (Chapparo & Ranka, 2008; Rassafiani, et al 2008; Smith et al, 2007). Decision-making involves processing and prioritising different pieces of information when
choosing among a number of possible options. In this study, when deciding which interventions to use, therapists prioritised reducing the risk of injury for patients with ULPSSI. Reducing risk is a primary motivator for interventions decisions across many health professions (Fish & Higgs, 2008). However, the extent to which study participants prioritised interventions for increasing patient’s safety was dependent upon a number of clinical and contextual factors such as the severity of the sensory impairment and the support available to the patient at discharge.

Focusing on domain specific clinical factors was evident in most decisions participants made when choosing interventions and in deciding how much time to spend on interventions. Domain specific features included sensory impairment severity, rate of recovery, medical complications and coexisting medical conditions. These findings are consistent with Benner, Hughes, and Sutphen’s (2008) review of nurses’ clinical reasoning that concluded that clinicians consider the patient’s individual clinical trajectory, conflicting co-morbid conditions, and response to previous therapies in decision-making.

Participants’ responses suggest that contextual factors also influenced their decisions; most notably the clinical settings’ constraints and expectations, the patient’s point in the continuum of care, consideration of the context of their patient’s discharge setting, and the social and professional influences of colleagues on decision-making. When researching 14 acute care physiotherapists’ decision-making, Smith et al. (2007) noted that decision-making could not be separated from the external context in which it occurred. For example, organisational factors such as high workloads influenced physiotherapists’ decisions, requiring therapists to prioritise which patients they attended to, which issues to address, the amount of time on assessment versus interventions, limited time for involving patients in decision-making, and not being able to select and deliver optimal interventions (Smith et al., 2007). They further suggest that understanding factors influencing decisions enables therapists to more explicitly manage their influence on decision-making to enable selection of optimal courses of action.
4.7.3. Strategies and information used in decision-making.

Given their reported lack of knowledge, confidence and uncertainty regarding ULPSSI, how then did participants actually manage to make decisions? A number of strategies were particularly prominent. These included reasoning by analogy or extrapolating information from one practice area to another to reduce their uncertainty; relying on a belief that it is worth trying something; and relying on their clinical experience and that of others.

Use of analogy is fundamental to human cognition and is commonly used in decision-making particularly when research evidence is not available (Patel, Arocha, & Zhang 2004). Reasoning by analogy allows comparisons between different options and conditions and to make inferences. Extrapolating information from an area or condition that may have a degree of certainty to one of less certainty is a means for reducing uncertainty (Gray, 2010). However, while there are advantages to reasoning by analogy this form of reasoning is prone to error because of the potential that factors that are different but unknown are likely to be operating in the two areas or conditions (Gray, 2010). For this reason Roberto (2009) recommends decision-makers should use strategies to recheck conclusions drawn from this approach. It is likely that this is a common approach used by therapists in other areas where uncertainty exists and therefore warrants further research in order to understand its advantages and limitations.

When faced with uncertainty regarding the effectiveness of interventions, participants also relied on their belief that it was worth a try. A qualitative study of 64 mental health professionals (Leydon & Raine, 2006) found clinicians felt a need to act, despite the lack of evidence, based on a need to help and for practitioners to maintain their own self-worth. Similarly in interviews with physiotherapists, Smith et al (2007) concluded decisions were not only made to optimise health outcomes for clients, but sometimes motivated by ensuring clinicians’ emotional comfort, further illustrating the highly interdependent nature of clinical, professional, personal, and contextual factors in decision-making.
How participants made and managed decisions depended to some extent on their knowledge of the interventions and the degree of certainty they had about their effects. Although participants seemed confident when choosing interventions to improve patient’s safety or to teach compensatory skills, decisions related to remediation approaches seemed to be made with limited knowledge about ULPSSI, how to carry out these interventions, or about their potential effectiveness. Lack of knowledge increases levels of technical uncertainty, placing greater demands on therapists’ clinical reasoning (Cranley, et. al., 2009; Kuipers & McKenna, 2009).

Similar to studies about EBP that found therapists commonly rely on their clinical experience and that of others when making decisions (Bennett et al 2003; Copley & Allen 2009), participants relied on information from experts and colleagues when deciding on interventions for ULPSSI rather than theoretical or research knowledge. This is referred to by Smith et al (2008) as the social context for CDM. Difficult decisions are discussed with others to check their decision-making, generate new ideas, and set their decisions in the context of decisions previously made by others. In order to more fully embrace knowledge from clinical experience, methods to strengthen the validity of knowledge developed from practice may be important to consider.

After interviewing nine paediatric occupational therapists about evidence used in decision-making, Copley and Allen (2009) recommended developing a structured model with processes and standards to guide practitioners and reduce the risk of bias and reasoning errors when using experience. Developing and testing this approach is likely to be of benefit across all fields of occupational therapy. Kuipers and McKenna (2009), in a qualitative study of 11 expert occupational therapists, noted that occupational therapy neurological practice is characterised by uncertainty and lack of confidence and even expert therapists sought guidance and structure for their CDM. They recommended using evidence-based decision aids and training therapists in CDM skills. Development of a model linking understanding of ULPSSI, recovery patterns, and therapeutic interventions may reduce this technical uncertainty.
4.8. Limitations.

Understanding decision-making and the factors that influence decision-making is a complex research undertaking. Study findings were based on interviews and are limited by participants’ ability to recall and verbalise their thoughts about CDM. Ideally, being able to videotape interactions between the therapist and patient has been used and provides an opportunity for the researcher and participants to discuss their decision-making immediately after it occurred (Unsworth, 2005). It was not possible to use this process in this study due to pragmatic reasons although it may be a fruitful approach to use in the future.

The primary researcher developed the questions and conducted all the interviews which may have influenced the findings. Review by other researchers, a structured interview script and frequent debriefings were techniques utilised to minimise bias (Cohen & Crabtree, 2008). The primary researcher’s preconceived ideas related to the research questions may have also impacted on the interpretation of the results. These were recorded in a reflexivity statement at the beginning of the research project and were reviewed during the content analysis process to evaluate their impact with the co-investigators. Further member checking of the categories and outcomes of the content analysis with the participants may have strengthening the trustworthiness of the findings.

While the participants were drawn from a wide variety of practice settings to obtain maximum variation in the data, larger numbers of participants, five to eight, from each setting may have allowed for comparisons between each setting and increased the robustness of the results. It is also possible that the wording of the questions may have provided some bias. For example, participants may have felt they needed to describe interventions for sensory impairment regardless of whether they used them or not. Participants were asked: “How effective do you think these strategies are?” In retrospect, asking: “Do you think these strategies were effective or not?” may have been a better way to phrase this question. Also participants were not asked about how they identified patients who had sensory impairments and what sensory measures they used in this process. Having done so may have provided further understanding of the participants’ decision-making process.
4.9. Conclusion.

This study is the first that describes occupational therapists' CDM in the area of ULPSSI, uncertainty faced by therapists and their strategies for managing decision-making. Participants described considerable uncertainty in CDM related to addressing ULPSSI and utilised strategies such as searching for knowledge from peers, reasoning by analogy, and trialling interventions to deal with this uncertainty. They did not report using EBP strategies such as searching for evidence to deal with this uncertainty and further training in EBP and making available clinical practice guidelines and systematic reviews of the evidence may also increase use of interventions for which some evidence exists. Participants focused on domain-specific clinical factors and pragmatic contextual factors when making decision about interventions. Participants reported using interventions despite lacking confidence in their effectiveness and it appeared that interventions utilised differed from those with emerging research support. Given participants’ self-reported lack of knowledge and confidence, the development of a model that summarises the current existing knowledge regarding tactual sensation and ULPSSI, as well as an evidence based decision-making guide similar to that used by Kuipers and Grice (2009) is recommended. Additionally training to increase understanding of CDM especially in areas of uncertainty may assist therapists in being more aware of their biases and possible errors and to manage the influence of the myriad factors influencing their decisions. Further studies of CDM in areas of uncertainty in occupational therapy are warranted as well as studies evaluating the effectiveness of interventions commonly used to address ULPSSI.
CHAPTER 5: OCCUPATIONAL THERAPY FOR UPPER LIMB POST-STROKE SENSORY IMPAIRMENTS: A SURVEY

Study three was a survey that addressed aims 3 and 4 of the thesis, to describe practice choices occupational therapists commonly make when managing ULPSSI, the sources of information they use to make these decisions, and to compare current clinical practices with the best currently available evidence for assessment and interventions for ULPSSI. This Chapter reports the first part of study three which describes therapists practice choices when managing ULPSSI. The study used a purpose designed questionnaire, based on results of the qualitative study described in Chapter four and the literature reviewed in Chapter 2, to ascertain the current practice patterns of occupational therapists related to ULPSSI. Data was collected for this study in April 2010. The results of this study informed the need for and content of the educational intervention addressing the needs of occupational therapists, which is described in the final study of this thesis in Chapter 8.

This Chapter is based on the peer reviewed manuscript titled “Occupational therapy for upper limb post-stroke sensory impairments: A survey” which has been published in the British Journal of Occupational Therapy. In this Chapter, the published manuscript has been expanded and modified to allow the inclusion of additional detail for this thesis and has been formatted to maintain consistency throughout the thesis. To reduce repetition in the context of the thesis, a significant portion of the background material from the published manuscript has been removed as a comprehensive background to the issues related to ULPSSI at the time of this study are covered in Chapter 2 and throughout the earlier thesis Chapters.

Occupational therapy for upper limb post-stroke sensory impairments: A survey

5.1. Abstract

5.1.1. Purpose.

Upper limb post-stroke sensory impairments (ULPSSI) have an impact on a significant number of stroke survivors. There is comparatively limited research about assessments and interventions for the management of ULPSSI, with the best evidence about interventions, for example, coming from individual randomised controlled trials. In a time-constrained rehabilitation environment it is unclear how occupational therapists are addressing sensory impairments in clinical practice. This is important to understand because this information can inform further research, help understand what support (if any) therapists might need in this area, and potentially improves the outcomes for stroke survivors. This study aimed to investigate the clinical practice patterns of occupational therapists, perceived barriers to providing interventions, and information sources used when addressing ULPSSI.

5.1.2. Methods.

A survey was sent to 500 randomly selected occupational therapists in the United States of America.

5.1.3. Results.

The majority of the 145 respondents reported frequently assessing sensation although most were not using standardised assessment measures recommended by professional guidelines. Half reported providing interventions for sensory impairments. Interventions primarily focused on providing passive sensory stimulation followed by compensatory strategies. Most therapists provided patient/caregiver education about safety. Therapists cited lack of knowledge and skills, patients’ short length of stay, and lack of time as barriers to utilising interventions. Most therapists reported not being up to date with current research and requested continuing education to support practice.
5.1.4. Conclusion.

This survey established a profile of American occupational therapists’ practice with people with ULPSSI. Therapists reported a need for information and training in all aspects of the management of ULPSSI. Further research exploring therapists’ clinical decision making when choosing assessment measures and interventions is also needed.

5.2. Introduction

Stroke survivors constitute the largest diagnostic group treated by occupational therapists (National Board for Certification in Occupational Therapy (NBCOT), 2008) with the majority of stroke survivors experiencing upper limb sensory impairments (Acerra, 2007; Carey, 1995). Sensory impairments significantly impact not only upper limb functional use (Nowak et al., 2007; Rand et al., 2001) but also outcomes (e.g. independence in self-care, mobility, or handicap) for stroke survivors (Desrosiers et al., 2003; Rand et al., 2001; Tyson et al., 2008).

Stroke survivors receive rehabilitation in a number of different settings, but usually for short periods of time. In 2005 the average acute hospital length of stay for persons who have had a stroke in America was only 2.5 – 5.6 days (Russo & Andrews, 2008); with inpatient rehabilitation units average length of stay 16.5 days in 2007 (Granger, Markello, Graham, Deutsch, & Ottenbacher, 2009). However the potential for recovery of ULPSSI has been demonstrated to continue for four to six months (Connell, Lincoln, & Radford, 2008), past the time that rehabilitation is often provided. The minority receive outpatient rehabilitation with a survey of 4,689 American stroke survivors, Xie et al. (2007) finding that only 30.7% received outpatient rehabilitation services. These time constraints could potentially impact therapists’ CDM and the choices they make regarding the management of ULPSSI.

Understanding the current practice patterns of therapists when addressing ULPSSI is important not only to provide information on current intervention utilisation, but also
to allow a comparison between current practice and best practice (Menon, Korner-Bitensky, & Straus, 2010), or to identify research-practice gaps (Koh, Hoffmann, Bennett, & McKenna, 2009; Korner-Bitensky, Wood-Dauphinee, et al., 2006). Ultimately, understanding current practice patterns can inform the development of assessments and interventions, and approaches to support therapists working in this area, as well as therapist training (Koh et al., 2009). This study therefore seeks to describe current practices in the management of ULPSSI specifically by occupational therapists.

There have been six studies, prior to the commencement of this study, examining general practice patterns of occupational therapists working with people who have had a stroke (De Wit et al., 2006; Latham et al., 2006; Moulton, 1997; Natarajan et al., 2008; Richards et al., 2005; Walker et al., 2000), and in specific post stroke impairment areas such as cognitive impairments (Koh et al., 2009), unilateral neglect (Menon-Nair, Korner-Bitensky & Ogourtsova, 2007), secondary complications of the upper limb (Gustafsson & Yates, 2009), post stroke shoulder pain (Pomeroy, Niven, Barrow, Faragher & Tallis, 2001), dressing practices (Walker, Walker, & Sunderland, 2003), and provision of information to stroke survivors (Eames, Hoffmann, McKenna, & Worrall, 2008). While no studies specifically address practice patterns of occupational therapists when addressing ULPSSI, a few studies provide some limited information and are described briefly below.

5.2.1. Use of assessments for ULPSSI.

CDM often commences with gathering data from multiple sources and interpreting that data (Smith et al., 2008). One key source of data utilised by therapists is data obtained from assessment measures. The reliability and validity of the assessment measure used (reviewed in Chapter 2) impacts the accuracy of the data obtained which in turn can impact the outcomes of CDM.
While there are no studies looking specifically at occupational therapists use of ULPSSI assessments, there are a few studies describing ULPSSI assessments that multi-professional groups, including occupational therapists, commonly use. In these studies, therapists regard sensory assessments as important for guiding practice. Winward et al. (1999) surveyed 260 British occupational therapists, physiotherapists and physicians and found 90% or more felt sensory assessment provided significant information to determine clinical prognosis after stroke and 77 to 87% routinely performed sensory assessments as part of their evaluation. The most utilised assessments were for proprioception and light touch, consistent with parts of the “standard” neurological examination, and were most commonly used at initial assessment (Winward et al., 1999). Winward et al. (1999) had a return rate of 36% which may influence the results obtained. The population sample was both random and broad but given that the study is more than 11 years old, significant practice pattern changes are expected since its publication. A few years later, Dannenbaum et al. (2002) surveyed 55 Canadian physical and occupational therapists and found 73% regularly tested sensation when evaluating clients with stroke. Eighty-four per cent reported using the “standard” neurological evaluation. This survey had a small sample size with convenience sampling in one metropolitan area of Canada and provided limited details of the survey questions. No recent studies surveying the current use of sensory assessments were identified so it is unclear if therapists have adopted any of the more recent assessment tools that have a greater focus on functional aspects of sensation or use the recommended standardised assessments.

The most recent survey about the use of sensory assessments with stroke patients was undertaken eight years prior to this current study and was based in Canada (Dannebaum et al., 2002). It is unclear if current research developments and recommendations from stroke clinical practice guidelines have been incorporated by occupational therapists into CDM regarding ULPSSI management. Further research to identify if available standardised clinical ULPSSI assessments are currently utilised in practice is warranted.
5.2.2. Use of interventions for ULPSSI in clinical practice.

Once therapists have identified the presence of ULPSSI, they need to decide whether or not to address those impairments, and if so which intervention approach and specific strategies to use. A summary of the intervention approaches, strategies and the evidence available was presented in Chapter 2 and 3 of this thesis. While there were limitations with these individual studies, systematic reviews, and guidelines, all except the systematic review by Doyle et al. (2010), were widely available for therapists at the time this survey was undertaken. This research represents the best available evidence to inform therapists’ decision-making, but it is unclear if and how therapists used this evidence in practice.

Walker et al. (2000), in a survey of 61 British occupational therapists, found therapists more frequently chose a Bobath approach (44% 27/61) to intervention planning versus other intervention approaches (functional approach 26% 16/61, cognitive approach 3% 2/61, other approaches 21% 13/61) if their client had sensory impairments. Moulton (1997) surveyed 43 occupational therapists in home health that treated stroke patients and found that 93% provided compensatory interventions for ULPSSI and 31% provided remedial interventions. No specific details of the interventions used were provided. De Wit et al. (2006) observed 15 occupational therapists’ and physiotherapists’ treatment sessions in each of four European rehabilitation centres and noted the areas they addressed. Occupational therapists spent significantly more treatment time in sensory training activities than physiotherapists but no details of the interventions observed were given, the category sensory training activities included sensory, perceptual and cognitive interventions, and the overall frequency of therapists’ use of sensory training activities was low compared to other intervention categories (De Wit et al., 2006). No further studies were identified at the time of this study which described the interventions therapists were using when addressing ULPSSI.

From a survey of the literature available at the time of this study, it appears that therapists are utilising some interventions for the management of ULPSSI, though no
details of interventions used have been provided other than in one small study (Moulton, 1997). That study indicated therapists appeared to focus predominantly on compensatory approaches to address ULPSSI. In order to understand occupational therapists’ CDM for ULPSSI management, a focus of this thesis, a more detailed understanding of current practice patterns in this area is important. Therefore a survey of current practice patterns is warranted and was undertaken as part of this thesis.

5.3. Study aims
The aim of this study, therefore, was to survey occupational therapists working with people who had had a stroke in order to describe current occupational therapy practice with regards to addressing ULPSSI (both assessment and intervention practices), perceived barriers to assessment and providing interventions for ULPSSI, and information sources guiding their practice decisions in this area.

5.4. Methods

5.4.1. Design.

This study was by means of a postal survey approach conducted in March and April of 2010. The study was approved by an Ethics Review Board at the University of Queensland, Australia (Project number: 2010000150. Approval date: 16/02/10).

5.4.2. Subjects and procedure.

To be eligible for this survey, participants were required to be practicing occupational therapists who worked with stroke survivors. Participant information sheets and questionnaires were mailed to 500 members of the American Occupational Therapy Association’s (AOTA) Physical Disabilities Special Interest Section (PDSIS), selected by the Association, through computer-generated randomisation, from its 4,049 members. The names were purchased from the Association in accordance with its
membership guidelines, which allows members to opt out of receiving mailings. Reminder notices and methods were utilised to maximise response rates that Edwards et al. (2009) in their Cochrane Systematic review found and reported as effective. There is some concern about the ethics of using multiple reminders to increase response rate in surveys (Schirmer, 2009) due to concern about coercion. However this was minimised in this study by using only 1 or 2 reminders for those who did not respond initially and making it clear that participation was voluntary.

5.4.3. Instrument.

The questionnaire consisted of 31 questions designed to collect demographic data and practice patterns information related to addressing sensory impairment. Seven questions addressed clinical decision making in this area; these will be reported separately.

The ten demographic questions were related to therapists’ level of education, years of experience, practice setting, and percentage of clients with stroke as well as time since stroke. Fourteen practice pattern questions included:

a) Four open ended questions, requiring respondents to list three responses regarding choice of assessments used, choice of interventions used, components used in education interventions, and interests for further education about management of sensory impairment;

b) Four five-point Likert scale questions with the anchors ‘always’ to ‘never’ to determine frequency of assessing sensation, frequency of providing interventions including education, and perceived effectiveness of interventions used with the anchors ‘very effective’ to ‘never effective’ ;

c) Six multiple choice questions for identifying the number of intervention sessions used, therapists’ knowledge of interventions, barriers to
addressing sensory impairments, and sources of information about interventions.

Practice pattern questions were based on interviews with 12 occupational therapists conducted by the first author (Doyle, Bennett, & Dudgeon, 2014) and adapted from surveys of practice patterns in other areas (Griffin & McConnell, 2001; Natarajan et al., 2008). Information obtained from the interviews was used to provide choices in the questions related to barriers, sources of information, and also prompted the inclusion of the question related to education as an intervention and the perceived effectiveness. This information combined with the example of information from the prior practice pattern studies (Griffin & McConnell, 2001; Natarajan et al., 2008) guided the development of the questions related to choice and frequency of assessment and intervention use.

The questionnaire was piloted with ten occupational therapists in order to determine the ease to which the content could be understood. Comments received from these therapists suggested clarification of some wording and improvements in formatting which were then made by the researchers prior to distributing the questionnaire.

5.4.4. Data analysis.

Data were entered into PASW Statistics GradPack 18. Descriptive statistics were calculated for the Likert type questions and demographics. The first two researchers coded responses to open ended questions into independent categories and disagreements were resolved by discussion. For each open ended question, the number of responses in each category was divided by the total number of responses to determine the frequency for each category.

5.5. Results

A total of 187 surveys were returned, for a return rate of 37% and 145 met the inclusion criteria of participants who were currently treating stroke patients. The
results below are based on the surveys (145) that met the inclusion criteria.

5.5.1. Respondent characteristics.

Respondent characteristics are presented in Table 5.1. Respondents worked primarily in metropolitan regions and a broad range of clinical settings. Respondents had a mean of 14.32 years (SD=10.65) experience treating people with stroke. Respondents saw an average of 5.75 stroke survivors per week (SD=6.53) with the largest group within six weeks of stroke (48%). Over half of the respondents (77/145, 53.1%) reported that clients’ upper limb functional use had always or often been impacted by sensory impairments. A full analysis of those who did not respond was not possible due to the lack of data as the only information we had access to was name and address.

5.5.2. Assessing sensation.

Most respondents (135/145, 93.1%) reported always or often testing sensation on initial assessment and two thirds also did on discharge (91/138, 66%) (See Table 5.2 for further details). When asked to list up to three sensory assessments they frequently used, respondents provided a total of 383 responses predominantly describing the sensory modality assessed (e.g. light touch) and less often the specific sensory assessment measure used (e.g. Semmes-Weinstein monofilaments). The responses were grouped into categories according to the sensory modality or feature being assessed and some groupings remained broad as limited detail was provided by some respondents. One third of the assessments nominated evaluated light touch (126/383, 33%), followed by proprioception/joint position sense/kinaesthesia (55/383, 14.5%), sharp or dull/pain (46/383, 12.1%) and stereo gnosis (40/383, 10.5%) (see Table 5.3 for further details). Only one participant reported using any of the newer measures or more standardised multi-modal assessments such as the Nottingham Sensory Assessment (Lincoln et al., 1998).
5.5.3. Interventions for sensory impairment.

Half of the respondents (77/144, 53.5%) always or frequently utilised interventions that targeted specifically ULPSSI while 24/144 (17.1%) reported providing interventions targeting ULPSSI half of the time and 42/144 (29.2%) never or only sometimes do. Of those providing interventions for ULPSSI (N=137), 15 (10.9%) respondents saw the client only once, 34 (24.8%) provided 2-3 sessions, 31 (22.6%) provided 4-6 sessions, and 23 (16.8%) provided interventions over 7-10 sessions over the timeframe of their intervention plan. One quarter (34/137, 24.8%) of respondents did not nominate the number of sessions provided explaining they used interventions in ‘most sessions’ or ‘until goals were achieved.’

Respondents were asked to list up to three most frequently used interventions for sensory impairments, providing 321 responses. Non-specific sensory stimulation was the most frequent reported intervention for ULPSSI (116/321, 36.1%). Examples of specific interventions most frequently included this category were rubbing, brushing, electrical stimulation and vibration. This category included six responses indicating sensory stimulation was specifically used for desensitisation. Compensatory approaches, incorporating ADL retraining and safety education, were the next most frequently used interventions (69/321, 21.5%), followed by sensory retraining (incorporating graded interventions with cognitive strategies and specific approaches such as use of mirror therapy that incorporated re-education principles) (40/321, 12.5%), motor approaches (neurodevelopmental, Bobath, or constraint induced approaches) (39/321, 12.1%), and discrimination activities such as texture discrimination (38/321, 11.8%). Fewer respondents reported using ‘general education’ including education of family members about sensory impairment (9/321, 2.8%) and ‘other’ (3.12%).

Although education was not voluntarily nominated as the most frequent intervention used, when specifically asked about education provided to stroke survivors about their sensory impairment and its management, the majority of respondents (114/143, 79.8%) indicated they provided education often or always, 9.1% (13/143) half of the time, and 11.2% (16/143) sometimes or never.
Components most often included were education on safety issues (35.71%), followed by education about sensory stimulation or re-education programs (n=38, 14.86%), and a home program (12.78 %) (See Table 5.4). Overall, less than half (40.6%, n= 56) of therapists thought interventions for ULPSSI were moderately effective or very effective while 35.5 % (n=49) thought they were effective half of the time, and 23.9% (n=33) thought they were effective only a little bit or never.

5.5.4. Perceived barriers to the delivery of interventions for sensory impairment.

When asked to select which factors were barriers to utilising interventions for sensory impairment, half of the respondents (71/137, 51.8%) identified 'lack of knowledge/skills' related to interventions for ULPSSI and ‘the client’s length of stay being too short’. Having a lack of time to provide interventions was similarly reported as a barrier by almost half of the respondents (67/137, 48.9%). Perhaps not surprisingly, insufficient research evidence to support interventions was identified as a barrier to providing interventions for ULPSSI (45/137, 34.3%). Other reasons less frequently perceived as barriers to providing interventions for ULPSSI included interventions for ULPSSI not being a priority for the client or not being identified as a priority in the treatment plan. Very few were concerned about the cost of providing the service, interventions for ULPSSI not being considered part of the occupational therapy role by the facility, or the travel distances for the client to receive the service. (See Table 6.5 for further details).

5.5.5. Need for further information to guide practice.

Most respondents (111/142, 78.2%) felt they were not up to date with their knowledge of current research evidence about the effects of sensory interventions for stroke survivors. The methods respondents thought most useful to increase their use of interventions for ULPSSI were receiving information about interventions through continuing education workshops (23.1%), research that demonstrates the effectiveness of specific interventions for improving sensation (22.2%) or improving
upper limb function (21.6%). Less thought clinical guidelines (n=19, 14.1%) or experts visiting the practice (12%) would increase their use of interventions for ULPSSI, and only 12 (9.2%) nominated more time in practice as a means of increasing the use of interventions for ULPSSI.

Respondents suggested 121 topics for further training with respect to sensory impairments following stroke. These ideas were categorised as relating to intervention, assessment, knowledge about sensory impairment, or how to support/train others. Training regarding interventions for sensory impairment was most requested (n=70, 57.9%), followed by information about sensory impairment (n=28, 23.1 %), training about assessments for sensory impairments (n=16, 13.2%), and information about training others to care for someone with sensory impairments (n=4, 3.3%) with the remaining three (2.5%) responses being unclear.

5.6. Discussion

ULPSSI is of increasing interest to clinicians and researchers due to a growing awareness of its impact on function and other outcomes. This study described the current clinical practice patterns of occupational therapists when addressing ULPSSI, barriers to providing interventions, and sources of information guiding practice.

Of those who did respond, all mainland states of the USA were represented but not in large enough numbers to see if there were practice differences due to geographical location. According to the USA census bureau 19.3% of Americans live in rural areas. An Occupational Therapy Advance magazine salary survey of occupational therapists (low numbers 2,138) reported that the percentage of occupational therapists reporting working in rural areas was 19.1%. In this survey 32.9% reported working in rural areas. There is some overlap with the criteria in our survey and that used by the USA Census Bureau in how urban areas are identified, and therefore it appears that therapists working in rural areas were probably well represented by the respondents and the sample was likely representative of the population in terms of geographic distribution.
The majority of therapists in this study agreed that sensory impairment impacted stroke survivors’ functional upper limb use. Therapists predominantly evaluated sensation through testing specific, discrete sensory modalities based on the standard neurological examination. Both the type and frequency of sensory assessment is consistent with previous research about somatosensory assessment practice (Winward et al., 1999, Dannenbaum et al., 2002). Participants did not report using any of the recently developed or recommended measures that address aspects of sensation affecting hand function and only one reported using the more standardised assessments such as the Nottingham Sensory Assessment. This is concerning in that this limits not only therapists ability to identify stroke survivors who have ULPSSI but also the therapist ability to identify if the interventions they choose to use are effective. This may indicate a need for therapists to receive information and training in the use of these more functionally-orientated sensory assessments as well as the importance of standardised assessment measures to identify impairments and their use as outcome measures to evaluate the effectiveness of their interventions for that client. This is also particularly important where the existing research evidence about interventions comes from either single RCTs or from non-randomised studies.

The most frequently nominated interventions for addressing sensory impairments were passive sensory stimulation strategies with very few reporting use of interventions that used a graded specific sensory retraining approach (including use of mirror therapy using re-education principles). Some comparisons and comments can be made about the use of these interventions in the light of the results of the systematic review by Doyle et al. (2010) presented in Chapter 3, (but not yet published at the time of this survey). The systematic review found individual trials (for which effect sizes could be calculated), that reported use of remedial approaches such as graded mirror therapy, thermal stimulation, and intermittent pneumatic compression having some impact on sensation. Notably, the trial of mirror therapy incorporated some principles of sensory re-education and as such, was graded and specific in nature. Of these interventions, only mirror therapy was reported as having
been used by respondents in this survey and this was by only a small proportion of participants.

It is important to consider however, how the evidence from this systematic review might inform practice decisions. The systematic review located 13 RCTs and concluded that there was insufficient evidence to support or refute the effectiveness of the interventions tested. However, considering the framework of evidence based practice, this systematic review, and the individual trials within it currently represents the best available evidence and may still inform CDM. The question of when evidence is sufficient to inform practice is an interesting one and partly depends on whether one is considering practice choices with an individual patient in mind, or as a practice choice to use routinely across a particular patient group. This thesis takes the position that these individual trials currently provide the best available evidence and may inform intervention choices made with individual patients (particularly in instances where ULPSSI is the patients’ expressed priority) but are not conclusive enough at this point to make changes to practice routinely. More specifically, when considering such evidence with individual patients, clinicians need to consider factors such as the quality of the evidence, potential clinical significance of the results, and integrate this information with the goals, values and preferences of the patient, and their own clinical experience (Bennett, Hoffman, McCluskey, McKenna, Strong, and Tooth, 2003; Sackett et al., 1996). This also means considering alternative priorities for intervention (if any are indeed required), given the short time frame often available for intervention. If therapists do decide to use these interventions, ideally they should then carefully measure and monitor outcomes for the individual patient. Finally, Gustafsson and Yates (2009), when surveying occupational therapists use of interventions for the post-stroke upper limb, concluded that therapists frequently used techniques for which there was limited evidence and that further investigation not only of the effectiveness of these techniques but the reasoning processes underlying their choice is warranted.

After non-specific sensory stimulation, compensatory approaches (22%) were the next most frequent intervention utilised. However the effectiveness of compensatory strategies for sensory impairment has not been established. As well as utilising either
remedial or compensatory approaches, a majority of therapists (80%) reported providing client education focusing largely on safety issues related to sensory impairments, but also included education related to sensory stimulation programs and home programs. This is consistent with the Royal College of Physicians (2008) recommendations that the stroke survivor be educated regarding safety concerns and techniques to avoid injury to the upper limb.

Results from this survey indicate the majority of therapists did not report using interventions for which RCTs demonstrate some beneficial effects, and that rigorous research is lacking for interventions that therapists more frequently utilise. While further research is required to replicate results from individual trials, currently utilised intervention strategies (passive sensory stimulation, education, and compensation) for sensory impairments is also warranted. Approaches to disseminate information, and provision of education and training to increase therapists’ awareness of research that is available needs consideration.

Therapists reported not feeling up to date with research evidence regarding the effectiveness of interventions for ULPSSI and 51.8% rated their lack of knowledge as a barrier to using these interventions. Respondents frequently used theories or models to provide information about interventions for ULPSSI but infrequently utilised clinical guidelines (which had made recommendations for assessment and intervention), research studies and systematic reviews. Therapists reported lack of evidence to support interventions for ULPSSI as a barrier to utilising interventions for ULPSSI. This is not surprising considering there are only individual RCTs providing information about the effects of interventions, however their awareness that this research exists is not known. Even when therapists feel confident with their knowledge of interventions, client’s short length of stay and lack of time that therapists have to provide rehabilitation seems to limit ULPSSI being adequately addressed. This might be addressed by a change in focus for therapy to incorporate self-management techniques (Barker & Brauer, 2005). Therapists in this study were providing some education regarding home programs and sensory re-education which
may be the start of this approach. This is particularly concerning as well, given the limited number of stroke survivors who receive outpatient therapy after discharge. Interestingly only few therapists (9.2%) nominated more time in practice as a means of increasing the use of ULPSSI interventions, and while time available may be a potential barrier, lack of knowledge and lack of evidence were also seen by therapists as significant barriers by approximately half of all the respondents.

Therapists in this survey wanted further information about ULPSSI after stroke, identifying further continuing education courses as important and suggested a total of 121 different topics predominately related to interventions for, knowledge about, and assessment of ULPSSI, as well as information about training others. There is some evidence that information from continuing education courses may help change practice. A Cochrane systematic review that evaluated the effectiveness of continuing education programs to alter clinicians practice concluded that continuing education programs had some effect on practice and patient outcomes either as a stand-alone intervention or combined with other interventions (Forsetlund et al., 2009). Given that the evidence for ULPSSI interventions comes from individual RCTS or non-randomised studies, therapists may also benefit from information and guidance about clinical decision-making in areas of uncertainty how to think about research which is limited to these types of studies. Further information about using standardised sensory measures and information on how to evaluate their practice would be beneficial.

5.7. Limitations

Participants were randomly selected from the AOTA PDSIS. As members of the American Occupational Therapy Association (AOTA) the respondents have access to current journals, association publications and conferences that may provide them with access to current information and encourage evidence based practice that non-AOTA members are not exposed to and therefore may not be representative of all occupational therapists who treat stroke patients.
The response rate of 37% is consistent with research looking at current response rates for mail surveys (34.6 - 39.6%) though lower than research for mixed (mail and online) methods (60%) (Greenlaw & Brown-Welty, 2009), hence the respondents reflect a small proportion of the sample. It is likely that a number of members of the AOTA PDSIS would not have responded to the survey because they did not work with people who have had a stroke. It was not possible to identify a broad random sample of practitioners who had stroke as a specific clinical focus. The effective response rate for the data analysis was around 29% for each question and this may have underpowered the data analysis and hence impact the results of the study. Other methods to increase response rate may need to be trialled for other studies to describe therapists practice patterns more accurately on a larger scale to enhance response rate and increase the representativeness of the respondents. There is a potential that geographical differences in practice behaviours may have influenced the results but the low numbers of participants in each geographical area or state limited the ability to evaluate this impact. This is an area for further exploration.

Categorisation of open ended responses was limited to some extent by the ability of the authors to interpret responses provided. When categorising frequently used interventions, a few interventions were unclear in their intended use. For example, the category ‘discrimination activities’ included responses simply stating ‘texture discrimination’ or ‘rice buckets’. Whether these activities were intended as sensory stimulation or as sensory re-education is unknown. It was therefore kept in a separate category. However it is unlikely that these activities (‘texture discrimination’ or ‘rice buckets’) belong to only one of the aforementioned categories and therefore it is unlikely to alter the order of categories of the most frequent interventions.

Respondents were asked to self-report the frequency of which they performed certain behaviours such as assessments, education and interventions using Likert scale questions and how effective they perceived these behaviours to be. Self-reporting is open to several biases included social acceptability and memory. The respondents’ interpretation of the wording of the questions or the anchors may also be different to the researchers and other respondents. The multiple choice questions
may have limited the therapists responses or suggested options they had not recalled. The answers to these multiple choice questions may also be impacted by memory or perceived social acceptability.

There were several questions with missing data, with up to eight respondents not answering some questions, resulting in at most 5% missing data for those questions. For most questions with missing data only one or two respondents did not answer the question (around 1%). All analyses were compiled based on those who did answer each question using the traditional list-wise or case-wise deletion method. No analysis was completed to see if there was a pattern related to the missing data, but due to the low number of missing items overall this was not considered a major concern and is unlikely to have affected the conclusions.

5.8. Conclusion

ULPSSI management is complex and relies on sound choice of sensory measurement tools and well-reasoned intervention choices. Although therapists responding to this survey measure ULPSSI in stroke survivors, their infrequent use of recommended standardised measurement tools is of concern not only with regards to identifying ULPSSI, but also with the ability to evaluate the effectiveness of the intervention choice especially given the small number of research studies available in this area. Interventions therapists most commonly reported using focused on providing non-specific sensory stimulation, compensation, and safety education to clients with ULPSSI. Although education is important for all clients with ULPSSI, therapist's choice of specific remedial interventions generally differed from interventions that have some evidence for benefit from individual trials.

This survey highlighted the lack of knowledge and confidence that occupational therapists have in this area of practice and therefore it was not surprising that therapists wanted further information about ULPSSI in general and about its management. Time constraints were also raised as an issue in being able to provide interventions for ULPSSI and this concern requires closer investigation. Given the
complexity of practice in ULPSSI, it is likely that occupational therapists could benefit from approaches that support their decision-making in this area.

Respondents also reported needing more research to demonstrate the effectiveness of interventions not only for ULPSSI but also for improving upper limb function after stroke. Consulting therapists in the research design phase may also result in increasing the likelihood that research might meet the therapists’ needs by addressing their specific clinical concerns.

5.9. Tables

Table 5.1 Respondent Characteristics  (N=145)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Highest Academic Qualification</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diploma</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>65</td>
<td>44.8</td>
</tr>
<tr>
<td>Entry Level Masters</td>
<td>51</td>
<td>35.2</td>
</tr>
<tr>
<td>Entry Level Clinical Doctorate</td>
<td>5</td>
<td>3.4</td>
</tr>
<tr>
<td>Postgraduate Coursework (Certificate/Diploma/Masters)</td>
<td>15</td>
<td>10.3</td>
</tr>
<tr>
<td>Postgraduate Research Degree (Masters/PHD)</td>
<td>8</td>
<td>5.5</td>
</tr>
<tr>
<td><strong>Work location</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan region (popl'n&gt;100,000)</td>
<td>97</td>
<td>64.3</td>
</tr>
<tr>
<td>Regional / Rural region (popl'n 10,000-99,000)</td>
<td>47</td>
<td>32.9</td>
</tr>
<tr>
<td>Remote region (popl'n &lt;10,000)</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td><strong>Primary Practice Setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outpatient Services-Clinic</td>
<td>39</td>
<td>26.9</td>
</tr>
<tr>
<td>Acute Hospital- Inpatient</td>
<td>28</td>
<td>19.3</td>
</tr>
<tr>
<td>Inpatient Rehabilitation Services</td>
<td>26</td>
<td>17.9</td>
</tr>
<tr>
<td>Mixed</td>
<td>19</td>
<td>13.1</td>
</tr>
<tr>
<td>High Care Facilities/ Skilled Nursing Home</td>
<td>18</td>
<td>12.4</td>
</tr>
<tr>
<td>Community Health Centre or Home Health Agency</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td>Day Therapy Centre</td>
<td>4</td>
<td>2.8</td>
</tr>
<tr>
<td>Private Practice</td>
<td>4</td>
<td>2.8</td>
</tr>
</tbody>
</table>
Community Agency  2  1.4
Other  1  0.7

**Time since stroke (of patients seen)**

<table>
<thead>
<tr>
<th>Time since stroke</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6 weeks</td>
<td>69</td>
<td>47.9</td>
</tr>
<tr>
<td>6 weeks-3 months</td>
<td>36</td>
<td>25.0</td>
</tr>
<tr>
<td>3 months- 6 months</td>
<td>19</td>
<td>13.2</td>
</tr>
<tr>
<td>6 months- 1 year</td>
<td>9</td>
<td>6.3</td>
</tr>
<tr>
<td>&gt;1 year</td>
<td>11</td>
<td>7.6</td>
</tr>
</tbody>
</table>

**Upper limb functional use impacted by sensation**

<table>
<thead>
<tr>
<th>Sensation</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always/often</td>
<td>77</td>
<td>53.1</td>
</tr>
<tr>
<td>Half of the time</td>
<td>42</td>
<td>29.2</td>
</tr>
<tr>
<td>Sometimes/Never</td>
<td>24</td>
<td>16.8</td>
</tr>
</tbody>
</table>

Note: Frequency data indicate the actual number of people who responded to each question.

Table 5.2 Reported frequency of specific clinical practice behaviours

<table>
<thead>
<tr>
<th>Reported Behaviour</th>
<th>Always (n)</th>
<th>Often (n)</th>
<th>Half of the time (n)</th>
<th>Sometimes (n)</th>
<th>Never (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessing sensation</td>
<td>Initial evaluation (N=145)</td>
<td>110 (75.9)</td>
<td>25 (17.2)</td>
<td>3 (2.1)</td>
<td>7 (4.8)</td>
</tr>
<tr>
<td>Reassessment (N= 137)</td>
<td>44 (32.0)</td>
<td>50 (36.5)</td>
<td>17 (12.4)</td>
<td>21 (15.3)</td>
<td>5 (3.6)</td>
</tr>
<tr>
<td>Discharge (N=138)</td>
<td>52 (37.7)</td>
<td>39 (28.3)</td>
<td>13 (9.4)</td>
<td>22 (15.9)</td>
<td>12 (8.7)</td>
</tr>
</tbody>
</table>
Table 5.3 Sensory modalities most frequently assessed. (*Total Number of responses=383)

<table>
<thead>
<tr>
<th>Sensory modality</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Light touch</td>
<td>126</td>
<td>32.9</td>
</tr>
<tr>
<td>Proprioception/ joint position sense/kinaesthesia</td>
<td>55</td>
<td>14.3</td>
</tr>
<tr>
<td>Sharp/dull/pain</td>
<td>46</td>
<td>12.1</td>
</tr>
<tr>
<td>Stereo gnosis/ object recognition</td>
<td>40</td>
<td>10.4</td>
</tr>
<tr>
<td>Temperature</td>
<td>29</td>
<td>7.6</td>
</tr>
<tr>
<td>Two point discrimination</td>
<td>24</td>
<td>6.3</td>
</tr>
<tr>
<td>Other</td>
<td>24</td>
<td>6.3</td>
</tr>
<tr>
<td>Deep Pressure</td>
<td>17</td>
<td>4.4</td>
</tr>
<tr>
<td>Touch Localization</td>
<td>10</td>
<td>2.6</td>
</tr>
<tr>
<td>No formal assessment</td>
<td>8</td>
<td>2.1</td>
</tr>
<tr>
<td>Hand function</td>
<td>4</td>
<td>1.0</td>
</tr>
</tbody>
</table>

* Open ended questions required respondents (n=145) to list the three assessments most frequently used. The number of responses in each category above was divided by the total number of responses to determine the frequency of response for each category.

Table 5.4 Components included in educational program. (*Total Number of responses= 266)

<table>
<thead>
<tr>
<th>Component</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education about safety issues</td>
<td>95</td>
<td>35.7</td>
</tr>
<tr>
<td>Education about sensory stimulation/re-education program</td>
<td>38</td>
<td>14.9</td>
</tr>
<tr>
<td>Home program</td>
<td>34</td>
<td>12.8</td>
</tr>
<tr>
<td>Education about using vision for compensation</td>
<td>29</td>
<td>10.9</td>
</tr>
</tbody>
</table>
Other (e.g. providing handouts) 22 8.3
Understanding sensory impairment, neurological, motor, deficits 29 10.9
Caregiver family education 14 5.3
Education about incorporating upper extremity in functional activities 5 1.9

* This open ended question required respondents (n=145) to list the three topics most frequently included in client education. The number of responses in each category above was divided by the total responses to determine the frequency for each category.

### Table 5.5 Perceptions of barriers to utilising interventions for sensory impairment.
(n=137)

<table>
<thead>
<tr>
<th>Barrier</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge/skills</td>
<td>71</td>
<td>(51.8)</td>
</tr>
<tr>
<td>Short length of stay</td>
<td>71</td>
<td>(51.8)</td>
</tr>
<tr>
<td>Lack of time</td>
<td>67</td>
<td>(48.9)</td>
</tr>
<tr>
<td>Insufficient evidence to support interventions</td>
<td>45</td>
<td>(32.8)</td>
</tr>
<tr>
<td>Not priority of client</td>
<td>34</td>
<td>(24.8)</td>
</tr>
<tr>
<td>Not priority in treatment plan</td>
<td>21</td>
<td>(15.3)</td>
</tr>
<tr>
<td>Costs too much to deliver</td>
<td>11</td>
<td>(8)</td>
</tr>
<tr>
<td>Role restriction</td>
<td>6</td>
<td>(4.4)</td>
</tr>
<tr>
<td>Distance you or your client needs to travel</td>
<td>2</td>
<td>(1.5)</td>
</tr>
</tbody>
</table>
CHAPTER 6: CLINICAL DECISION-MAKING WHEN ADDRESSING UPPER LIMB POST-STROKE SENSORY IMPAIRMENTS

This Chapter is the second Chapter that reports the results of the survey, specifically focusing on addressing aim 2 of the thesis: to explore how occupational therapists make and manage decisions for the management of ULPSSI. This Chapter focuses on the factors involved in CDM by occupational therapists when addressing ULPSSI. Questions in the questionnaire were designed to explore therapists’ CDM based on the results obtained from the earlier qualitative study of therapists’ decision-making reported in Chapter 4. The results of this study were also used to inform the content of the final pilot study.

The study results were published in a peer-reviewed manuscript titled “Clinical decision making when addressing upper limb post-stroke sensory impairments” in the British Journal of Occupational Therapy. In this Chapter, the published manuscript has been modified to allow the inclusion of additional detail for this thesis and has been formatted to maintain consistency throughout the thesis. Although the content from the introduction of the paper has been condensed (as much of this material has been discussed in Chapter 2 and 4), key information is re-presented here still to contextualise the study.

Clinical decision-making when addressing Upper Limb Post-stroke Sensory Impairments

6.1. Abstract

6.1.1. Aims.
This study aimed to understand factors influencing occupational therapists clinical decision making when choosing to assess upper limb post-stroke sensory impairments (ULPSSI) and selecting interventions.

This was a survey of 187 American occupational therapists working with stroke survivors.

6.1.3. Results.
Respondents most commonly assessed ULPSSI to determine the impact on occupational performance and guide interventions, and most commonly did not undertake assessment if clients reported no impairments or were unable to participate in testing. Being unaware of interventions, believing motor interventions addressed ULPSSI, and lack of time most commonly led to the decision not to use interventions for ULPSSI. Clients' cognitive status, severity of ULPSSI, and time since stroke influenced therapist’s choice between compensatory or remedial approaches. Prior experience, effects seen when trialling interventions, and consulting other therapists most commonly influenced specific intervention choice.

6.1.4. Conclusions.
Deciding to assess ULPSSI was influenced by theoretical knowledge and domain-specific clinical knowledge while decisions about interventions were largely influenced by the therapists’ domain-specific clinical knowledge, clinical experience and specific contextual factors such as time available for therapy. Respondents used both automatic and reflective or deliberate decision making processes. Education on evidence-based interventions and strategies for decision making in areas of clinical uncertainty is warranted.
6.1.5. Key Words.
Sensory impairment, occupational therapy, clinical decision making

6.2. Introduction
Occupational therapists make multiple clinical decisions daily including deciding on assessments to utilise, whether or not to provide interventions, determining the most effective interventions, and when to try alternative intervention strategies. Decisions in clinical practice are often complex and involve considerable uncertainty (Copley et al., 2010; Smith et al., 2008). The clinical decision-making process is dynamic and fluid, involving gathering data or information from multiple sources, interpreting the data, collaborating with both the client and other professionals, choosing a course of action, and evaluating the outcomes of that choice (Smith et al., 2008).

Decision-making can be thought about in terms of both process and content which are contextually situated and influenced by the nature of the decision and decision-maker (Atkins & Ersser, 2008; Chapparo & Ranka, 2008; Leicht & Dickerson, 2002). In terms of processes of decision-making, many clinical decisions make use of specific strategies such as weighing up strengths and weaknesses, prioritising or using a process of elimination, some decisions are simply made based on what has been done in the past (either by oneself or by others) or by following a pre-determined pathway (Harries & Harries, 2001). As seen in Chapter 4, the degree to which decision making is a conscious and deliberate process is the focus of the dual processing theory from cognitive science (Harries & Harries, 2001). It postulates that there are two distinct reasoning processes, the first of which is intuitive and automatic, drawing on past experience to allow decisions to be made quickly (System 1 thinking), and the second (System 2 thinking), a slower, more deliberate and logical cognitive process, utilising a system of weighing information, analysis and reflection to reach decisions, particularly when dealing with uncertainty (Evans, 2003). To what extent these are two different processes or whether intuition and analysis actually occur along a continuum as described in cognitive continuum theory (Hammond et al., 1997) is debated. Regardless, it appears that the nature of the decision task such as its familiarity, certainty, level of risk, stability and
congruence (Shanteau, 1992, Smith et al., 2008), as well as the personal attributes and expertise of the decision maker impact the reasoning processes (Schell & Schell, 2008, Smith et al., 2008).

Knowledge underpins clinical reasoning and decision-making, and has been referred to as the content of clinical reasoning (Higgs and Jones 2000, Rassafiani et al 2008). Such knowledge is highly contextualized — influenced by the setting, current societal and organisational influences — and forms an overall frame within which clinical decisions are made (Chapparo and Ranka 2008, Larsen et al 2008, Copley et al 2010). Making sound clinical decisions is dependent on the type and quality of the knowledge utilised in the CDM process (Higgs et al., 2008) and understanding the sources of this knowledge will allow for understanding the basis for the decision outcome as well as providing ways to support or improve the knowledge basis for CDM. Thus, a therapist’s interpretation of different pieces of information or ‘factors’ about the client, available evidence, the impairment process, the external context or therapy environment, theoretical models, occupational needs and opportunities has an impact what information is prioritised and how decisions are made (Hooper, 2008; Smith et al., 2008). Although several studies (Harries, 1998; Kuipers et a., 2006; Rassafiani et al., 2008) examining factors influencing occupational therapists’ CDM recognise the importance of context, the clinical information content that influenced decisions varied. Being aware of the influence of these multiple factors, whether contextual or content-based, on their decision making (Smith et al., 2008) may help clinicians to achieve greater accuracy and consistency in the process (Rassafiani et al., 2008). Rassafiani et al. (2009) argue that information obtained from studies of decision-making with one client group cannot be generalised to another client group since expertise is domain specific. To improve CDM we need to understand the factors that have an impact on decision-making (Rassafiani et al., 2008, Smith et al., 2008). Studying these factors in different practice areas can help therapists be more cognizant of their clinical decisions and the type of information they require. A majority of stroke survivors (50 – 85%) experience some form of somatosensory impairment in the upper limb contralateral to the lesion (Carey, Macdonnell & Matyas, 2011) and several cross sectional studies have demonstrated that these ULPSSI have been associated with poorer outcomes for the stroke survivor.
Understanding therapists’ CDM when addressing ULPSSI has the potential to impact outcomes for a large proportion of stroke survivors. This study explores occupational therapists’ decision-making when addressing ULPSSI to identify factors influencing occupational therapists' decision-making and the type of information used when addressing ULPSSI.

6.3. Study Aims
This study aims to understand CDM utilised by occupational therapists when addressing ULPSSI. Specifically, the research questions were:

1) Why do therapists decide to (or decide not to) assess for ULPSSI?
2) What factors influence choice of interventions?
3) What sources of information do therapists use when making decisions about interventions for ULPSSI?
4) Identify signs of automatic or more effortful analytic cognitive processes used by therapists when deciding on interventions for ULPSSI.

6.4. Methods
Approval for study procedures for this survey was given by one of the Ethics Review Boards at the University of Queensland, Australia.

6.4.1. Subjects and procedure.
Five hundred occupational therapists, members of the American Occupational Therapy Association's (AOTA) Physical Disabilities Special Interest Subsection (PDSIS), who were randomly selected by computer by AOTA from a total of 4,049 members, were mailed a study explanation, questionnaire, addressed, postage paid envelope, and a link to an online questionnaire should they prefer this format of responding. Eligibility criteria included currently practicing as an occupational therapist and being involved in treating stroke survivors. Mailed reminder notices were sent at two weeks and four weeks after the initial mailing to increase return rate (Edwards et al., 2009). Adequate data was not collected to allow for the calculation of the effectiveness of these reminders. There is some concern about the ethics of
using multiple reminders to increase response rate in surveys due to the possible perception of coercion; however, this was minimised in this study by sending a maximum of 2 reminders for individuals who had not responded, and making it clear that participation was voluntary.

6.4.2. Instrument.

The questionnaire contained 31 questions addressing practice choices, CDM and demographics. This paper reports on the results from the decision-making questions. Therapists were asked 10 demographic questions on their level of education, years of experience, practice setting, and percentage of clients with stroke as well as time since stroke. The CDM questions for this survey were based on the results a qualitative study of 12 occupational therapists that treat stroke patients, undertaken by the first author and reported in Chapter 4 of this thesis. Therapists in the survey were asked about their use of sensory measures and interventions when addressing ULPSSI. The CDM questions for this survey included:

a) Two open ended questions that required respondents to provide reasons for completing/not completing a sensory assessment.

b) A fixed response question that provided a choice of six reasons why therapists do not or only sometimes provide specific interventions for sensory impairments.

c) One question that asked respondents to indicate the frequency with which they considered each of 14 different factors when deciding between providing remedial versus compensatory interventions. An open ended option was also provided.

d) One question that asked respondents to rank the frequency with which 10 different factors influenced their choice of specific interventions from ‘most frequently’ to ‘least frequent’. Respondents could specify additional options.

e) An item that asked about sources of information respondents were aware of that might demonstrate/support the benefit of interventions for ULPSSI from a list of 12 options or to specify another option.

f) One question that contained six items from the Self-Assessment of Clinical Reflection and Reasoning SCARRS (Scaffa & Wooster, 2004) which was
designed to measure reasoning and reflection. Only six items were selected to limit the length of the overall questionnaire, but items were selected that had wording that best described automatic thinking and experience compared to more effortful analytic approaches to decision-making.

The questionnaire was reviewed by two experts in the field and then piloted with 10 therapists prior to use.

6.4.3. Data analysis.

Data was entered into PASW Statistics 18 (formerly SPSS Statistics) and descriptive statistics were calculated for the Likert type questions and demographics. Some questionnaire categories, for example ‘almost never/sometimes’, were collapsed for ease of interpretation (Treiman, 2009). Open ended questions were reported as frequencies after being coded and categorised by the first two researchers with disagreements resolved by discussion. For the item requiring respondents to rank the frequency with which 10 different factors influenced their decision about specific interventions, each ranking was assigned a score with the 1\text{st} rank receiving 11 points through to the 11\text{th} rank receiving one point (The University of Reading Statistical Services Centre, 2001). For each factor being considered, the number of responses for each ranking were then multiplied by the relevant score for that rank and summed to produce a total score. The overall ranking of factors was based on the ranking of the total scores for each factor.

6.5. Results

A total of 187 surveys were returned of the 500 sent out giving a return rate of 37%, with 145 meeting the inclusion criteria.
6.5.1. Respondent characteristics.

The majority of the respondents had either a bachelor's degree in occupational therapy or entry-level master's degree (Table 6.1). Respondents mostly worked in metropolitan regions of the USA and in a broad range of clinical settings, across inpatient and outpatient hospital settings, inpatient rehabilitation services, skilled nursing facilities, community services, private practice or a combination of settings (Table 6.1). Respondents were experienced occupational therapists (m=16.35 years) especially with stroke patients (m=14.32 years) (Table 6.1) and reported seeing an average of 5.75 clients with stroke per week with the majority of their clients having had a stroke within the last 6 weeks (48%). Respondents were from all mainland states of the USA and the distribution of occupational therapists from rural and metropolitan areas was similar to the general population in the USA and what is known about the geographic distribution of therapists who work in the USA (see Chapter 5 for more details). Limited information was available on those who did not respond and hence no analysis was conducted.

6.5.2. Deciding whether to assess sensation.

Most respondents (93.1%) reported testing sensation on initial assessment and two thirds frequently reassessed sensation at discharge. Respondents provided 244 reasons for completing a sensory assessment and 173 for not completing a sensory assessment. The most common categories of reasons for completing a sensory assessment were to select/guide interventions (34.5%), particularly interventions about safety (59 out of 76 respondents), and to determine the impact on occupational performance (32.5%). Other reasons given were to define impairments or determine level of nerve damage or dermatome (12.1%), monitor progress (8.1%), other (6.8%), or following protocol (6%). Those categorised as ‘other’ included answers such as ‘providing insight for patient and family’, ‘update medical record’ or ‘complete physical exam’.

The most common reasons respondents reported they did not complete sensory assessments were because clients either did not report having a sensory impairment
(31.5%) or were unable to participate (for example, having cognitive or communication deficits) (30.4%). Other reasons given for not completing sensory assessments include no time/length of stay too short (22%), other (7.7%), do not formally assess/ not required by protocol/not needed (4.8%), and goals achieved/patient does not want assessment (3.6%). Concomitant medical conditions such as oedema, skin integrity, or pain only accounted for 3% of the decisions not to evaluate sensation.

6.5.3. Interventions for sensory impairment of the upper limb.

6.5.3.1. Frequency of interventions.
When implementing an intervention plan for stroke survivors, just over half of respondents 53.5% frequently used interventions that specifically targeted ULPSSI. However, 17.4% did so half the time and 29.2% sometimes or never specifically included ULPSSI interventions.

6.5.3.2. Factors influencing use of interventions.
The 67 respondents who only half the time or less used interventions specifically targeting ULPSSI were asked to indicate their reasoning from a list provided (respondents could choose more than one reason). The most frequent reasons chosen for not using interventions for ULPSSI were being unaware of specific interventions (38.8%), believing ULPSSI are addressed by motor interventions (32.8%), and having no time to provide specific ULPSSI interventions (29.9%). Other reasons given for not using interventions for ULPSSI include client needs to focus on motor return prior to sensory return (26.9%), not clients priority (25.4%), other (25.4%), and no evidence that any interventions are effective (14.9%).

When asked how frequently 14 different factors had an impact on their decision to take a remedial versus compensatory approach to intervention planning, the following factors were considered “most of the time” or “often” by more than 50% of the respondents: cognitive status of the client, client’s goals or motivation, severity of the sensory deficit, time since stroke, level of motor return, effectiveness of the
intervention technique and unilateral neglect. In contrast factors considered “most of the time” or “often” by less than 50% of the respondents when choosing the overall intervention approach were: familiarity with the intervention technique, aphasia, time available, oedema, stroke clinical guidelines, age of the client, and dominant versus non-dominant arm. See Table 6.2 for more details.

6.5.3.3. Factors influencing specific intervention choice. Respondents ranked the frequency with which 10 factors influenced their decisions about specific interventions. The system for determining the ranking of these factors was described in the methods section of this Chapter. The top three factors in order of ranking were ‘personal prior experience with similar clients’, ‘results of assessment used’, and ‘effects when trialled with a client’. In contrast the lowest ranked factor was ‘searches of the internet’. The rankings of each of the 10 factors can be seen in Figure 6.1.

6.5.3.4. Sources of information about interventions. Participants were asked about information sources they were aware of that support or demonstrate the beneficial effect of interventions for ULPSSI. Respondents were most aware of: information from personal observation (85.2 %), colleagues (67.4 %), continuing education courses (58.5 %), and practice theories or models (53.3%). Information sources about interventions respondents were least aware of included: systematic reviews (7.9%), pre-post studies (13.3%), clinical trials (23%), and clinical guidelines (26.7%).

6.5.4. Processes used in CDM. In the modified SACRRS, six items asked about therapists’ decision-making processes with regard to choosing interventions for ULPSSI. Almost all therapists agreed or strongly agreed that they “regularly think back over specific client sessions and ask myself how well that worked and what they could do differently”. Approximately three quarters of respondents agreed or strongly agreed that they “make decisions based mainly on my previous experiences” and that they “think in
terms of comparing and contrasting information about a client’s problem and proposed solutions to them.” Interestingly a number of respondents recognised that they did not wait for sufficient data in order to make decisions and almost a third reported using clinical protocols for most interventions. See Table 6.3.

**6.6. Discussion**

This study explored factors influencing occupational therapist’s decision-making, and the information sources and processes used when choosing sensory measures and interventions for ULPSSI.

**6.6.1. Deciding about sensory measures.**

Unsurprisingly, therapists indicated that they chose to assess for ULPSSI in order to determine its impact on occupational performance (problem definition) and to select/guide interventions - both key elements of procedural reasoning. This use of discipline specific propositional knowledge is part of the lens through which each discipline approaches clinical problem solving and for occupational therapy, is articulated in models and frameworks for practice such as the Occupational Therapy Practice Framework (AOTA, 2008). Of concern however is that the technical and scientific knowledge base underpinning the reliability, validity and clinical usefulness of current sensory measures for this ULPSSI have not been sufficiently established and needs considerably more research effort (Carey, 1995, Winward et al., 1999, Yekutiel, 2000).

The most common reason respondents decided not to assess sensation was because stroke survivors did not report or demonstrate impairment. In a study by Acerra (2007), 16% of stroke survivors reported ULPSSI but on testing 53 – 89% of survivors were found to have ULPSSI. This suggests that the decision about testing ULPSSI may not always be reliably informed by clients reporting ULPSSI and a need exists for training to increase therapists’ awareness about the incidence of ULPSSI, survivors’ perceptions, and appropriate testing strategies to use.
Communication and cognitive impairments were cited as the next most common reason for deciding not to assess ULPSSI; given demands for attention and verbal responses by current assessments this would seem logical. This is consistent with concerns raised by Gladstone, Danells, and Black (2002) and Korner-Bitensky, Kehayia, et al. (2006). While Korner-Bitensky, Kehayia, et al. (2006) trialled sensory testing using a visual analogue scale, limited options exist for reliably evaluating ULPSSI in the presence of cognitive and or communication impairments, supporting therapists concerns about the use of assessment tools in these circumstances.

6.6.2. Choosing interventions.

Therapists provided information about their decision making related to whether or not to provide interventions, what overall approach to use, and which specific interventions to use.

6.6.2.1. Deciding whether to provide interventions.

In this survey, respondent’s decisions about providing interventions for ULPSSI were influenced by their level of domain-specific propositional knowledge and contextual factors. The predominant reason for not providing sensory interventions was being unaware of specific interventions to use. Lack of awareness and knowledge contributes to technical uncertainty in decision-making and may be addressed by providing therapists with training or information about existing evidence on the effects of interventions for ULPSSI (Hall, 2002). The use of evidence-based clinical decision making aids and training therapists in clinical reasoning skills has been recommend to facilitate decision- making in areas of uncertainty (Kuipers & McKenna, 2009).

Another reason therapists gave for not providing interventions that specifically address ULPSSI is that they assumed sensation is covered by interventions addressing motor impairment. Information from neuroscientists suggests, however, that sensory reorganisation after stroke may precede motor reorganisation, and may help drive motor recovery. Hence, focusing on sensory remediation early may
facilitate motor return (Carey, 2006). Knowing this is an indication of the level of
detailed propositional knowledge required to reason and make decisions in this field,
and illustrates the importance of continuing to update knowledge specific to the
domain in which they are working.

Therapists cited lack of time as key factor that had an impact on deciding whether to
utilise interventions for ULPSSI. This may be seen in respondents’ perception that
clients need to focus on motor return prior to sensory return, and in the amount of
time available to provide interventions in the settings in which most respondents
worked. Average length of stay for stroke survivors in USA in acute hospitals is 2.5 -
5.6 days (Russo & Andrews, 2008) and in inpatient rehabilitation 16.5 days (Granger
et al., 2009). Additionally, only 30.7% of stroke survivors in America report receiving
outpatient rehabilitation services (Xie et al., 2007). Recovery of sensation takes time
but, given the significant impact on function and outcomes (Carey, 2006; Tyson et al.,
2008), it also demands attention. Therefore models for ULPSSI intervention
commencing immediately post stroke and extending beyond discharge from acute
care are required.

6.6.2. Choosing between compensatory or remedial approaches.
Domain-specific clinical information most commonly influenced decisions about
whether to use a compensatory or remedial intervention approach, although clients’
goals were also considered. Therapists considered the client’s cognitive status, client
goals and motivation, severity of the deficit and time since stroke, level of motor
return, effectiveness of the intervention technique, and the presence of unilateral
neglect as factors influencing choice of approach. However, respondents were not
asked about the direction of the decision. Consistent with this study, a qualitative
study of 11 occupational therapists also found that the clients’ cognitive status,
condition, and acuteness or chronicity of the condition significantly influenced
decision making about interventions when addressing impaired upper limb
performance following brain injury (Kuipers et al 2006). Some remedial approaches
such as intensive graded retraining programs require a reasonable level of cognitive
skill and hence may be problematic. Connell et al. (2008) found severity of stroke
was related to ULPSSI and the initial severity of the ULPSSI was able to significantly
predict the ULPSSI levels at six months. When choosing remediation or compensation approaches considering the severity of the initial deficit as a factor would appear to be logical. These findings were also consistent with the results of the earlier qualitative study (Chapter 4) where the level of stroke severity and time since stroke was also reported by therapists as a significant factor that influenced their decision making.

Occupational therapy aims to be a client-centred profession and the majority of respondents in this study reported taking the client’s goals and motivation into account “most of the time” or “often” although it is not clear how the therapists were guided by client goals or client motivation as this was not able to be determined from this question. This is important because the client’s participation in goal setting positively impacts their motivation in rehabilitation and motivation in the rehabilitation setting impacts the outcomes (Holmqvist & von Koch, 2001). Participation in remediation approaches requires the client’s commitment and motivation. A qualitative study of 22 people receiving rehabilitation post stroke has identified level of motivation to be a key factor in whether a person participates in rehabilitation, and that this motivation can be influenced by the information provided by and their interaction with rehabilitation professionals and family members (Maclean, Pound, Wolfe, & Rudd, 2000).

Other factors that frequently impacted on the decision to remediate or compensate for sensory impairments in this survey were level of motor return, whether or not the intervention was effective, and familiarity with the intervention. Consistent with the therapists in the earlier qualitative study (Chapter 4), the respondents in this survey reported using the level of motor return as a factor in decision-making with regards to the interventions approach e.g. remediation versus compensation. In the earlier qualitative study, therapists felt that sensory and motor return goes hand in hand and that increasing motor function was possibly linked to increasing sensory function or potential for increasing sensory function. While therapists may see a link between sensory and motor return, at least one fourth of the respondents (26.9%) felt that clients needed to focus on motor return prior to sensory return. Further investigation of this is warranted as Carey (1995) summarises several studies showing an
associated between somatosensory evoked potentials and motor recovery as well as
the negative impact of somatosensory impairments on recovery of motor control.
Motor recovery and somatosensation appear intimately connected with adequate
sensory function associated with higher levels of motor function of the upper limb
(Carey, 1995). Further information on this may provide information for therapists’
CDM regarding prioritising or timing of ULPSSI interventions.

Almost half (49.2%) of the respondents reported “most of the time” or “often” that
they considered how familiar they are with the intervention as a factor influencing
whether they would take a remedial or compensatory approach. Smith, Higgs and
Ellis (2006) note that a number of attributes of a decision make decisions easier or
harder to make. One of those attributes is familiarity. The more familiar one is with
the task, the less difficult it is to make the decision. It is unclear from this study what
therapists choose to do to increase their familiarity with a specific intervention, and
further investigations of how therapists respond when they are faced with decision-
making with which they are unfamiliar with some of the interventions may be useful.

What is interesting is that more than half (56%) of the respondents reported only
“sometimes” or “almost never” using stroke clinical practice guidelines to help in the
decision-making process regarding which intervention approach to take. When this
survey was undertaken, in April 2010, remedial, compensatory and educational
approaches were recommended in the current standard texts for occupational
therapy and while four clinical practice guidelines recommended formal assessment
of ULPSSI, only one recommended a remedial approach (sensory specific retraining
and electrical stimulation) for clinicians (Australian National Stroke Foundation,
2005), one focused on safety and compensatory strategies (Royal College of
Physicians, 2008) and two made no recommendations regarding specific
interventions or intervention approaches for ULPSSI (Canadian Stroke Network and
Heart and Stroke Foundation of Canada, 2006; Duncan et al., 2005) (See Chapter 2
for further details). Clinicians were not asked if they were aware of the existence of
the clinical practice guidelines, so it is unclear whether or not the lack of use was due
to the lack of awareness of their existence or a specific decision based on the
usefulness of the clinical practice guidelines. Further studies asking therapists about
their awareness of the clinical practice guidelines and their usefulness would be informative.

In the current health care climate in the USA, shortened length of stays and increasing demands for higher levels of productivity by clinicians would seem to make time an increasing contextual factor that therapist might consider in their decision making. Interestingly, 52.6% of the respondents in this study indicated that they “always never” or “sometimes” considered the amount of time available as a factor when deciding on the intervention approach that they will use. However lack of time was clearly identified as a barrier in utilising specific interventions for ULPSSI in the survey (described in Chapter 5). This is an area where further exploration may help clarify how the temporal context of treatment impacts therapists’ decision-making.

6.6.2.3. Factors influencing specific intervention choices.

When choosing a specific intervention, therapists ranked “personal prior experience with similar clients” as the factor that most influenced their choice. This past clinical experience is a type of non-propositional practice knowledge that is commonly used by health professionals when making decisions (Thompson, 2003). From the perspective of dual processing theory, relying on clinical experience is a heuristic that allows decisions to be made quickly as it requires little reflection (Stanovich & West, 2000). Using heuristics to inform decisions requires the therapist to rapidly assess the similarities and differences between the current situation and previous situations and their use depends on the ease with which the individual can access memories of past experiences (Cioffi, 2001). Some experts (for instance R. Scherer, in personal communication to the author, 11 April, 2008) have suggested that the strongest influence on decision-making is the effect of the treatment on your last patient. There are inherent biases in fast, automatic use of clinical experiences and Thompson (2003) suggests that since this a commonly used process clinicians should be educated on reducing biases that impact on their CDM.

In focus groups with nine research-experienced occupational therapists, Copley and Allen (2009) found that while therapists valued research, practiced-based evidence
(from their own professional experience) was the key source of evidence informing their practice. Importantly however, these therapists developed methods to evaluate and systematise practice-based knowledge, in an approach consistent with a deliberate and reflective System 2 decision making approach. The authors concluded that a structured model to guide practitioners in developing practice-based knowledge, reducing the risk of bias and reasoning errors, is important. Higgs et al. (2008a) proposed cross checking and critiquing practiced based knowledge as well as verifying it. Teaching therapists how to generate and evaluate practice-based knowledge may reduce the biases involved in decision-making.

In the present study, therapists frequently nominated the effects seen when interventions were trialled with a client as a factor influencing their intervention choice. This is akin to a process of ‘trial and error’, a common approach to making decisions that requires adequate observation and reflection to avoid bias. A structured approach to this decision making is the N-of 1 trial or single system design studies that test the effects of an intervention on an individual (Backman & Harris, 1999) and may also be used to generate practice-based evidence.

Therapists responding to the survey did not frequently nominate utilising information from the internet, practice magazines, or from research when deciding on specific interventions. Barriers to the use of research in decision-making have been highlighted by numerous authors and include lack of time to access research, attitudinal barriers, lack of knowledge and skill for interpreting research, and lack of availability of specifically targeted research to inform decisions amongst others (Bennett et al., 2003; Dysart & Tomlin, 2002). With the slowly growing body of research evidence about the effectiveness of interventions for ULPSSI, efforts to assist therapists in integrating research evidence in decision-making are important.

6.6.3. Information sources about intervention effectiveness.

Belief that an intervention may be effective influences the therapist’s decision to use it. Consistent with other studies, respondents in this study relied on personal observation, advice from or observing colleagues, and continuing education as the
main sources informing them about the effectiveness of sensory interventions. Sweetland and Craik (2001), after surveying 200 British occupational therapists treating adult stroke patients, also found that 76% of therapists reported their knowledge was ‘greatly’ influenced by peers, 69% were most influenced by attending post graduate courses and 61% were ‘greatly’ influenced by their prior experience of working with patients. Being reflective, observing what works well and learning from experience is recommended in particularly complex, uncertain areas of practice (Plesk & Greenhalgh, 2001). The fact that relatively few respondents were aware of existing research that demonstrates the beneficial effects of some specific interventions for ULPSSI may reflect the difficulty in keeping up to date with research in busy clinical settings. Methods to increase therapist awareness of existing research are required.

6.6.4. Processes used for CDM.

Respondents were able to identify use of both automatic and more effortful thinking processes when choosing interventions for sensory impairments following stroke. Decision-making that is automatic (such as relying on past experiences, not having to wait for information to make a decision) can be thought of as System 1 thinking whereas more effortful processes (involving conscious reflection and weighing up and analysis of information) have been described as System 2 thinking (Evans, 2003). Understanding these processes and their use is of interest because psychologists are beginning to consider how we might improve decision-making by learning when to use System 2 processes, how to move from System 1 to 2 processes, and how to make the best use of System 1 decision-making processes (Milkman, Chugh, & Bazerman, 2009).

Use of more automatic (System 1) processes in decision-making was evident from respondents’ reliance on clinical experiences for decision-making but also by a number of respondents who either identified they do not necessarily wait until they have sufficient data to make decisions (19.3%), or neither agreed or disagreed for the need to have sufficient data (30.7%). Such use of automatic decision-making can be particularly efficient in familiar situations when time is of the essence and
immediate action is required; however it can also be prone to bias (Stanovich & West, 2000).

Respondents also used more effortful (System 2) processes for decision-making, frequently reporting using reflective practices, with almost all respondents agreeing that they ‘regularly think back over specific client sessions and ask myself how well that worked and what I could do differently.’ Craik and Rappolt (2003) suggest structured reflection on past, current and future clinical encounters enable therapists to learn more consciously from their clinical experiences. This reflection, considered a System 2 process, was also evident with therapists agreeing they ‘think in terms of comparing and contrasting information about a client’s problem and proposed solutions to them’ and in ‘identify assumptions underlying the different views’ when faced with conflicting information.

6.7. Limitations
Subjects were randomly selected from the AOTA’s PDSIS and may not be representative of all occupational therapists treating stroke patients. The response rate of 37% is consistent with research of response rates for mail surveys (34.6 - 39.6%) though lower than research for mixed (mail and online) methods (60%) (Greenlaw & Brown-Welty, 2009); hence the respondents reflect a small proportion of the sample. The AOTA’s PDSIS is not focused solely on stroke rehabilitation but on therapy for a wide range of diagnostic groups including hand therapy and hence some members who were sent surveys did not respond, simply because they did not treat stroke patients. No information was available with regards to the characteristics of the therapists who did not respond and hence analysis of non-responders was not able to be completed. However as discussed in the limitations of Chapter 5, a comparison with the data from the USA Census Bureau seemed to indicate that therapists working in rural areas were well represented by the respondents and the sample was likely representative of the population in terms of geographic distribution. The characteristics of those who did and did not reply may also have impacted the findings of this study. AOTA members represent a small proportion of all occupational therapists, who choose to be a member of a professional association, and who as a consequence, have access to evidence-based practice
materials, research articles, and discussion groups as part of the AOTA membership. These factors may have influenced the results of this study. Further studies that obtained lists from state licensure boards instead of professional organisations may find different results.

There are limitations when using survey methods for studying clinical decision-making. Therapists’ recall hinders gathering accurate information about decision-making that might be better achieved through observing and questioning therapists ‘in the moment’, where they might be in a position to explain their reasoning. Although qualitative methodologies may be informative, use of more rigorous quantitative methods to determine factors influencing decisions may also be valuable. In particular, social judgement theory, which incorporates the relative importance of factors and their relationship to clinicians’ judgments (Wigton, 1996), may also be fruitful.

Wording used for some questions may have influenced the results. When asked to provide the reasons for utilising specific sensory measures, therapists were not asked to differentiate between the uses at the initial assessment, reassessment or discharge time points. This not only limited the data obtained, for example, whether specific measures were utilised specifically to evaluate the effectiveness of the interventions versus initially identifying if clients had a specific sensory impairment, but may have resulted in several different types of reasons being combined or some reasons not being articulated. A similar limitation also occurred in the questions regarding the choice of interventions. This is problematic because therapists face multiple decision points, not just one when initially choosing a specific intervention strategy. For example therapists need to decide whether to intervene, which intervention to use, when to discontinue using that strategy, or change to another intervention strategy. Without this being clearly stated in the question about choice of interventions, it is possible that each therapist answered this question from a slightly different perspective or that the survey missed capturing the nuances of each of those decision points. This type of decision-making may be difficult to capture in generic questions as well, and may require the use of case specific questions,
vignettes or other forms of research that allow for more detailed investigation of the reasoning process.

Another limitation of the questionnaire was that the questions used to determine use of more automatic (System I) versus more effortful (System II) thinking, drawn from the SCARRS, had not been tested as a measure of these forms of cognitive processes. Rather, the SCARRS was developed to measure clinical reasoning skills and reflection of occupational therapy and physical therapy students (Royeen et al. (2001). While the wording of the six questions utilised appeared on face value to describe strategies that could be identified as either automatic or more effortful reasoning strategies, further studies to verify this may be needed and the development of appropriate measurement tools are warranted.

Finally, decisions that were made during data analysis, such as collapsing the categories of responses in order to make it easier for the reader to interpret data, may have influenced the findings by clustering the responses. For example, the data related to factors that impacted the choice of intervention approach was at times bimodal, which may have resulted from this decision.

6.8. Conclusion
This study found that respondents’ decisions to undertake assessments were influenced by scientific knowledge and domain-specific clinical knowledge, whereas decisions about interventions were largely influenced by the therapists’ domain-specific clinical knowledge, reliance on clinical experience, and the timeframes within which interventions needed to be delivered. In the theoretical literature on decision-making these factors are identified as content and contextual factors that influence decisions (Hooper, 2008; Smith et al., 2008). Identifying specific factors that influence therapists’ CDM is important in order to develop means to refine decision making (Rassafiani et al., 2008). While the importance of previous experience and practice knowledge for decision-making is clear, further research to develop ways to decrease bias in this process is warranted.
A number of factors that influenced whether assessment of ULPSSI was undertaken or whether and which interventions were selected warrant further attention in order to consider approaches that might improve management of ULPSSI. First, therapist’s decision about testing ULPSSI may not always be reliably informed by clients reporting ULPSSI and a need exists for training to increase therapists’ awareness about the incidence of ULPSSI, survivors’ perceptions, and appropriate testing strategies to use. Second, therapists reported a lack of awareness of interventions for ULPSSI and this indicates they may benefit from education about methods to stay up to date with information about interventions, the range of information sources available, as well as information or education about currently available evidence and incorporating strategies for evidence-based decision-making. Further research on methods to encourage evidence-based decision-making and evaluating practice by therapists is warranted. Finally, lack of time to provide interventions was a concern. This may be partly addressed by development of models for ULPSSI intervention commencing immediately post-stroke and extending beyond discharge from acute care.

Finally it was evident that respondents used both intuitive or automatic (System 1) and more effortful or reflective (System 2) decision-making processes when deciding on interventions for post-stroke upper limb sensory impairments. Understanding when to use System 2 decision-making processes, how to make the best use of System 1 processes, and how to move between both approaches (Milkman et al., 2009) is a further research challenge to be addressed in order to optimise the quality of care delivered.

### 6.9. Tables

Table 6.1 Participant Characteristics  N=145

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest Academic Qualification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diploma</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>65</td>
<td>44.8</td>
</tr>
<tr>
<td>Entry Level Masters</td>
<td>51</td>
<td>35.2</td>
</tr>
<tr>
<td>Course Type</td>
<td>N</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>----</td>
<td>-----------</td>
</tr>
<tr>
<td>Entry Level Clinical Doctorate</td>
<td>5</td>
<td>3.4</td>
</tr>
<tr>
<td>Postgraduate Coursework (Certificate/Diploma/Masters)</td>
<td>15</td>
<td>10.3</td>
</tr>
<tr>
<td>Postgraduate Research Degree (Masters/PHD)</td>
<td>8</td>
<td>5.5</td>
</tr>
</tbody>
</table>

**Work location**

- Metropolitan region (popl'n>100,000): 97, 64.3
- Regional / Rural region (popl'n 10,000-99,000): 47, 32.9
- Remote region (popl'n <10,000): 4, 2.8

**Primary Practice Setting**

- Acute Hospital- Inpatient: 28, 19.3
- Outpatient Services-Clinic: 39, 26.9
- Inpatient Rehabilitation Services: 26, 17.9
- Community Agency: 2, 1.4
- Community Health Centre or Home Health Agency: 4, 2.8
- Day Therapy Centre: 4, 2.8
- Private Practice: 4, 2.8
- High Care Facilities/ Skilled Nursing Home: 18, 12.4
- Mixed: 19, 13.1
- Other: 1, 0.7

Years worked in as an occupational therapist, \( \text{mean (SD)} \)

- Years worked: 16.4, (11.81)

Years worked with people with stroke, \( \text{mean (SD)} \)

- Years worked: 14.3, (10.65)

Percentage of caseload with people with stroke, \( \text{mean (SD)} \)

- Percentage of caseload: 29.9, (24.38)

Average number of people with stroke seen each week, \( \text{mean (SD)} \)

- Average number of people: 5.5, (6.53)

Average time since stroke, of patients seen

- 0-6 weeks: 69, 47.9
- 6 weeks-3 months: 36, 25.0
- 3 months- 6 months: 19, 13.2
- 6 months- 1 year: 9, 6.3
- >1 year: 11, 7.6

Note: Frequency data indicate the actual number of people who responded to each question.
<table>
<thead>
<tr>
<th>Factor</th>
<th>(N responding)</th>
<th>Almost Never/Sometimes N (%)</th>
<th>Half the time N (%)</th>
<th>Most of the time/Often N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive status of client</td>
<td>(140)</td>
<td>28 (20.0%)</td>
<td>13 (9.3%)</td>
<td>99 (70.7%)</td>
</tr>
<tr>
<td>Client goals or motivation</td>
<td>(139)</td>
<td>31 (22.3%)</td>
<td>16 (11.5%)</td>
<td>92 (66.2%)</td>
</tr>
<tr>
<td>Severity of the sensory deficit</td>
<td>(139)</td>
<td>33 (23.7%)</td>
<td>16 (11.5%)</td>
<td>90 (64.8%)</td>
</tr>
<tr>
<td>Time since stroke</td>
<td>(140)</td>
<td>42 (30%)</td>
<td>12 (8.6%)</td>
<td>86 (61.4%)</td>
</tr>
<tr>
<td>Level of motor return</td>
<td>(140)</td>
<td>32 (22.9%)</td>
<td>30 (21.4%)</td>
<td>78 (55.7%)</td>
</tr>
<tr>
<td>Effectiveness of intervention</td>
<td>(138)</td>
<td>36 (26.1%)</td>
<td>29 (21.0%)</td>
<td>73 (52.9%)</td>
</tr>
<tr>
<td>Unilateral Neglect</td>
<td>(139)</td>
<td>51 (36.7%)</td>
<td>17 (12.2%)</td>
<td>71 (51.0%)</td>
</tr>
<tr>
<td>Familiarity with intervention</td>
<td>(138)</td>
<td>47 (34.1%)</td>
<td>23 (16.7%)</td>
<td>68 (49.2%)</td>
</tr>
<tr>
<td>Aphasia</td>
<td></td>
<td>60 (43.2%)</td>
<td>25 (18.0%)</td>
<td>54 (38.8%)</td>
</tr>
</tbody>
</table>
Table 6.3 Processes used when making decisions about sensory interventions

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree/Agree N (%)</th>
<th>Neutral N (%)</th>
<th>Disagree/Strongly disagree N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I regularly think back over specific client sessions and ask myself how well did that work and what could I do differently</td>
<td>131 (92.9%)</td>
<td>9 (6.4%)</td>
<td>1 (0.7%)</td>
</tr>
<tr>
<td>I make decisions based mainly on</td>
<td>107 (75.9%)</td>
<td>27</td>
<td>7 (5%)</td>
</tr>
</tbody>
</table>

(139)

Time available 72 (52.6%) 17 (12.4%) 48 (35.5%)
(137)

Oedema 69 (51.5%) 24 (17.8%) 42 (31.1%)
(135)

Stroke clinical guidelines 76 (56.3%) 21 (15.6%) 38 (28.1%)
(135)

Age of client 88 (63.3%) 15 (10.8%) 36 (25.9%)
(139)

Dominant vs non-dominant arm 82 (58.6%) 24 (17.1%) 34 (24.3%)
(140)

Other (4)
my previous experiences (N=141) (19.1%)
I think in terms of comparing and contrasting information about a client’s problem and proposed solutions to them (N=136) 102 (75.0%) 31 3 (2.2%) (22.8%)
When there is conflicting information about a clinical problem I identify assumptions underlying the different views (N=137) 81 (59.1%) 48 8 (5.8%) (35.0%)
I do not make judgements until I have sufficient data (N=140) 70 (50.0%) 43 27 (19.3%) (30.7%)
I use clinical protocols for most of my interventions (N=139) 44 (31.6%) 54 58 (41.4%) (38.8%)

6.10. Figures

Figure 6.1 Ranking of factors in terms of how frequently they influence decisions about specific interventions N=135
CHAPTER 7: UPPER LIMB POST-STROKE SENSORY IMPAIRMENT: THE SURVIVORS’ PERSPECTIVE

An essential source of information for clinical decision making comes from stroke survivors themselves. This Chapter presents a qualitative study of stroke survivors that addresses the fifth aim of the thesis, to describe the stroke survivors’ perspective with regard to ULPSSI. Findings from this study informed part of the content for the educational program used in study five.

This Chapter is based on a peer reviewed manuscript, published in the journal *Disability & Rehabilitation*, titled, “Upper limb post-stroke sensory impairments: The survivors’ perspective”. It reports the results of a qualitative study with 15 stroke survivors about their perspectives of experiencing ULPSSI and associated rehabilitation. This article has been expanded and modified to allow the inclusion of additional detail for this Chapter and has been formatted to maintain consistency throughout the thesis.

Upper limb post-stroke sensory impairments: The survivors’ perspective

Submitted: April 9th, 2012

Decision for revisions received: August 29th, 2012

Resubmitted: January, 2013

7.1. Abstract

7.1.1. Purpose.

This study described stroke survivors’ experiences of upper limb post-stroke sensory impairment (ULPSSI) and its rehabilitation.


This study was a qualitative descriptive study of 15 stroke survivors with ULPSSI using semi-structured interviews. A focus group of eight survivors reviewed thematic outcomes. Analysis was completed by three authors.

7.1.3. Results.

Three themes emerged: 1) What happened to my hand?: A description of the significant impact of sensory impairments on survivors roles and participation; 2) I was only just getting started: Survivors felt sensory impairments and the upper limb were ignored in rehabilitation and described being left on their own to devise their own rehabilitation; and 3) If I work hard then maybe someday: Survivors felt sensory impairments recovered slowly and was aided by working towards recovery and maintaining hope.

7.1.4. Conclusions.

Sensory impairments are significant for survivors and are deserving of greater clinical and research attention. In particular, assessments and interventions need further development and testing. This study’s findings revealed the need to ascertain individual survivors’ preference for involvement in decision making related to their rehabilitation planning. It also found survivors view recovery as extending well beyond current rehabilitation frameworks, necessitating further description of recovery and re-evaluation of service delivery to address survivors’ needs.
7.2. Background

7.2.1. The Importance of the stroke survivor’s perspective.

An essential source of information for CDM comes from stroke survivors themselves. Evidence-based practice encourages clinicians to not only use the best available evidence and clinical expertise, but to take into account the values and goals of the client (Sackett et al., 1996) when making clinical decisions. Similarly, client centred care is a key element of rehabilitation and prioritising the client’s story, their values and main concerns is fundamental to the process (Bright, Boland, Rutherford, Kayes, & McPherson, 2012). Thus when devising intervention plans for ULPSSI, it is important for clinicians to understand and incorporate the stroke survivor’s experience and perspective.

Qualitative research plays a pivotal role in helping clinicians and researchers understand the survivor’s perspective and thus to identify how to develop and provide services that might address the survivor’s needs and priorities (Carpenter, 2004). It appears that there is little or no existing research regarding the stroke survivor’s experience of ULPSSI. However there has been some qualitative research undertaken which illustrates the survivors’ perspective on the experience of having a stroke in general, their perspective on recovery and how it progresses, and the survivors’ experience of rehabilitation.

7.2.2. Stroke survivors experience of stroke, recovery and rehabilitation.

Several studies have explored the impact of having a stroke from the survivor’s perspective identifying not only the medical and physical impact of stroke but the psychological impact on both the stroke survivors and their caregivers. Stroke survivors focus on issues surrounding their independence, usefulness, self-care and socialising (Hopman & Verner, 2003) and they experience a distancing from their pre-stroke self, leaving survivors feeling estranged from themselves (Murray & Harrison, 2004). Survivors report significant changes such as lack of confidence and
negative self-evaluations in response to stroke, reduced social interactions, disrupted participation that resulted in a sense of loss of self, emotional difficulties, changes to social, romantic and sexual relationships and negative impacts on quality of life (Murray & Harrison, 2004). A qualitative meta-synthesis of nine studies highlighted that while stroke survivors face the sudden and overwhelming impact of stroke that leads to loss, uncertainty and social isolation, in general they learn to adapt and move forward to recovery (Salter, Hellings, Foley, & Teasall, 2008).

Qualitative studies exploring recovery and adjustment following stroke describe it as a slow and uncertain process (Becker & Kaufman, 1995), and one that is highly individualised with many survivors comparing their recovery to their pre-stroke lives (Burton, 2000; Dowswell, Lawler, Dowswell, Young, Forster, & Hearn, 2000). Wiles et al. (2002) suggest that part of the difficulty survivors have in coping with the recovery process may derive from high expectations about what might be achievable. Maintaining stroke survivor’s hope and motivation without encouraging over-optimistic expectations was identified as a challenge for therapists (Wiles et al., 2002). Barker and Brauer (2005), interviewed 19 Australian stroke survivors and nine spouses regarding their perspectives of upper limb recovery, and found that survivors had an optimistic, open-ended approach to upper limb recovery. They described survivors keeping hope for recovery by working at it and supporting each other while adjusting to life after stroke. Recovery was seen as a long term process, only ending if the survivor gives up. Survivors viewed a good upper limb recovery in terms of hope and functional use while a bad recovery was where hope was lost and no attempt was made to use the upper limb. In a survey of stroke survivor’s using questions developed from their qualitative study, Barker et al. (2007) found survivors’ identified the single most important factor for recovery was ‘use of the arm in everyday tasks’. Survivors also identified ‘not having enough movement to work with’ as the greatest barrier to upper limb recovery. Barker et al. (2007) identified a mismatch between the survivor’s desires for a long term view of upper limb recovery versus the reality of acute timeframes for rehabilitation and made recommendations for more flexible and creative solutions to the delivery of rehabilitation that might suit various stages of recovery and address individual needs.
A number of qualitative studies have examined stroke survivors' experience of rehabilitation and these have been synthesised in a systematic review (Peoples, Satink & Steultjens, 2011). One of the important findings from the review was the centrality of the concepts of power and empowerment in stroke rehabilitation, and that this too may differ between individuals. Although the provision of adequate information, active participation in rehabilitation, collaboration, and respectful communication by health professionals may contribute to the survivor's sense of control during rehabilitation, not all participants may be ready to assume power and responsibility or to be involved in decision-making. Importantly, this review indicated a need for therapists to evaluate how and when clients are ready to receive information, make decisions, and to assume power and responsibility in rehabilitation. Consideration of individual differences in both the recovery and rehabilitation process and nature of the individual's involvement in rehabilitation is therefore essential (Peoples et al., 2011).

While these studies focused on survivors' perspectives of post-stroke recovery, upper limb recovery, and rehabilitation, they did not specifically address sensory impairment and subsequent functional limitations, the impact of sensory impairment on participation and future plans, or the sensory rehabilitation experience. Despite the prevalence of sensory impairments and its importance to an individual's function and participation, little is known about the stroke survivor's experience of upper limb sensory impairments or the associated rehabilitation experience. At time of undertaking this study there were no published papers addressing this issue from the survivor's perspective. Studies that specifically consider ULPSSI, are likely to further enrich what is currently known about survivor's experience of stroke and its rehabilitation and this in turn may enhance occupational therapist's clinical decision making and ultimately improve the provision of services to stroke survivors.

This paper reports the results from a qualitative study of stroke survivors' experience of ULPSSI and its associated rehabilitation in order to better inform the development
of intervention plans and service delivery models that address the survivors’ needs. The aim of this study was therefore to describe stroke survivors’ experience of upper limb sensory impairments (ULPSSI), its impact, as well as their experience of sensory rehabilitation and recovery.

7.3. Methods
Qualitative descriptive methods (Ritchie, Spencer, & O’Connor, 2003) were used to explore and describe the experience of stroke survivors who had ULPSSI. This approach was taken to allow for a detailed analysis and description in the stroke survivors’ own words (Ritchie, Spencer, & O’Connor, 2003). Study procedures were approved by an Ethics Review Board at the University of Queensland, Australia. Participants were recruited using purposeful sampling techniques through advertising with local stroke survivor support groups and assisted living facilities in a metropolitan area of the Pacific Northwest USA. Subsequently, interviews were conducted to assure eligibility criteria were met that included being older than 18 years, having had a stroke that impacted upper limb movement and sensation at least six months prior to the interview, adequate language and cognitive skills to respond to the questions, and living in the community, either at home or an assisted living facility. The criteria were kept broad to obtain variation in sampling of those who at least initially experienced sensory impairments after stroke based on their self-report. Exclusion of some participants was based on scoring in the dementia category on the Saint Louis University Mental Status exam (SLUMS) (Tariq, Tumosa, Chibnall, Perry III, & Morley, 2006).

A sample size of 15 was used in this study as previous research that a sample size of at least twelve participants enables data saturation to be achieved for studies that aim to describe shared perceptions (Guest, Bunce, & Johnson, 2006; Johnson, 1998). On recruitment into the study, survivors were invited to participate in both individual interviews and focus group discussions. The focus group was used for member-checking as well as to increase credibility by theme clarification or elaboration (Cohen & Crabtree, 2008; Shenton, 2004). Fifteen stroke survivors that
met eligibility criteria participated in the initial interviews and eight of these fifteen survivors chose also to participate in the focus group. Three volunteers were screened and subsequently excluded from the study due to living in a nursing home or having low scores on the SLUMS.

Participants ranged in age from 30 to 78 years and were 6 months to 16 years post stroke. The demographics of the study participants are shown in Table 7.1. All participants received rehabilitation after their stroke with 93% (O’Connell, Hanna, Penney, Pearce, Owen, & Warelow, 2001) reporting that they were initially in an inpatient rehabilitation centre and one survivor reported going to a skilled nursing facility initially. Fourteen of the participants also reported receiving outpatient occupational therapy and physical therapy after their inpatient rehabilitation stay, with one survivor reporting no further therapy after discharge from the acute hospital setting.

A semi-structured interview guide utilising open ended questions explored participants’ description of ULPSSI, as well as his or her rehabilitation experience and recovery process. See Table 7.2. for the questions and probes used. Participants completed one audio-recorded and transcribed interview with the primary researcher, ranging in time from 30 minutes to 1.5 hours. Resources did not allow hiring of an interviewer from outside the research team and all interviews were completed by the primary author. Bias was minimised by having an interview script, research intention described in consent documents and frequent debriefing sessions with the other authors to assure a participant led versus researcher manipulated interaction (Shenton, 2004). Data was analysed using qualitative content analysis (Ritchie et al., 2003), with codes derived from the interview data itself as the transcripts were reviewed. The researchers reviewed interviews and developed the codes and definitions individually and then in group discussions. Themes were initially proposed individually and then as a team, based on emerging patterns from the data coding and the common elements linking them in relationship to the study aims and interview questions, utilising the method described by Ritchie et al. (2003).
Ethnograph V6 (Qualis Research, 2008) was used in formatting codes and citing subsequent thematic exemplars. Upon completion of initial thematic analysis, participants were then invited to attend a focus group that reviewed the themes developed by the researchers. The 1.5 hour focus group was recorded and transcribed. The additional transcript was reviewed by all three authors and coded using previously developed codes and the feedback incorporated into further development of the themes. Using descriptive methods described by Ritchie et al. (2003), findings were organised in a way that best fits the data and representing the major topics about which information was elicited.

Reflexivity statements were developed at the beginning of the research process that identified the biases and perspectives of the researchers. This was reviewed as the data was interpreted to assess the impact of preconceived ideas on the development of coding and themes. An audit trail was also kept to allow for tracking of the decision making process. In this trail, discussion of the rationale for the use of probing questions during the interviews and for adding additional questions to some of the interviews were monitored.

7.4. Findings
Three themes emerged from the data: 1) *What happened to my hand?* Sensory impairment and its impact. This captures the descriptions of the experience of upper limb sensory impairment and its functional implications. 2) *I was only just getting started:* Readiness for rehabilitation. This theme provides a description of the rehabilitation experience. 3) *If I work hard then maybe someday:* Hope for recovery. This theme explores the concepts of working towards recovery and hope expressed by survivors.
7.4.1. What happened to my hand? Sensory impairment and its impact.

This theme addresses the participants’ descriptions of his or her upper limb sensory impairment, the functional implications of that impairment and how important participants thought sensation was. It also illustrates participant’s emotional responses to the impact of sensory impairments and the effort required to manage daily activities.

Many participants described post stroke sensation as being altered in some way: as a ‘strange, odd feeling’, ‘feeling numb’ or ‘heaviness.’ Participants also described periods of hypersensitivity and of feeling cold in the impaired limb. They used similes to describe the feeling: ‘like wearing a glove’, ‘like Novocain’ ‘like it was asleep’ or feeling ‘like it was dead’. At times participants stated they could not feel their hand or arm at all and expressed a lack of awareness of their limb: “I asked [him] where my hand was. What happened to my hand? It was gone. So I thought it had been (gestured cut off).” (P2) “So it felt like dead weight and I did not even remember that it was a part of my body.” (Participant (P) 12). Participants also provided detailed descriptions of difficulties controlling the amount of pressure or force to use when manipulating objects, receiving feedback and judging distances. “The real overwhelming thing was the lack of force and positional feedback from it.” (P4)

Participants reported that, frequently, decreased sensation was associated with decreased use of the impaired arm. “I couldn’t feel it and I just sort of immediately forgot about it and only focused on the abilities on the right side that were not affected.” (P12) “I just never used the arm that much…. Because I was afraid I was going to drop things.” (P6)

Sensory impairments affected performance of all activities of daily living with participants particularly noting difficulties with eating, dressing (manipulating buttons, clothing items, belts, pants, etc.), bathing (knowing they had adequately cleaned themselves), styling hair, and simple meal preparation (having to do tasks with one
hand, difficulty grading control, objects slipping or dropping, arm getting into harm’s way), and safely judging water temperature.

“Either it would slip out of my hands or I would be trying to unscrew the convenient screw tops and I would be putting more and more and more force on them and either could not budge them… or I would put so much pressure on the container that it would erupt all over the counter top or the floor……. I think the, that the force feedback, the feeling of being able to feel force and being able to feel position are just huge. That without those it becomes very difficult to do coordinated activities.” (P4)

Participants focused not only on personal tasks, but also described many significant instrumental ADL and meaningful leisure tasks that became difficult due to impaired sensation. These included driving (adequately feeling and managing the steering wheel, changing gears or turning on the indicators without taking eyes off the road), managing child care, grading the pressure on guitar strings or even knowing where the hand was on the guitar, playing the piano, using the computer, gardening, and difficulty with a range of other leisure activities. In each of these tasks sensory impairments made the task difficult or placed the survivor at risk for injury.

“I burnt myself and I did not know it, until a day later and I had a scar on my arm. So I could not feel that. It was significant in having to be more careful of what I was doing in terms of being around any power equipment and that sort of thing.” (p2)

Participants described the extra amount of time and effort needed to do things due to the decreased sensation in the upper limb. “Because I couldn’t feel beyond there, I had to constantly be visually assessing the hand. Am I sitting on it? Am I in a bad position? Or just anything because if I bumped it against a wall it did not register just as to how hard I had hit it, did I bruise it? I just had to physically look at it.” (P12)

Participants also reported that this was physically, mentally and emotionally fatiguing. “You are always thinking about things that you really should not have to be thinking about. They were automatic before. This can be emotionally taxing.” (P12)
“You just have to be so methodical, so slow and it takes me forever to do stuff.” (P6)
“Frustration comes from that too. Things that you could do so automatically before require so much concentration now. Just one slip and then the whole thing, you know you just have to start all over.” (P16) Some participants report having to think through every step as they attempt to move their upper limb. “All the steps, all the muscles. Where is my finger? Where is my elbow? Where is my biceps?” (P16)

Participants also reported emotional responses to the impairments in the upper limb. “Having stuff hit the floor in the kitchen was incredibly depressing. I cannot tell how much my heart would sink each time something would hit the floor in the kitchen. It was more than just oh darn now I have got to clean this up.” (P4) Other participants reported frustration, being self-conscious, bewilderment, despair, anger, changes in self-confidence, feelings of worthlessness, vulnerability, and changes in personal identity such as change in perception from being a very active person to sedentary. “I just felt like a lousy mum. You know it was really hard [not] to.” (P8)

When asked about the relative importance of sensation to motor return several reported that they were equally important, particularly if they had neither movement nor sensation, but a few stated that motor return was initially the most important. Further it seemed that once there was some motor return then the survivor became aware of the importance of sensory input for functional use of the upper limb. “At first it [sensory loss] wasn’t very [important] but now that I am getting to a point that I am getting fairly good movement in that hand, it is definitely more of a priority now.” (P1) “Once that I started, I had the ability to begin walking again, ….then if I could have started addressing it [sensation] more aggressively at that time it would have been important. Little steps at a time. Got the walking, now let’s attack the feeling.” (P2)
7.4.2. “I was only just getting started”: Readiness for rehabilitation

In this theme, discussion about rehabilitation can be seen in terms of readiness for rehabilitation. Not all were ready to participate in rehabilitation for sensory impairment or ready to be involved in associated decision-making during their hospital stay, however those who did feel ready to participate noted the priority given to rehabilitation of motor skills and in particular lower limb rehabilitation. This theme also acknowledges the seeming restrictions placed on their readiness for rehabilitation by therapists, with survivor’s believing some therapists recognised their readiness to be involved where others did not.

Some participants recalled having some therapy for their arm especially once they were in the outpatient setting, yet as a whole most participants felt like their arm was ignored in the rehabilitation process. “I do not recall any therapy that had to do with my arm. Everything was just balance and walking” (P16); “They just worked with my leg. Nothing was really done with the arm” (P13); “I wish they would have concentrated more on my arm.” (P10). In fact one participant dealt with this by enrolling themselves in an orthopaedic arm group: “...they were recovering from like mainly shoulder pain and all kinds of stuff. So I just told them would it be OK if I just went to the arm class.” (P11) Generally participants reported little or no attention paid to sensory impairments in their rehabilitation experience. “You know they did not talk about the sensory stuff. I had a nurse …she was not a therapist she just worked on the stroke unit. She just handed me a rough wash cloth and she said when you are sitting there you just rub that on your arm.” (P12)

Participants reported that rehabilitation appeared to focus on compensatory strategies if the impairment was noted at all. “They ignored the sensation. I think. They made you replace your sensory awareness with your visual awareness… You know, use your eyes to figure out where your hand is. Do not use this exercise or anything to restore the sensation or [even] try, [just] use your eyes.” (P12) This left participants with the feeling that little could be done to improve their sensation. “I
think movement I can work on and just practice that, but the feeling; I do not know what to do to get that [sensation] back other than just wait.” (P16)

While a large number of participants would have liked early focus on sensation and upper limb return, some participants also felt that they were not ready to address upper limb sensory impairments until later, even six months after stroke or until they were walking or doing other personal tasks. “I really was not really focusing on anything. I guess a lot of it was because of the damage to the brain. What it affected. It kind of really took away a lot of my drive. … I started to get it back over time.” (P1)

Yet others wondered what might have happened if therapy had started sooner. “You know I think mine was neglected earlier on. So I only know what I got and mine was late. But now I do wonder in hindsight if they had worked a little harder with me earlier on where might my arm be now.” (P12)

Participants saw their rehabilitation needs as ongoing, well past the time that rehabilitation finished, and found they spent a lot of time on their own devising plans for upper limb recovery. “When I finished up with physical therapy, I was just at a point when I just felt I could do a lot more.” (P1) “I would have liked more guidance because I really felt like I was writing the book as I was doing it.” (P4) “Actually it was my own therapy that got movement back in my arm. I really did not have any kind of therapeutic process with therapy.” (P16)

Survivors reported both positive and negative experiences with the rehabilitation professionals with some, but not all, therapists seeming to be aware of the survivor’s readiness to participate in rehabilitation for sensory impairments. For some, therapists were a source of encouragement. “The positive reinforcement. There was one spot I could not do it, but they never gave me the chance to think that.” (P16)

However, participants also at times felt that rehabilitation professionals had low expectations for their recovery and limited their possibilities.
“The particular physical therapist that I worked with, I just wish the guy was more positive about making progress. It just seemed like he just had a lot of like well, it is never going to be as good as it was. Well I can accept that. I just felt like he was drawing boundaries that were just like not too far from where I was, and saying it was not going to get better than that..I responded a lot better to positive encouragement.” (P4)

Most participants felt that they generally had little input into planning or deciding their sensory rehabilitation program especially in the inpatient setting, although this may have been because they were not ready for this level of involvement. “I was told this is what you need to do and I just did it. I am not sure that I had the insight to really know. I relied on the professionals and I had the trust that they knew what I could do and what I couldn’t do.” (P2) While some participants felt that this was reasonable, because they did not have the expertise or ability to direct their care, other survivors felt that they would like to have had more input so that their goals and values were addressed. “I think it was all planned out for me. I had certain days for walking. Certain days for lifting weights, balancing. …Well I think I would have liked to have been consulted about what I thought was important to work on first.” (P16)

7.4.3. If I work hard then maybe someday: Hope for recovery.

This theme describes a slow, open-ended recovery from sensory impairment, one that survivors felt they might influence by working hard; that was encouraged by support and help of family and friends; and most importantly by maintaining hope.

While a few participants reported significant changes in the first few days or weeks after stroke most participants reported that changes with sensory impairments occurred slowly. “Initially there was quite a bit of progress, but now I really have to work very hard to see any improvement.” (P16) The numbness and tingling was generally described as improving first, but several participants reported that this
fluctuated especially when they were fatigued or ill. “When I started using it. The numb feeling went away, within the course of a few days. And then while I was in the hospital, maybe I started feeling things like cold. I feel pain in there sometimes.” (P1)

Sensory return, for most participants, appeared to be more gradual than the motor return, and was often described by the participants as occurring after a significant improvement in movement or use. “It came back differently. At first it was just movement and I wasn’t aware of movement at first and I would kind of surprise myself when I did move. The feeling started coming back slowly after that.” (P16).

The majority of participants considered progress in their recovery of sensation in terms of functional use of the upper limb. “And I think a good recovery would be where you have enough function back so that you can at least care for yourself and live independently and potentially do other things so that you are a contributing member of society.” (P4) However, a few focused on the person’s overall attitude or perspective as being the most prominent feature of a recovery. “Being positive about their own self, ….it seems like a lot of people who have strokes give up on themselves. To me it is just a dead end for them.” (P16)

Participants were not always sure what specific activities seemed to lead to sensory return, but did feel that stimulation, increased movement, constantly trying to use their arm did help. “But I noticed that the more I went to that arm class and gave the stimulation to the arm the better it got.” (P12) Regardless of what specific approach was used participants strongly held the belief that if they were going to get back as much functional use of their upper limb as possible they needed to work hard. “I won’t accept anything less than maximum recovery and I will do anything that I have to do. I will sweat; I will go through the pain to get where I think I am not going to get any better.” (P7) Participants also viewed their pre-stroke motivation and discipline impacting on their recovery and providing them with tools they could use to work towards improving functional use of the arm. “That is something that a lot of folks that have strokes do not have the benefit of. I mean by that, they are not in good physical shape when they have their stroke.” (P7); “[I] knew it would take a lot of
hard work [pause], being an athlete, I think was the number one thing is that competitive drive to get better." (P2) Participants also hypothesised that not working hard and complaining would lead to a poor recovery. “I do not know what they have done or have not done, but it seems to me that they do a lot of complaining so I can, based on that, draw the conclusion that perhaps they did not work as hard as they could have and that is why they are at where they are at right now." (P7)

Hope was a common message expressed throughout the interviews. “Because you never know until you try. Just never give up because the doctor says you can make progress for 2 years and that is not true. It is more than 2 years; it could be all your life.” (P3) Hope often comes from seeing changes or small improvements. “I really have to work very hard to see any improvement, but I see improvement so that keeps me going.” (P6) Hope appeared at times to have come from a restructuring of their life story, with survivors describing developing a sense of a new normal.

The mobility is back but the numbness is there. It probably always will be…. [it is] extremely important to me to try to resume some normal life. What I call normal or my new normal. Being able to drive and being able to do things for myself. (P2)

Survivors also found that helping others and feeling like they were contributing back to society also provided hope and a feeling of meaning for their lives. “Then as months went by it moved up to a good level where I felt I could do many things. I could contribute to society. I was like, Oh wow! I will be able to do all that volunteer work at the church I intended to do.” (P4)

Many survivors reported that support from their family, friends and church was important in giving them purpose, hope, and encouraging recovery. Survivors also reported that their faith helped place their stroke in perspective and helped reduced their feelings of depression. “Support of my family, my wife and family. You know, faith. Without them I would be pretty lost.” (P5)
7.5. Discussion

This study is the first to explore stroke survivors’ perspectives on upper limb sensory impairments, its recovery, and rehabilitation. These findings describe the importance of upper limb sensation to stroke survivor’s participation in activities, their desire for greater attention to upper limb rehabilitation in the acute setting, and for access to therapy to support recovery of sensation in the long term. The importance of support from health professionals, family and friends was acknowledged and the importance of hope was emphasised.

Soon after the completion of the data collection for this study a conference poster (Connell & Adams, 2011) was published, this also sought to understand the experience of sensory impairment post stroke. Interviews with five stroke survivors explored the experience and impact of sensory impairment and the rehabilitation experience (Connell & Adams, 2011). The author emphasised the need for assessment of sensation and that clinicians recognise this impairment as an issue of concern to those who experience it. This preliminary study also demonstrates the need for further rigorous qualitative investigation about the experience of sensory impairment post stroke.

Survivors described having altered sensations, and in a number of cases complete lack of sensation that contributed to a feeling of detachment from their upper limb and specifically contributed to the amount of attention they gave to their arm. Sensory impairments such as difficulty with temperature discrimination contributed to safety concerns and functional difficulties. This sense of detachment and safety concerns was also noted in a qualitative study undertaken with five stroke survivors about their experiences of sensory impairments which was published in a poster presentation just after the completion of this current study (Connell & Adams, 2011). In our study the impact of proprioceptive and kinaesthetic deficits that survivor’s highlighted was also very evident. Survivors provided rich and poignant descriptions of their struggles to complete personal and instrumental functional tasks due to these impairments in particular with many also frustrated at the impact on leisure or work-
related activities. Comparatively limited research exists regarding the effects of interventions specifically targeting proprioceptive and kinaesthetic deficits for the upper limb. These impairments are significant for survivors and hence deserve more clinical as well as research attention.

Participants noted the amount of effort and conscious thought processing required for adapting to impaired sensation reporting that this was not just physically fatiguing but mentally and emotionally fatiguing also. This increase in perceived effort has been identified as one among many factors potentially contributing to post-stroke fatigue (McGeough, Pollock, Smith, Dennis, Sharpe, Lewis, at al., 2010) however is not addressed in handouts from the National Stroke Association (Daniels, Winding, & Borell, 2002) on fatigue. The aetiology of post-stroke fatigue is unclear and lack of clarity exists about the mechanisms by which any intervention may work. This study confirms the role that additional mental effort plays in adding to the overall post-stroke fatigue burden. Only recently has attention been given to interventions for post-stroke fatigue with a number of randomised controlled trials testing a range of different interventions for managing fatigue, but concluding that more attention to find effective interventions is necessary (McGeough, Pollock, Smith, Dennis, Sharpe, Lewis, at al., 2010).

Regardless of the neuro-scientific relationship between sensory and motor recovery post-stroke, from the survivor’s perspective, the full importance of sensory impairments may only come to their attention once they start to achieve some motor recovery. In this study, it was at this point that participants seemed to better understand the intricate interplay between these two systems and became more committed to addressing sensory impairments alongside motor training. Survivors described inconsistent attention being given to upper limb recovery and little or no attention paid to sensory impairments during rehabilitation. Survivors described being on their own to devise ways to facilitate their upper limb recovery, with one survivor describing it as “I felt like I was writing the book.” (P4). Similarly Barker and Brauer (2005) found in their study that survivors perceived more time being spent in
providing rehabilitation for the lower than upper limb. Sensory impairment and its impact is clearly important to stroke survivors, an observation confirmed in the study by Connell and Adams (2011) who emphasised the need for assessment of sensation and that clinicians recognise this impairment as an issue of concern to those who experience it. Given the importance of sensory impairments to survivors, and the impact it has on the functional use of the upper limb and on participation, it is important that ULPSSI be addressed in rehabilitation.

Participants reported that when sensory impairment was addressed in rehabilitation the focus was on compensation, however many survivors wanted to focus on remediation. This is consistent with the dilemma noted in a study involving two focus groups with 13 occupational therapists experienced in stroke rehabilitation (Daniels, Winding, & Borell, 2002). While these therapists found it difficult to balance remedial and compensatory approaches there remain arguments for both to be offered during rehabilitation when appropriate. Daniels, Winding and Borell (2002) suggest that using an occupation-based approach to rehabilitation may ease the distinction between remedial and compensatory approaches in the rehabilitation. Safety and the ability to use compensatory approaches to participate in activities and enable positive experiences are important. However the growing evidence that recovery of sensation may continue for many months (Connell, 2007; Winward, Halligan, & Wade, 2007) indicates a longer term view of the potential for remediation may be also be necessary. This is reinforced by the experience of survivors in this current study who consistently reported struggling to devise means to continue remediation by themselves, long after rehabilitation had ended. This suggests an important role for education of both therapists and clients regarding the nature of recovery and rationale for uses of differing rehabilitation approaches.

The restrictions of the rehabilitation context must be acknowledged. The average rehabilitation stay for stroke survivors in the USA is 16.5 days (McGeough et al., 2010) with only 30.7 % receiving outpatient therapy services after discharge (Xie, George, Ayala, McGruder, Denny, Croft, & Vaderrama, 2007). Only limited
rehabilitation services can be provided to stroke survivors within this service model. It is clear that this timing of rehabilitation services does not match the needs of stroke survivors with most describing need for support and advice regarding remediating sensory and upper limb impairments that extend far beyond these timeframes. This is consistent with Barker and Brauer’s (2005) study of survivors and their experience of recovery and rehabilitation for upper limb impairments. Further evaluation of the delivery of rehabilitation services to stroke survivors over their recovery trajectory is important.

Most survivors reported that they had little input into directing their own rehabilitation program or goals, and while they respected the input of professionals who they saw as having more experience and expertise in this area, they would have liked to have had more involvement. However, some also acknowledged that they would not have been ready to participate in decisions in the early stages of rehabilitation and welcomed therapists being directive. A synthesis of qualitative studies about stroke rehabilitation concluded that an individual has the right to be involved in decision making as well as to not be involved in decision making and for some, paternalistic approaches may at times be appreciated (Peoples et al., 2011). Therefore there is a need for therapists to be aware of the readiness of a client to participate in rehabilitation and decision-making.

The discussion on rehabilitation and recovery of sensory impairments post stroke is not complete without consideration of the central role that hope plays. Hope for recovery was a common message conveyed by participants. Their hope was maintained through participation in activities, spiritual faith, and receiving encouragement and support from others, including rehabilitation professionals. Participants hope was diminished if therapists expressed low expectations for their recovery. The balance between maintaining hope and not encouraging over-optimistic expectations was raised in qualitative interviews with physiotherapists working in stroke rehabilitation (Wiles, Ashburn, Payne, & Murphy, 2002). They concluded that therapists need to be aware that even if they try to avoid raising
survivor’s expectations for recovery, patients will maintain high expectations as a means of coping regardless (Wiles et al., 2002). Participants in our study also emphasized the importance of continuing to work hard to facilitate recovery in the hope that incremental improvements would continue over a long period of time. Having an open-ended view of recovery was noted by Barker and Bauer (2005) as a way of allowing survivors to continue to work towards and hope for improvement. The balance between maintaining hope and having realistic expectations is an important challenge for therapists. Understanding the role of hope and processes inherent in coping and adjustment is therefore essential.

7.6. Limitations
While we have generalised our findings from the participants’ interviews, the heterogeneous and individualised nature of post-stroke recovery and experiences also need to be acknowledged. Participants in this study were primarily drawn from Stroke Support Groups and thus may be more active overall after stroke and in pursuit of improving their participation and quality of life than stroke survivors who do not participate in stroke support groups. This group may also have other characteristics that differentiate them from other stroke survivors. This group of survivors also volunteered to participate and this may also represent a group of survivors who are more willing to discuss or review their experience and explore or pursue opportunities to enhance their recovery than those who did not volunteer. Survivors self-reports may also not truly reflect what actually occurred in therapy due to issues of recall and distance in time since receiving therapy and this should be considered when interpreting the findings in this study. This study did not verify the presence of ULPSSI at the time of participation and it is unclear how many of the participants were relying on recall versus their current experiences. This may have impacted how they perceived or interpreted the experience. Participants also were not tested for the presence of hemianopsia or for unilateral neglect or asked about experiencing this neglect after their stroke. The presence of hemianopsia or unilateral neglect may have altered their experiences or the interventions which they received. Response bias or the survivors’ reports possibly being influenced by the need to provide socially acceptable answers or answers that they feel the
researcher wanted may have impacted the study, though some studies have concluded that there is very little evidence that this occurs (Collins, Shattell, & Thomas, 2005). Having the primary researcher conducting the interviews and focus groups may have influenced the findings, though attempts to minimise the bias by using a structured interview script and frequent debriefings were made.

7.7. Clinical Implications and Conclusions
This study confirmed that sensory impairments impact significantly on survivors’ roles and participation after stroke. A number of issues illustrated in this study underpin the importance of scaling up both the clinical attention to, and research effort for, interventions for sensory impairments post stroke. First, from the survivor’s perspective sensory return was as important to them as motor impairments although the importance of sensory return seemed to become more evident to them after motor return had commenced. Second, survivors described sensory impairments that are not frequently addressed or described by therapists or investigated in intervention research; these specifically being the ability to judge force and arm position. Finally, participants clearly wanted the option of receiving remedial as well as compensatory rehabilitation for upper limb sensory impairments during their inpatient stay however they perceived remediation was rarely offered or attempted.

Another important finding from this study was that sensory impairments clearly increased the physical and emotional effort required by participants to carry out daily activities. This increased effort may in turn contribute to post-stroke fatigue. Further attention to post-stroke fatigue and sensory impairment as a contributing factor is warranted by both clinicians and researchers.

Confirming results from previous research, this study illustrated stroke survivors desire to pursue rehabilitation well past the period offered in their inpatient stay to support recovery in the long term. As a number of other authors have noted, consideration of models of rehabilitation past the acute stay is important and
potentially achievable, particularly if supplemented with well-developed, tailored information, and use of existing support services. Further research into such models is essential to inform both clinical practice and policy decisions. Finally, this study highlighted the need for clinicians to ascertain the preference of individual survivors with respect to involvement in decision-making and to carefully consider how to balance the need to maintain hope while adjusting to life post-stroke.
### 7.8. Tables

Table 7.1. Demographics of study participants.

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**Age:** Mean = 55.5 years, sd 15.7; Range 30 – 78 years

**Time since stroke:** Mean = 4.7 years, sd 4.6; Range 6 months - 16 years

HA – Home Alone, HSF – Home with spouse or family, ALF - Assisted Living Facility,
1. Please explain what it is like to have changes in feeling or sensation in your arm after a stroke.

Probes: What type of difficulties did you experience because of the changes in feeling in your arm after your stroke? How did that impact what you could or could not do? What activities were impacted? How did this change over time? How significant were your sensory difficulties (how you could feel) after your stroke? How important would you say that having normal feeling in your arm again is?

2. Please describe your experience of your rehabilitation of your arm after your stroke. Include how the loss of feeling in your arm was addressed or not addressed.

Probes: What type of therapy did you experience after your stroke? How much was focused on the arm? Did anyone address sensory difficulties in your arm? How? Which therapy interventions appeared to work the best for getting feeling back in your arm? What did you like about your therapy experience? What would you have liked to have had done differently? How important is it that treatments that focus on feeling in your arm are included in your rehabilitation experience? Is there a particular time after your stroke when you think it would have been best to work on the difficulties with feeling in your arm? How much were you consulted or involved in planning your rehabilitation experience? Would you have liked it to have been more or less?

3. Please describe how your arm recovered after your stroke. Include both how your feeling and movement recovered.

Probes: What is a good sensory recovery after stroke? Why? What is a bad sensory recovery after stroke? Why? Did you have a good or bad recovery? Explain how your recovery changed over time. Did the way the feeling came back in your arm match or differ from how the movement came back? What factors do you think influenced your recovery the most? Where there any specific factors that influenced the recovery of sensation?
CHAPTER 8: FEASIBILITY AND EFFECTS OF A PROFESSIONAL EDUCATION WORKSHOP FOR OCCUPATIONAL THERAPISTS’ MANAGEMENT OF UPPER-LIMB POST-STROKE SENSORY IMPAIRMENT

The final study of this thesis, which forms the basis of this Chapter, evaluated the feasibility of a continuing professional education program (CPE) workshop to provide evidence-based information supporting therapists’ clinical decision-making (CDM) regarding the management of upper limb post-stroke sensory impairments (ULPSSI). The Chapter is based on a published article (co-authored with S. Bennett) about a feasibility study examining the development, implementation and effectiveness of a theory-based workshop to facilitate evidence-based practice for occupational therapists addressing ULPSSI. For the purposes of this thesis, the article has been modified to include additional detail and formatted for consistency with the rest of the thesis.

However before presenting details of the study, a review of the work in this thesis justifying the need for a CPE workshop, and the need for theory underpinning CPE is addressed. Because it was important for participants in the CPE program to be provided with the most current research evidence, an update of the research about ULPSSI measures and interventions since the Cochrane review and literature reviews earlier in this thesis was also undertaken and is presented within this Chapter. The Chapter finishes with the presentation of the methods and evaluation of the feasibility study of a continuing professional education program (CPE) to support occupational therapists’ CDM for the management of ULPSSI.

8.1. Abstract
We examined the development, implementation and effectiveness of a theory-based workshop to increase knowledge and confidence in the management of ULPSSI, evidence based practice (EBP) and shared decision making (SDM), and to facilitate utilisation of key management strategies for occupational therapists addressing ULPSSI.

Nineteen therapists participated in a quasi-experimental pre-test-post-test study that included an eight hour evidence-based workshop designed using the Theory of Planned Behaviour. We measured changes in knowledge, attitudes and perceived behavioural control and intended behaviours regarding ULPSSI management, research utilisation and SDM.

We noted significant changes in knowledge, attitudes and perceived behavioural control and intended behaviours about ULPSSI management, research utilisation, and SDM and made recommendations for changes in recruitment strategies, outcome measures and workshop content.

A theory-based workshop can potentially affect knowledge, attitudes and intended behaviours about ULPSSI management, research utilisation, and SDM. A randomised controlled trial (RCT) evaluating this intervention is warranted and will potentially improve understanding of methods that facilitate evidence-based CDM.

8.2. Background
According to the American Academy of Physical Medicine and Rehabilitation (2014) over 72 million Americans have had a stroke and fewer than 40% of stroke survivors have received appropriate rehabilitation. Stroke survivors form a large percentage of the population of adult clients seen by occupational therapists (National Board for Certification in Occupational Therapy Inc, 2004). These clients experience a large
range of impairments and require therapists to engage in complex CDM. While occupational therapists utilise multiple sources of information as a basis for their CDM, EBP encourages therapists to utilise the best available research evidence, along with clients’ goals and values, and the therapists’ expertise as the information sources (Hoffman, Bennett, & Del Mar, 2010). However preceding studies in this thesis have indicated that occupational therapists have insufficient knowledge to confidently make decisions in this area. A summary of the finding from these studies is provided to establish the need for education to support CDM. The concepts underlying the use of theory-based CPE to increase therapists’ knowledge, attitudes and intended behaviours with regard to ULPSSI management are then discussed.

8.2.1. Practice patterns and CDM in ULPSSI management.

Having accurate information on which to base CDM is important for good outcomes. In the preceding studies therapists reported using sensory measures with documented concerns regarding their reliability and validity for stroke survivors (Chapter 5 & 6) and where almost none reported using the available standardised measures such as the NSA as recommended in clinical practice guidelines. This could impact the accuracy of the data therapists rely on for CDM. Another concern is that therapists recounted most commonly not utilising sensory measures if clients reported no impairments (Chapter 5 & 6). Stroke survivors may not always be aware of ULPSSI (Accera, 2007) and relying on survivors’ report may not reliably inform CDM. Therapists would benefit from this information to better inform their CDM regarding utilising sensory measures.

Having identified ULPSSI, therapists must then decide whether or not to intervene and if so which interventions to use. The survey of 145 U.S. occupational therapists that treated stroke survivors (Chapter 5 & 6) found that 46% provided ULPSSI interventions half or less than half the time. Respondents reported providing non-specific sensory stimulation, compensation, and safety education to clients with ULPSSI. Only 12.5% of the reported ULPSSI interventions included sensory re-education (graded interventions using re-education principles) and none reported
using mirror therapy, two interventions that now have more than one RCT supporting their use (see update of research from RCTs later in this Chapter). This indicates potential existence of a research-practice gap. These findings emulated those of the qualitative study (Chapter 4) in which therapists focused interventions predominately on compensation and safety.

In contrast, EBP invites therapists to utilise the best available research evidence in CDM. Few therapists in either study recounted using interventions for which some research evidence exists, nor did they refer to clinical practice guidelines or search for research evidence to inform CDM. Instead therapists used prior experience, effects seen when trialling interventions, and consulting other therapists as information sources regarding ULPSSI interventions (Chapter 4 & 6). In the qualitative study (Chapter 4), therapists also described using information from other practice areas in a form of reasoning by analogy. Therapists reported not providing interventions for ULPSSI because they lacked knowledge; believed motor interventions addressed ULPSSI, and were short of time (Chapters 4, 5, & 6). Education on potentially effective interventions and how to evaluate their practice could help address some of the concerns noted in these studies.

In short, CDM regarding ULPSSI management was characterised by uncertainty. Half the survey respondents reported a lack of knowledge and skills as a barrier to addressing ULPSSI, and 78.2% reported that their knowledge of ULPSSI was not up to date and identified a need for information and training in ULPSSI management (Chapters 5 & 6). While therapists generally did not report searching for research evidence, when they did they reported difficulty finding evidence regarding ULPSSI. What is needed is training in EBP strategies to support CDM, how to manage uncertainty in CDM, as well as strategies to reduce bias when therapists use clinical experience.

Survey respondents themselves identified further continuing education courses and further research evidence as the most useful methods to increase their use of ULPSSI interventions. Numerous topics for education and training were nominated related to knowledge about, measures of, and interventions for ULPSSI. Education
aimed at increasing therapists’ awareness of the growing research evidence regarding ULPSSI management may be useful and potentially result in therapists incorporating this evidence in their CDM. Therapists could benefit from training in EBP strategies they could use to locate new evidence and stay up to date.

8.2.2. The stroke survivors’ perspective.

Understanding the stroke survivors’ perspective is not only informative for CDM but a key component of EBP and potentially impacts therapy outcomes. In the qualitative study (Doyle, Bennett, & Dudgeon, 2013b), 15 stroke survivors reported that ULPSSI significantly affected their participation in meaningful activities yet recounted little if any ULPSSI rehabilitation. They also reported neither being asked about their preferences for rehabilitation nor being included in decision-making. Legare, Ratté, Gravel, and Graham (2008) explained that SDM involves not only valuing clients’ views about treatment options but also their role in decision-making. Clearly, education about stroke survivors’ perspectives and training in SDM is warranted, potentially improving outcomes for stroke survivors.

8.2.3. Implications for the study.

In summary the qualitative studies and survey within this thesis provide a basis for understanding areas where therapists reported a lack of knowledge or where practice patterns did not always reflect recommendations from guidelines, such as using standardised measures. These studies identified a need for training to increase therapists’ awareness about ULPSSI, survivors’ perceptions, and existing evidence about sensory measures, and available interventions. Not surprisingly then, therapists’ requested continuing education in all aspects of ULPSSI management. The results spurred this feasibility study of a continuing education program for therapists to support evidence-based decision-making.
8.2.4. Continuing professional education.

Continuing professional education (CPE) is a primary approach occupational therapists use to maintain and improve their knowledge and skills and to stay current with research evidence (Bennett et al., 2003; Grimshaw et al., 2012). This section reviews what is currently known about the use and effectiveness of CPE with healthcare professionals and occupational therapists in particular, and then it explores theories that have been used to design CPE.

8.2.4.1. Effects of CPE.

CPE aims to improve health professionals’ knowledge, skills and confidence, assuming that doing so improves health care practices and ultimately patients’ health outcomes. Although behaviour change from CPE has been found to be small, larger effects may be achieved when CPE is interactive, uses multiple methods, and is designed for a small, single disciplined group (Grimshaw et al., 2012; Mansouri & Lockyer, 2007). Mansouri and Lockyer (2007) completed a meta-analysis of 31 studies evaluating the effectiveness of CPE on physicians’ knowledge, performance, and patient outcomes. They reported that active and mixed methods had a moderate effect size, while passive methods had a small effect size on physician knowledge; overall, all methods had a small effect size on physician performance and patient outcomes. Moore, Dellert, Baumann, & Rosen (2009) completed evidence-based guidelines for CPE based on an extensive systematic review by the John Hopkins Evidence-Based Practice Center. These guidelines recommended the use of CPE to improve physicians’ knowledge, application, psychomotor skills, and practice performance. They also concluded that multiple instructional techniques were more effective than single-technique CPE programs and that multiple exposures were also superior. Forsetlund, Bjørndal, Rashidian, Jamtvedt, O’Brien, Wolf, Davis, Odgaard-Jensen, and Oxman (2009) completed a Cochrane systematic review evaluating the effects of educational meetings on professional practice and healthcare outcomes. They reviewed a total of 81 trials involving more than 11,000 health professionals. The authors concluded that professional practice and health care outcomes are improved by educational meetings alone or combined with other interventions.
Grimshaw et al. (2012) summarised two overviews of systematic reviews, completed by the Cochrane Effective Practice and Organisation of Care (EPOC), reviewing over 300 systematic reviews addressing interventions for professionals' behavioural change including the Forsetlund et al (2009) review. They calculated an effect size for median improvement in care of 6% (range ±1.8 % to 15.3 %) for educational programs. This was consistent with or above other intervention strategies aimed at professional behaviour change. No studies were found that specifically addressed the effectiveness of these methods or multiple methods in CPE for occupational therapists.

### 8.2.4.2. Theory base for CPE.

While CPE can be effective in improving professionals’ knowledge and lead to behaviour change, it must be well designed to maximise potential outcomes. Incorporating EBP techniques, utilising new measures and intervention strategies in practice can all be seen as behaviour change, and CPE has the potential to impact these behaviours. Graham et al. (2006) proposed that continuing education for health professionals should consider conceptual frameworks that address increasing research use in practice and be based upon the best evidence available. Using a theory base that identifies strategies for changing therapists’ behaviour may potentially increase the size of the behaviour change and as a result impact the effectiveness of CPE.

Using theory to design and evaluate educational interventions to facilitate changes in practice behaviours allows refinement of each intervention and informs future educational activities (Colquhoun et al., 2010; Davies, Walker, & Grimshaw 2010). Two theories commonly used to design educational interventions are Adult Learning Theory (ALT) (Knowles, Holton, Swanson, & Holton, 1998) and the Theory of Planned Behaviour (TPB) (Fishbein & Ajzen, 1975).

ALT focuses on how adults learn best, recognising that they are internally motivated, goal and relevancy oriented, self-directed, and practical, bringing their life experiences and knowledge to bear on learning. They value being respected (Knowles et al., 1998). The Institute of Medicine (2010) called for the incorporation
of ALT principles into the design of CPE for health professionals, reporting improved learning outcomes when this was done. When using ALT interventions for the purposes of changing clinical practice, the CPE must also focus on approaches that target behavioural change.

TPB, a cognitive-behavioural model of individual behaviour change, has also been applied to CPE interventions, based on the premise that CPE ultimately results in behaviour change (Casper, 2007). TPB assumes that a person’s intention to perform a behaviour is a key determinant of that behaviour and is the best predictor of a deliberate behaviour (Fishbein & Ajzen, 1975). TPB posits that intentions are a function of three factors: attitudes, subjective norms, and perceived behavioural control. Attitudes reflect a person’s beliefs about the outcomes associated with the particular behaviour and whether the behaviour is viewed favourably or unfavourably. Subjective norms are the perceived social pressures or judgments of others on one performing or not performing the behaviour. Perceived skills and opportunities available to perform the behaviour are defined as the perceived behavioural control of the individual.

Evaluation of attitudes, subjective norms, and perceived behaviour control related to the target behaviour can help in the design of CPE to address these issues, thereby affecting intentions and behaviour (Casper, 2007). For example, in a RCT of CPE classes involving 94 mental health practitioners, Casper (2007) found a TPB-based CPE program was significantly more effective than a standard program for increasing practitioners’ utilisation of a measure of clients’ felt employment needs.

Few studies in the rehabilitation field have employed theory to develop and deliver CPE aimed at supporting evidence-based decision-making. Petzold et al. (2012) used the Knowledge to Action framework and incorporated principles of Learner Centered Theory and Bloom’s Taxonomy to guide design of a 1-day CPE and subsequent reinforcement session about post-stroke unilateral spatial neglect management with 20 occupational therapists. They found improved knowledge about best practice for post-stroke unilateral spatial neglect and self-efficacy in evidence-based practice activities. The researchers suggested that theoretically-driven CPE
may help close research-practice gaps in other areas of rehabilitation. The effectiveness of theory-driven CPE in the area of ULPSSI has not been addressed and could potentially be used to increase evidence-based decision-making and self-efficacy by occupational therapists.

In summary, a need exists to support therapists in the management of ULPSSI, dealing with uncertainty in CDM, and use of SDM. Development and evaluation of theoretically informed CPE may address this need and, ultimately, improve health outcomes for stroke survivors.

8.3. Evidence regarding ULPSSI management: An update

Up-to-date evidence should be utilised for CDM (Grimshaw et al., 2012). The initial review of the literature regarding measures of ULPSSI and the systematic review of the effectiveness of interventions for ULPSSI were completed in 2009. The workshop for the feasibility study in this Chapter was completed in late 2011. To provide the best available evidence for therapists, the literature review was updated prior to the workshop to include further studies addressing either measurement of or interventions for ULPSSI. A summary of this update follows.

8.3.1. Updating evidence regarding sensory measures.

The initial steps of CDM involve gathering data from multiple sources and interpreting that data (Smith et al., 2008). Using standardised measures provides therapists with valid and reliable data for CDM. These data are essential for developing an effective management plan and monitoring the effectiveness of the intervention plan. The literature review in Chapter 2 recommended that therapists utilise the Nottingham Sensory Assessment (NSA) and the Thumb Localisation Test because of their clinical utility, validity, reliability, and predictive values (Hirayama, Fukutake, & Kawamura, 1999; Leo & Soderberg, 1981; Prescott et al., 1982; Smith et al., 1983).
More recently, Dwyer and Backman (2011) completed a study of 24 stroke survivors and 25 healthy participants and found that the Semmes-Weinstein monofilaments were able to detect sensory impairments in 17 of the stroke survivors. They concluded that despite the small sample size, the monofilaments demonstrated potential to detect ULPSSI, although further studies are needed prior to recommending routine use. Hedman and Sullivan (2011) investigated the use of perceptual threshold testing with electrical stimulation as a means of evaluating detection of sensory input in 29 community-dwelling chronic stroke survivors. Significant differences were found between the threshold scores of the contralateral and ipsilateral upper limb for subjects demonstrating impairments on the NSA. The authors reported excellent intra-rater reliability but did not provide the data supporting this conclusion. The study concluded that electrical stimulation perceptual threshold testing measured different constructs than the NSA stereo gnosis component and was not correlated with functional upper limb motor use. This study was compromised not only by the small sample size but also by the mild sensory impairments of the sample. While electrical stimulation threshold testing may be useful for stroke survivors with significant sensory loss, further studies are needed prior to recommending its use in clinical settings.

The Fugl Meyer Assessment (FMA) has frequently been used as an outcome measure in stroke rehabilitation research, but concerns about clinical use have been expressed due to the psychometric properties (Sullivan & Hedman, 2008). Sullivan, Tilson, Cen, Rose, Hershberg, Correa et al. (2011) studied the measurement fidelity of the FMA in preparation for a multisite research project. They concluded that ULPSSI can be reliably identified using the sensory subscales of the FMA, with high intra-rater reliability (ICC sensory total, .96, light touch, 1.0, proprioception, .95) and high inter-rater reliability (ICC sensory total, .93; light touch, .87; proprioception, .96). The authors provided a standardised and reliable procedure for the sensory subscales which will potentially increase the reliability of this measure. This publication is an excellent resource for therapists and education regarding its availability may encourage incorporation into clinical practice.
Another measurement tool that has been studied is the Rivermead Assessment of Somatosensory Processing (RASP). Identifying redundancies in the number of sites that must be tested could result in a significant improvement in the clinical utility of the RASP, especially for the survivors with intact or absent sensation. Busse and Tyson’s (2009) cross-sectional study of 102 stroke survivors, two to four weeks after stroke in a hospital-based setting, revealed significant differences in functional mobility, independence in activities of daily living, balance and overall muscle strength between those who were identified as “intact” and those identified as “absent,” indicating some association between the scores on this measurement tool and functional performance. While the RASP is not currently clinically available, it may be soon (personal communication with publishers August, 2011).

In an attempt to improve the clinical utility of ULPSSI measures, Miller, Phillips, Martin, Wheat, and Goodwin (2009) developed the AsTex measurement tool, a plastic strip with graduated, parallel vertical ridges and grooves, specifically for clinician use with stroke survivors. Pilot normative data for 95 neurologically normal participants were collected. In the stroke population the test–retest reliability of the AsTex was excellent (ICC = .86; Miller et al., 2009). Study participants found the AsTex simple to use, and a small standard error of measurement (0.14 mm) and minimal floor and ceiling effects (12.5% and 8.3%) were reported. Excellent test–retest (intraclass correlation coefficient (ICC) = .98) and inter-rater reliability (ICC = .81) were demonstrated in the neurologically normal group. A prototype of the AsTex is available to therapists but at substantial cost (AU$880; personal communication with Kimberley Miller, 02/17/2011). Various electronic or robotic measures for sensory impairments are being developed in the hope that they will increase reliability and validity of the measures (Lambercy, Robles, Kim, & Gassert, 2011) but these are not currently available for clinical use.

Based on the psychometric characteristics and clinical utility of the sensory measures in this updated literature review, it is recommended that clinicians should use the NSA, Thumb Localisation Test, and Finger Shift Test. To identify ULPSSI,
therapists could also use the FMA sensory subscales following the newly published procedures and potentially the Semmes Weinstein Monofilaments. Clinicians should monitor the literature to be aware of new measures that become available with electronic and robotic measurement tools, as well as the AsTex and other acuity grid type measures showing potential. While these recommended measures cover several sensory modalities, modalities that stroke survivors report as impacting their upper limb functional use, such as ability to judge force pressure and identify object slippage, have not yet been addressed. Therefore, until standardised measures are available, therapists are advised to also critically observe functional use of the hand to attempt to identify whether these sensory impairments impact functional use. Providing this information about standardised sensory measures may potentially increase their use by therapists, thereby addressing the educational needs identified by therapists in the survey study.

### 8.3.2. Updated evidence regarding the effectiveness of ULPSSI interventions.

Chapter 3 reported the outcomes of a Cochrane systematic review; with the last search for RCTs done in January 2009. Workshops regarding ULPSSI management described in this Chapter were held in October 2011. To update the information provided in the workshops about existing RCTs, a search of MEDLINE was re-run from February 2009 to October 2011 using a similar search strategy reported in the 2010 systematic review and combined with search terms to identify RCTs. The quality of these studies was rated using the PEDro Scale, and level of evidence for each intervention was rated using the Stroke Engine Guidelines (McGill University, 2011; EBRSR, 2014). These are outlined in Table 8.1.

Thirty-nine records were retrieved by the search, with six new RCTs identified as meeting the inclusion criteria by the primary author and the PhD thesis advisor. With this updated search, 19 RCTs have now been identified evaluating interventions specifically targeting ULPSSI. The six new studies were evaluated using the PEDro
Scale and Stroke Engine Levels of Evidence (McGill University, 2011; EBRSR, 2014). The interventions studied included mirror therapy (two RCTs), visual imagery (one RCT), a perceptual learning based, graded sensory re-education program (one RCT), electrical and vibratory stimulation (one RCT) and novel intervention of neuromobilisation (one RCT).

Cacchio, De Blasis, De Blasis, Santilli, and Spacca (2009) focused on tactile allodynia in 48 persons diagnosed with complex regional pain syndrome after stroke. Pain was measured using a visual analogue scale after stroking the skin with a brush. The intervention was mirror therapy (30 minutes 5 days per week for 2 weeks and then 1 hour 5 days per week for 2 weeks) in addition to conventional therapy for the experimental group and for the control group conventional therapy with a sham treatment (completed the mirror therapy movements with the mirror covered with paper) for 4 weeks. Significant reduction in tactile allodynia was noted (effect size $r = -0.5196$) at the end of four weeks and again at 6 months’ follow up (effect size $r = -0.6410$). Dohle, Pullen, Nakaten, Kust, Rietz, and Karbe (2009) evaluated the effectiveness of mirror therapy on upper extremity function, as measured by FMA, with 38 survivors within weeks after first stroke. The intervention was six weeks of mirror therapy (30 minutes, five days per week) that incorporated principles of shaping and active participation. Significant improvement ($F[1, 35] = 7.7, P = .009$, effect size $\epsilon = 0.57$) in surface sensibility in favour of the mirror therapy group was found but no significant changes in proprioception were noted. Another RCT that included 30 acute stroke survivors (> 6 months post-stroke) with left neglect (Welfringer, Leifert-Fiebach, Babinsky, & Brandt, 2011) also used active participation, with visuomotor imagery (2 x 30 minutes/day for 3 weeks) focusing on imagined contralesional upper limb activation in addition to therapy as normal. This study found significant changes ($t = -2.19, p = 0.02, d = 0.52$) in detection of light touch (measured by detecting light touch) in the visuomotor imagery group when compared to the control group that received therapy as normal.
A perceptual learning based program focused on upper extremity sensory discrimination training was trialled by Carey, Macdonnell, and Matyas (2011) with 50 subacute stroke survivors (> 6 weeks post stroke). The control group received non-specific repeated exposure to passive sensory stimulation. Both groups received 10 one-hour sessions, three times per week, with follow-up assessments six weeks and six months after the intervention period. The sensory outcome measure used was a composite sensory discrimination measure consisting of texture discrimination, limb position sense and tactile object recognition standardised indexes. Significant changes (t(47) =2.75, P =.004, d =0.8023) in favour of the experimental group were reported at six weeks and maintained six months post-intervention.

Stein, Hughes, D’Andrea, Therrien, Niemi, Krebs, Langone, and Harry (2010) divided 30 chronic (> 6 months) stroke survivors into low and high upper extremity functioning groups and randomly allocated them to the experimental or control group. The experimental group received subsensory electrical and vibratory stimulation (passive) combined with regular occupational therapy. The control group received sham stimulation and regular occupational therapy. Both groups had therapy three times per week for four weeks. No significant differences were found between the groups on the sensory measures used (Semmes Weinstein monofilaments, vibration and proprioception) after the intervention.

A novel approach by Wolny, Saulicz, Gnat, and Kokosz (2010) compared the effects of Butler’s neuromobilisations, a passive intervention, combined with proprioceptive neuromuscular facilitation and standard therapy to proprioceptive neuromuscular facilitation and standard therapy or standard therapy alone in 96 chronic stroke survivors. Sensory outcome measures included two-point discrimination, stereognosis, and thermesthesia. The first group demonstrated significantly improved sensation in all three measures (2-point discrimination effect size $r =0.5569$, stereognosis effect size $r = -0.1611$, thermesthesia effect size $r = -0.5110$) when compared to standard therapy.
The Cochrane systematic review (Doyle et al., 2010; Chapter 3) found six single RCTs either demonstrating or reporting statistically significant results. The studies with data demonstrating positive effects included: (1) mirror therapy for improving detection of light touch, pressure and temperature pain (Acerra et al., 2007); (2) a thermal stimulation intervention for improving rate of recovery of sensation (Chen et al., 2005); and (3) intermittent pneumatic compression for improving tactile and kinaesthetic sensation (Cambier et al., 2003). Single RCTs also reported statistically significant results but inadequate data to calculate effect sizes for (1) repetitive peripheral magnetic stimulation (Heldman et al., 2000), (2) early intensive task-oriented training (Miller et al., 2004), and (4) graded sensory retraining (Byl et al., 2003; Posteraro et al., 2001). Accera, Souvlis, and Moseley (2007) also found no significant between group differences for stroke survivors experiencing sham therapy or mirror therapy on pain at rest as measured using a visual analogue scale.

When considering the studies that had statistically significant results from the Cochrane review in conjunction with those from the updated search it can be seen that there are now two RCTs that supported the use of mirror therapy as an effective intervention to improve detection of upper limb light touch; two RCTs reported significant effects for a graded sensory re-education program for improving upper limb sensory discriminatory skills and one RCT reported significant effects for a graded sensory re-education program for improving upper limb tactile extinction; two RCTs described significant effects for Butler’s neuro-mobilisations to improve upper limb thermesthesa, 2 point discrimination, and stereo gnosis (though one of these RCTs provided very little information). Other single RCTS supported the effects of thermal stimulation on rate of recovery of sensation, intermittent pneumatic compression on the NSA, and early intensive task oriented training on tactile spatial resolution.

While the initial Cochrane systematic review concluded that there was insufficient evidence to make clear recommendations for clinical practice, the publication of additional RCTS increases the evidence available. This new evidence could
potentially change the final conclusion and recommendations from the Cochrane systematic review as there is now increased evidence, particularly for mirror therapy and graded sensory re-education. However a formal update to the Cochrane review is needed to add these new trials and to re-analyse the data for meta-analyses where possible. (See Table 8.1 for summary of the evidence). While there are no clear recommendations from the systematic review on which to base recommendations for routine practice change, therapists are encouraged to utilise the best available evidence to support CDM which at this time comes from single RCTs (Bennett, Hoffman, McCluskey, McKenna, Strong, & Tooth, 2003; Sackett et al., 1996). To support CDM, the quality of the evidence available was appraised using methods utilised by Stroke Engine (McGill University, 2011) and Evidence Based Reviews for Stroke Rehabilitation (EBRSR, 2014), evidence based practice resources for stroke management. According to the criteria from the Stroke Engine Rating System, having results from a systematic review or two high quality RCTs (with a PEDro rating of 6 or more) provides strong evidence for an intervention and moderate evidence where at least one high quality RCT exists (McGill University, 2011).

In Chapter 2 clinical practice guidelines were also identified as a source of information for therapists' CDM and in preparation for the CPE program we searched for updates. The U.S. Veterans Affairs and Department of Defence Clinical Guidelines (The Management of Stroke Rehabilitation Working Group, 2010) recommend that ULPSSI should be assessed, and if impairments were detected, interventions should include sensory-specific training and electrical stimulation trials. However, neither summary nor evaluation of the strength of specific studies was provided. The Australian National Stroke Foundation’s Clinical Guidelines for Stroke Management (2010) concluded that some evidence supports sensory-specific interventions after stroke; however care should be taken when applying the research. This recommendation was based on four studies, only one of which was an RCT.
The New Zealand Clinical Guidelines for Stroke Management (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) reviewed one systematic review (Schabrun & Hillier, 2009) and the same four studies as the Australian National Stroke Foundation (2010). They recommended sensory-specific training consistent with the prior version of the guidelines. No mention of ULPSSI occurred in the Scottish Intercollegiate Guidelines Network’s Management of patients with stroke (2010).

In summary, some international guidelines had been updated, incorporating some earlier research identified prior to the systematic review. Overall they recommended therapists utilise standardised sensory measures, sensory-specific, graded sensory re-education, and possible electrical stimulation as interventions for ULPSSI.

8.4. Feasibility study: Method and evaluation

The preceding studies have shown that occupational therapists working with stroke survivors who have ULPSSI have a lack of confidence and knowledge regarding the ULPSSI and the nature of evidence currently available for its management. Comparing the results of the Cochrane systematic review and the updated literature review with occupational therapists practice patterns has indicated that a number of research-practice gaps for occupational therapists working with stroke survivors who have ULPSSI exist regarding assessments and interventions being used. This section describes the development, implementation and evaluation of a feasibility study to evaluate the potential of a theory-driven CPE to address these issues, encourage SDM, and ultimately support decision-making for the management of ULPSSI.

8.4.1. Study aims.

This study aimed to: 1) evaluate the feasibility of a 1-day CPE, based on TPB and ALT specific to ULPSSI; and 2) evaluate the effect of a theory-based CPE on therapists’ knowledge, attitudes, perceived behavioural control, and behavioural intentions about ULPSSI management, SDM, and research utilisation.
8.4.2. Methods.

8.4.2.1. Research design.
This study employed a single group pretest-posttest quasi-experimental feasibility design. Approval for study procedures was given by one of the Ethics Review Boards at the University of Queensland, Australia, and consent was obtained from all study participants.

8.4.2.2. Subjects.
Occupational therapists working with stroke survivors in the U.S. Pacific Northwest were recruited by posters placed in workplaces and therapy networks in that area advertising a free workshop on ULPSSI. Participants in the first workshop also recruited peers for the second session.

8.4.2.3. Procedure.
TPB recommends an initial elicitation study to identify commonly held behavioural, normative, and control beliefs about the target behaviour in a representative population to inform development of the questionnaire, intervention, or both (Ajzen, 2006; Ajzen & Fishbein, 1980). Accordingly, we emailed participants an elicitation questionnaire for completion online before the workshop. On the elicitation questionnaire, participants were asked to respond to open-ended questions regarding their beliefs about these behaviours, including: 1) the perceived advantages and disadvantages, 2) people who are important to them who might approve or disapprove or other social influences, and 3) factors or circumstances that would facilitate or provide barriers to these behaviours. Therapists then attended one of two 8-hour workshops (described in the next section). They completed a questionnaire at the beginning of the workshop in addition to a post workshop evaluation form.
8.4.2.4. Intervention.

8.4.2.4.1. Workshop design.
An eight hour workshop using ALT and TPB was designed to improve occupational therapists’ knowledge, attitudes, perceived control, and behaviours regarding ULPSSI management, research utilisation, and SDM. Broadly speaking, the behaviours of interest concerned using standardised sensory measures, utilising ULPSSI interventions that have support from more than one RCT, involving clients in decision-making, and keeping up to date with research about ULPSSI management.

We used the results of the pre-workshop elicitation questionnaire based on guidelines suggested by Francis et al. (2004) to inform the workshops’ design and content emphasis. Information from the systematic review and subsequent update of research on ULPSSI management, survey, and qualitative studies in this thesis was also incorporated. For example, participants identified lack of assessment skills, lack of available measures, and difficulty relating the test scores to function as barriers to utilising standardised sensory measures. These findings resulted in a module addressing how to obtain assessments, assessment details, how to relate assessment results to function, and practice in assessment use for skill development. This module aimed to improve perceived control (practitioners’ confidence in using standardised assessments) and reduce barriers (how to find and use the assessments). This process was repeated for each of the components of the elicitation questionnaire results.

The ALT principles utilised in this workshop included: drawing on participants’ knowledge and experience, acknowledging their experience, and incorporating experiential learning based on real cases during the workshop. Written action plan sheets, consistent with TPB, were used at the completion of each module, challenging therapists to identify new knowledge, behaviours they could incorporate in their setting, and resources needed to do this. They were asked to develop four-week behavioural goals for incorporating this new knowledge into their practice (Casper, 2008; Rodriguez, Marquett, Hinton, McBride, & Gallagher-Thompson, 2010).
The workshops were conducted by one educator (Susan Doyle), who has >30 years’ experience as an occupational therapist and was completing her doctorate in the area of stroke rehabilitation. A written manual, digital slide show and script were used to enhance consistency in content and presentation between workshops. To reduce any influence on the second workshop presentation, no alterations were made, nor were preliminary results reviewed before the second workshop.

8.4.2.4.2. Workshop content.
The workshop included six modules: (1) description of somatosensation, (2) understanding ULPSSI and the potential for recovery, (3) assessment of ULPSSI (e.g. use of standardised measures) based on research about the tool’s psychometric properties, (4) a review of the evidence for ULPSSI interventions, (5) SDM and the stroke survivors’ perspective, and (6) EBP strategies, resources for updating knowledge and CDM in areas of uncertainty. Table 8.2 summarises the content in each module. Information from our previous research was provided to participants to increase their awareness of research-practice gaps, including results from the survey of occupational therapists’ current practice patterns with ULPSSI and their related educational needs (Doyle, Bennett, Gustafsson, 2013); qualitative interviews about factors influencing therapists’ decision-making related to ULPSSI (Doyle, Bennett, & Dudgeon, 2014); and the qualitative study of stroke survivor’s perspectives on ULPSSI and rehabilitation preferences (Doyle, Bennett, & Dudgeon, 2013). Information from the systematic review of the effect of interventions for ULPSSI (Doyle et al., 2010) was also updated with findings from RCTs published since its completion.

8.4.2.5. Outcome measures.
We used specifically designed pre and post workshop questionnaires containing five sections, guided in part by TPB. The first section (only included in the pre-workshop questionnaire) collected information including age, gender, educational level, practice setting, experience, current caseload of stroke patients and previous attendance at a course on ULPSSI.
The second section consisted of nine questions utilising a five-point Likert scale with the anchors ‘strongly disagree’ to ‘strongly agree’. These questions asked about utilisation of ULPSSI standardised measures, remedial and compensatory ULPSSI interventions, information provision to clients, determination of client’s preferences for involvement in decision-making, and therapists’ searching for evidence and resources to support practice. These items were rephrased in the post-workshop questionnaire to ask about therapists’ intended future behaviours in these same areas.

The third section contained 14 five-point Likert scale questions using constructs from TPB also with anchors ‘strongly disagree’ to ‘strongly agree’. Specifically, eight items asked about perceived behavioural control (confidence performing the behaviour) regarding choosing and providing ULPSSI assessments and interventions, providing information to clients, sharing decision-making, and being up to date with research about ULPSSI. Four items asked about subjective normative beliefs about ULPSSI interventions and two items asked about attitudes towards providing interventions. Each item was scored using the Likert-scale choice as the individual raw score, with a possible range from 1 – 5.

The fourth section included 10 multiple-choice questions that sought to determine therapists’ knowledge about ULPSSI, including the incidence, types of sensory impairments, and research about ULPSSI interventions. We calculated the total number of questions correct for this section.

Finally, to measure attitudes towards client-centred practice, we used the Patient Practitioner Orientation Scale (PPOS) designed by Krupat, Hiam, Fleming, and Freeman (1999). The PPOS is an 18-item scale that measures attitudes on two dimensions, “Caring” and “Sharing” with item scores ranging from 1 to 6. It is designed to differentiate patient- versus practitioner-oriented perspectives in the patient-practitioner relationship (Ross & Haidet, 2011). The practitioner’s willingness to share information, control and power within the relationship is measured by the nine sharing dimension items (Ross & Haidet, 2011). The nine items in the caring dimension measures the value placed on warmth, support, and psychosocial issues.
by the practitioner (Ross & Haidet, 2011). The scale’s validity among medical students and practitioners was established by Krupat et al. (1999) and Shaw, Woiiszwilko, and Krupat (2012), and its reliability and internal consistency were established by Krupat et al. Pre and post workshop total scores for PPOS were calculated as well as caring and sharing sub-scale total scores. We calculated pre- and post-workshop scores for the PPOS as well as caring and sharing subscale total scores. Total PPOS scores range from 18 to 108; subscale score from 9 to 54.

To the post-workshop questionnaire, we added questions about participants’ evaluation of the workshop content, presentation, and perception of meeting the course objectives. Participants were also asked about their perceptions of the presenter’s knowledge of the material, adequacy of material presentation, and suitability of the facility using nine five-point Likert scale questions with anchors ranging from 1= “poor” to 5 = “excellent”. We also requested other comments about the workshop and whether participants would recommend it to others.

8.4.2.6. Data analysis.

We used content analysis to identify commonly occurring themes and issues in the elicitation questionnaire. Data from the pre- and post-workshop questionnaires was analysed using PASW Statistics 18 (SPSS Inc., Chicago). Descriptive statistics were calculated for the demographic data. Current behaviour and intended behaviour are highly related but different concepts and therefore were not directly compared. Instead, we calculated frequencies for the combined “strongly agree” and “agree” categories separately for each statement for pre-workshop current behaviour items and post-workshop intended behaviour questionnaire items. Total correct pre and post knowledge scores were compared using paired t-tests. We inspected data for attitudes, subjective norms, perceived behavioural control, and PPOS total scores for normality, and because limited evidence of skew existed, we compared pre and post-test scores using paired t-tests. Significance was set at p≤.01 to take into account multiple comparisons.

Descriptive statistics summarised data evaluating the workshop content and process. Data were collapsed with “very good” and “excellent” combined into one
category, “good” into another category, and “poor” and “fair” into a third category. This method is commonly used to make the data easier for the reader though some loss of detail may result (Peacock & Peacock, 2010; Treiman, 2009).

8.5. Results

8.5.1. Subjects and recruitment.

Nine participants attended the first workshop, and 10 attended the second workshop. Of the 19 participants, eight had bachelor’s degree entry-level qualifications and 11 had master’s degrees. One participant reported attending a prior CPE that addressed ULPSSI, and two did not answer the question. Three therapists reported working in acute hospital settings, four in outpatient clinics, two in inpatient rehabilitation, one in home health, three in skilled nursing facilities, and six in mixed practice settings. Therapists ranged in age from 26 to 65 years (M= 38.7, SD=10.8) with a large range of experience (1 – 42 years, M=11.4, SD=11.2) and specifically with stroke survivors (1- 42 years, M= 9.8, SD=11.6). The mean percentage of therapists’ caseload consisting of stroke survivors was 19% (range 1%-45%, SD=12.0) and the majority saw survivors who were <3 months since stroke (0 – 6 weeks = 31.6%; >6 weeks – 3 months = 42.1%; > 6 months – 1 year = 5.3%; and > 1 year = 21.1%; percentages total > 100% due to rounding).

8.5.2. Elicitation questionnaire.

Nine respondents anonymously completed the online elicitation questionnaire before the workshops. The advantages that were identified in the elicitation questionnaire were specifically acknowledged and discussed during the workshop. The key barriers and disadvantages participants identified that needed addressing included lack of skills and knowledge about the management of ULPSSI and SDM, as well as lack of time to locate evidence, use new assessments, interventions, and SDM, and lack of resources. Methods to address these barriers, such as using “cheat sheets” to remind them of the key principles of sensory retraining, knowing where or how to find full text of articles, or being provided with success stories or examples of SDM,
were either discussed in the workshop or incorporated into the educational modules, handouts, and action sheet questions.

8.5.3. Outcome measures.

8.5.3.1. Current and intended behaviours.
Table 8.3 depicts a large difference between pre- and post-workshop frequencies for current and intended behaviours. For example, although only four participants (21%) reported that they currently asked clients for their preferences regarding involvement in decisions about interventions for their ULPSSI, after the workshop 18 (97.4%) agreed they intended to do so in future. Percentage of agreement about current behaviours ranged from 5.3% (having read or looked for research articles in the last month) to 53.5% (using standardised assessments for initial ULPSSI assessment). After the workshop, percentage of agreement for intended behaviours ranged from 84.2% (intending to read or look for research articles in the next month) to 100% (intending to provide clients information about evidence for ULPSSI interventions).

8.5.3.2. Attitudes, subjective norms, and perceived behavioural control.
Pre- and post-test scores for attitudes, perceived behavioural control, subjective norms, and beliefs are presented in Table 8.4 together with change scores and t-test results. We found statistically significant improvements pre-workshop to post-workshop for participants’ attitude about interventions being beneficial for clients, their confidence in their capability to perform all behaviours addressed in the workshop (perceptions of behavioural control), and feeling more up to date in the area of ULPSSI (p=.00). The only significant change noted in subjective norms was that after the workshop participants felt under more “pressure to provide interventions for people with sensory impairments” than prior to the workshop. Participants’ beliefs that sensation impacts functional upper limb use, and that ULPSSI interventions are effective, were significantly greater post-workshop.
8.5.3.3. Knowledge.
The mean score for ULPSSI knowledge pre-workshop was 3.32 (SD = 1.06) and increased to 8.53 (SD = .91) post-workshop. This increase was statistically significant, \( t(18) = -15.0, df = 18, p = .00 \).

8.5.3.4. Client centred care.
We noted significantly lower PPOS scores, indicating more patient centeredness, post-workshop (\( M = 2.71, SD = .37 \)) compared with pre-workshop (\( M = 2.99, SD = .42 \)), \( t(17) = 2.80, p = .00 \). Significant improvements in other aspects of patient centeredness were also noted in both the Caring subscale scores (pre-workshop \( M = 27.67, SD = 4.10 \); post-workshop \( M = 25.72, SD = 4.72 \), \( t(17) = 2.87, p = .01 \)) and Sharing sub-scores (pre-workshop \( M = 7.16, SD = 4.29 \); post-workshop \( M = 23.63, SD = 3.95 \), \( t(18) = 4.35, p = .00 \)).

8.5.4. Feasibility of the workshop.
Use of TPB and the associated elicitation study was helpful in guiding the development of the workshop but also proved invaluable for proactively addressing beliefs, attitudes and concerns during the workshop. Recruitment proved more difficult than anticipated even though the workshop was free. Many participants reported that their peers would prefer the workshop on a weekday versus a Sunday to allow utilising a paid education day, easier access to child care, and decreased interruption to family time or activities. Participants requested further time for practicing evaluations and interventions that were reviewed in the workshop.

8.5.5. Evaluation of workshop content and process.
Eighteen participants returned workshop evaluations. Participants were asked to comment on different aspects of the content, process, facilitation and practical arrangements of the workshop. All 18 reported that all aspects of the workshop were “excellent” to “good” All the participants completing this question (17) would recommend this course to others. Ten participants provided comments to an open ended question about the workshop with many indicating the workshop would
support their clinical practice. These comments are illustrated by one participant, who wrote: “This was wonderful. I will be able to USE the information learned today and put it into practice”, and by another who stated: “Information provided was easily digestible with resources to back it up. Provided ideas that can be used immediately and information regarding what is current. Most importantly, you gave us tools to keep learning and stay current.” Finally, the workshop’s importance was highlighted by another participant, who wrote: “This is a topic that seems overlooked but deserves attention to improve therapist’s knowledge, comfort, and ability to access resources when evaluating/treating stroke patients”.

8.6. Discussion
This is the first study to test a theoretically-based workshop aimed at improving knowledge, attitudes, perceived behavioural control, and behavioural intentions about ULPSSI management, SDM, and awareness and use of research to inform practice. Results indicate the feasibility of a workshop, based on TPB and ALT principles, to improve key variables conceptualised as influencing practice behaviour. Specifically, we found improvements in knowledge, attitudes and perceived behavioural control, and changes from reports of current to intended behaviours for ULPSSI management. Additionally, a much higher percentage of participants agreed they intended to carry out behaviours related to remaining current with research evidence when compared with their self-reported use of these behaviours in the month prior to the workshop. Such active engagement in professional development activities is recommended to develop skills required for research utilisation (Craik & Rappolt, 2006).

Our results compare to those of a feasibility study of 20 occupational therapists attending a day-long workshop to improve their management of acute post-stroke unilateral spatial neglect (Petzold et al., 2012). The workshop was designed based on perceived barriers to the use of best practice for management of post-stroke unilateral spatial neglect identified in interviews of occupational therapists, and it used learning theories to guide its development. The workshop was followed by eight-week reinforcement with Web-based materials and discussion forum. The
researchers found that the workshop and follow-up reinforcement improved knowledge of best practice for unilateral spatial neglect management and perceived self-efficacy in carrying out evidence-based practice activities.

As in Petzold et al.’s (2012) study, the intervention in our study addressed barriers to using standardised measures and providing interventions with evidence of effectiveness. It was informed by research that identified gaps between a few key recommendations for ULPSSI management and common practice patterns amongst occupational therapists working in this area as well as barriers including the therapists’ lack of confidence and knowledge regarding ULPSSI and their limited use of EBP behaviours (Doyle, Bennett, & Gustafsson, 2013). The workshop attempted to address factors internal to the individual (knowledge, attitudes, perceived behavioural control and skills) and discussed external factors that might influence practice through the use of a range of theoretically guided strategies.

Regarding SDM, preliminary results of our study indicate improvements in therapists’ attitudes to, perceived behavioural control for, and changes from reports of current behaviour to intended behaviours, regarding informing clients about evidence for ULPSSI interventions and seeking their preferences for decision-making involvement. SDM is important because it improves client satisfaction and adherence to interventions and may improve health outcomes (Elwyn, Edwards & Kinnersly, 1999).

Our study also provided information about the workshop’s acceptability and feasibility. All participants were very positive about the workshop content and process, recommending further sessions to reinforce their confidence and develop their skills. In practical terms, issues that must be considered if this were to be tested using a RCT design in future include methods to recruit a sufficient sample size; training other workshop facilitators to provide the intervention; and manualising the intervention to enhance fidelity and consistency of delivery among workshop facilitators. Future research should also consider specifically addressing external barriers to ULPSSI management such as lack of time and resources and determining
methods for measuring actual behaviour change and relevant health outcomes for clients.

8.7. Implications for clinical practice.
The results of this study have the following implications for occupational therapy practice:

- Theory-driven CPE can improve attitudes, knowledge and perceived control for the management of ULPSSI and potentially influence practice.
- Attitudes, knowledge and perceived control for the use of behaviours important for SDM can be improved through theory-based CPE.

8.8. Limitations
Because this was a feasibility study designed to test recruitment, acceptability of the intervention, and appropriateness of outcome measures, the design was a reasonable choice. However the small sample size and simple pre-test-post-test design with no control group restricts confidence in the analysis and interpretation of results which therefore should be considered only as preliminary. It is recommended that a RCT design be utilised with potentially a stratification model to address some of these limitations.

Only nine of the 16 participants completed the elicitation questionnaire, and while this is consistent with the methodology of the TPB, the smaller sample may also have affected the ability to accurately identify the factors that impacted therapists’ intended behaviour and hence address these issues in the CPE. Moreover, the generalizability of the preliminary results is limited by the recruitment of participants from a convenience sample in one geographic location. The perception of the workshop by participants who were recruited by their peers may have been influenced by their peer’s perceptions. In future trials it is recommended that a randomised controlled trial design be utilised with potentially a stratification model to address some of these limitations. Power calculations should be undertaken to determine minimum sample sizes.
It was not possible to directly compare pre-workshop and post-workshop intended behaviours because the pre-workshop questionnaire asked about perceived current behaviours, which is a related yet different concept. Questionnaires designed to capture variables relevant to the TPB recommend that intended behaviours are measured pre and post the intervention (Francis et al., 2004). We recommend this in future studies. Further research establishing the reliability and validity of the outcome measures is recommended.

8.9. Conclusion
This feasibility study is important in improving understanding of CPE as a method to increase a broad range of knowledge required to support evidence-based CDM by occupational therapists. We argue that a theory-based CPE has the potential to affect clinicians’ knowledge, attitudes, perceived behavioural control and behavioural intentions about ULPSSI management, SDM, and awareness and use of research to inform practice. Further development of a RCT to evaluate this intervention is warranted, incorporating recommendations from this study to improve recruitment, study design, and usefulness of the outcome measures.
## 8.10. Tables
Table 8.1 Pedro and Stroke Engine Rating Scale of studies with statistically significant effects of interventions for ULPSSI.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Stroke Engine Level of evidence</th>
<th>Study Reference</th>
<th>Outcome</th>
<th>Pedro Quality Rating / effect size if available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mirror Therapy</td>
<td>Level 1b Moderate evidence</td>
<td>Cacchio, De Blasis, De Blasis, Santilli, &amp; Spacca (2009)</td>
<td>Allydonia</td>
<td>6/10 $r = -0.5196$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acerra, Souvlis, &amp; Moseley, (2007)</td>
<td>pain at rest</td>
<td>8/10 No significant difference</td>
</tr>
<tr>
<td></td>
<td>Level 1a Strong evidence</td>
<td>Dohle, Pullen, Nakaten, Kust, Rietz, &amp; Karbe (2009)</td>
<td>surface sensitivity</td>
<td>7/10 $\varepsilon = 0.57$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acerra, Souvlis, &amp; Moseley, (2007)</td>
<td>light touch.</td>
<td>8/10 $r = 0.5942$</td>
</tr>
<tr>
<td>Visuo-motor Imagery</td>
<td>Level 1b Moderate evidence</td>
<td>Welfringer, Leifert-Fiebach, Babinsky, &amp; Brandt, (2011)</td>
<td>light touch</td>
<td>8/10 $d = 0.52$</td>
</tr>
<tr>
<td>Graded Sensory Re-education</td>
<td>Level 1b Moderate Evidence</td>
<td>Byl, Roderick, Mohamed, Hanny, Kotler, Smith, Tang, &amp; Abrams</td>
<td>stereo gnosis, kinaesthesia, graphaesthesia</td>
<td>5/10 (significant results reported, insufficient data to calculate</td>
</tr>
<tr>
<td>Treatment</td>
<td>Evidence Level</td>
<td>Evidence Quality</td>
<td>Authors, Year</td>
<td>Measure of Effect</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>----------------</td>
<td>--------------------</td>
<td>----------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Carey, Macdonnell, &amp; Matyas (2011)</td>
<td>Level 2a</td>
<td>Limited evidence</td>
<td>Composite sensory discrimination measure</td>
<td>10/10</td>
</tr>
<tr>
<td>Posteraro, Corsini, Bidmi, Bassoli, Curti, &amp; Grassi (2001)</td>
<td>Tactile Extinction</td>
<td>5/10</td>
<td>(significant results reported, insufficient data to calculate effect sizes)</td>
<td></td>
</tr>
<tr>
<td>Chen, Liang, &amp; Shaw, (2005)</td>
<td>Level 1b</td>
<td>Moderate Evidence</td>
<td>Rate of recovery of sensation</td>
<td>7/10</td>
</tr>
<tr>
<td>Cambier, De Corte, Danneels, &amp; Witvrouw (2003)</td>
<td>RCT/NSA</td>
<td></td>
<td>MD 37.10, 95% CI 8.16 to 66.04</td>
<td>8/10</td>
</tr>
<tr>
<td>Wolny, Saulicz, Gnat, &amp; Kokosz (2010)</td>
<td>Level 1b</td>
<td>Moderate Evidence</td>
<td>Thermaesthesia, 2 pt., stereo gnosis</td>
<td>7/10</td>
</tr>
<tr>
<td>Wolny, Saulicz, Gnat, &amp; Bacik (2003)</td>
<td>Thermaesthesia, 2 pt. discrimination</td>
<td>(insufficient description to calculate study rating)</td>
<td>(significant difference reported, unable to calculate effect size)</td>
<td></td>
</tr>
<tr>
<td>Stein, Hughes,</td>
<td>Level 1b</td>
<td></td>
<td>Detection light touch</td>
<td>7/10</td>
</tr>
</tbody>
</table>
### Electrical and Vibratory Stimulation

<table>
<thead>
<tr>
<th>Evidence Level</th>
<th>Module Content</th>
<th>Authors</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate Evidence (no significant difference)</td>
<td>D’Andrea, Therrien, Niemi, Krebs, Langone, &amp; Harry (2010).</td>
<td>vibration, proprioception</td>
<td></td>
</tr>
</tbody>
</table>

### Repetitive Peripheral Magnetic Stimulation

<table>
<thead>
<tr>
<th>Evidence Level</th>
<th>Module Content</th>
<th>Authors</th>
<th>Evidence</th>
</tr>
</thead>
</table>

### Early Intensive Task Oriented Training

<table>
<thead>
<tr>
<th>Evidence Level</th>
<th>Module Content</th>
<th>Authors</th>
<th>Evidence</th>
</tr>
</thead>
</table>

Very limited details provided multiple abstracts only

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Table 8.2. Summary of module content.

<table>
<thead>
<tr>
<th>Module Name</th>
<th>Module Content</th>
</tr>
</thead>
</table>
| 1. Introduction to Somatosensation | Introduction to program  
Definitions of somatosensation and types  
Brief review of neurophysiology of somatosensation. |
| 2. Understanding ULPSSI | Incidence of ULPSSI  
Impact of ULPSSI  
Impairment Types (CNS versus PNS) |
<table>
<thead>
<tr>
<th>Section</th>
<th>Content</th>
</tr>
</thead>
</table>
| 3. Measuring ULPSSI | Summary of current practice patterns  
Concerns with current measurement tools  
Review of available standardised measurement tools  
Review of skilled observation strategies  
Practice with NSA, Thumb localisation test, Finger shift test, and FMA sensory subscale |
| 4. Interventions for ULPSSI | Summary of current practice patterns  
Summary of intervention approaches  
Best available evidence for client/caregiver education  
Best available evidence for compensatory strategies  
Best available evidence for remedial interventions for ULPSSI |
| 5. Shared decision-making | What is shared decision-making  
Strategies to facilitate shared decision-making  
Handling decisional conflict  
Decision aides and coaching  
The stroke survivors perspective on ULPSSI |
| 6. Decision-making skills in areas of uncertainty | Defining uncertainty  
Responses to uncertainty  
Errors associated with responses to uncertainty  
Tools to assist in areas of uncertainty |
Resources for finding evidence (e.g. EBRSR, clinical practice guidelines, OTSeeker, PEDRO)

<table>
<thead>
<tr>
<th>Behavioural statement (n)</th>
<th>Current Behaviour (Pre-questionnaire)</th>
<th>Intended Behaviour (Post-questionnaire)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I use (pre)/intend to use (post) standardised function based sensory assessments when I complete my initial evaluation with stroke patients (19)</td>
<td>10 (52.6)</td>
<td>18 (94.7)</td>
</tr>
<tr>
<td>I use (pre)/intend to use (post) standardised function based sensory assessments when completing my discharge evaluation of a stroke patient (18)</td>
<td>4 (22.2)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>I use (pre)/intend to use (post) graded sensory re-education based interventions targeted to remediate specific ULPSSI (19)</td>
<td>7 (36.8)</td>
<td>18 (94.7)</td>
</tr>
<tr>
<td>I use (pre)/intend to use (post) interventions specifically targeted to compensate for sensory impairments in the upper limb for stroke patient (19)</td>
<td>9 (47.4)</td>
<td>18 (94.7)</td>
</tr>
<tr>
<td>I provide (pre)/intend to provide (post) information to my clients about evidence for interventions for their sensory impairment (19)</td>
<td>9 (47.4)</td>
<td>19 (100)</td>
</tr>
</tbody>
</table>
I ask (pre) / intend to ask (post) my clients what their preferences are about being involved in decisions about interventions that might be used for their sensory impairments (19)

Prior to finishing rehabilitation with my client I usually (prior) / intend to (post) confirm they know what to do in future to either continue working on sensory impairment issues or know how to get further help for this (19)

I have (pre) / intend to (post) read or looked for research articles related to sensory impairments after stroke in the past 6 months (19)

I have (pre) / intend to (post) reviewed electronic databases regularly in the past 6 months to help inform my practice about sensory Impairments (19)
Table 8.4. Perceived behavioural control, attitudes, and perceived subjective norms and beliefs regarding the management of ULPSSI (N=19)

<table>
<thead>
<tr>
<th>Perceived behavioural control</th>
<th>M(SD) pre post</th>
<th>Mean Change †</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel confident treating patients with sensory impairments after stroke</td>
<td>2.42 (0.84)</td>
<td>1.37</td>
<td>-8.72</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>3.79 (0.42)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am confident deciding on the best assessment for sensory impairments</td>
<td>2.16 (0.69)</td>
<td>1.52</td>
<td>-8.61</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>3.68 (0.48)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am comfortable explaining how the results of the sensory assessments relate to the functional use of the arm</td>
<td>2.63 (0.96)</td>
<td>1.21</td>
<td>-5.75</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>3.84 (0.69)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am comfortable choosing interventions to remediate sensory impairments based on my assessment results</td>
<td>2.11 (0.66)</td>
<td>1.94</td>
<td>-13.66</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>4.05 (0.41)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am confident explaining these sensory interventions to my patients</td>
<td>2.16 (0.77)</td>
<td>1.58</td>
<td>-8.96</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>3.74 (0.56)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel confident assessing how effective my interventions for sensory impairment are</td>
<td>2.16 (0.69)</td>
<td>1.47</td>
<td>-7.10</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>3.63 (0.60)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am comfortable choosing interventions that are the most effective for sensory impairments</td>
<td>4.16 (0.60)</td>
<td>0.63</td>
<td>-4.03</td>
<td>18</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>4.79 (0.42)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel up to date with current research evidence about the effectiveness of sensory interventions for people with sensory impairments following stroke</td>
<td>1.92 (0.76)</td>
<td>2.16</td>
<td>6.40</td>
<td>12</td>
<td>.00*</td>
</tr>
<tr>
<td></td>
<td>4.08 (0.86)</td>
<td></td>
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<td>Attitudes</td>
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<td>Overall I think that providing interventions for sensory impairments is beneficial</td>
<td>4.32 (0.58)</td>
<td>0.52</td>
<td>-3.75</td>
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<td>4.84 (0.38)</td>
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Overall I think that providing interventions for sensory impairments is good practice

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<td>3.79</td>
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**Perceived subjective norms**

It is expected of me that I provide interventions for people with sensory impairments

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<td>3.37</td>
<td>0.16</td>
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Other therapists think I should provide interventions for people with sensory impairments

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<td>2.74</td>
<td>0.21</td>
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I feel under pressure to provide interventions for people with sensory impairments

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<td>2.47</td>
<td>1.58</td>
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**Beliefs**

Sensory interventions for clients after stroke are effective

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<td>3.06</td>
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Upper limb functional use after stroke has been impacted by sensory impairments

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<td>3.84</td>
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<td>4.42</td>
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† - mean change scores represent the difference between the mean score of the sample on the post-workshop measure and the pre-workshop measure.

* - significant at p ≤ .00
CHAPTER 9: SUMMARY, IMPLICATIONS, STRENGTHS AND LIMITATIONS, AND FUTURE DIRECTIONS

This thesis explored occupational therapists’ CDM in the context of ULPSSI management. Therapists’ decisions cover the course of clinical interactions, including whether to complete an assessment, which measurement tools to use, whether to design an intervention plan, which intervention approaches and strategies to use, engaging the client in the process and understanding their values and goals, sharing the decision-making, when and how to end the intervention process, and appraising the process and outcomes. These decisions are made utilising information from the therapists’ knowledge base regarding how the impairment presents, the impact of the impairment on a client and potential outcomes, how this changes over time, and the potential for recovery, accurate measures, and effective interventions. While therapists use multiple sources of information during CDM, EBP invites therapists to use the best available research evidence as well the client’s values and preferences combined with the therapist’s expertise when making decisions regarding care for individual clients (Sackett et al., 2000). This Chapter summarises the contributions of this thesis, the implications for clinicians, educators and researchers with regards to CDM for the management of ULPSSI as well as the limitations of the studies and potential future directions for further research.

9.1. Summary of findings
A review of the literature, located in Chapter 2 of the thesis, concluded that a high quality systematic review evaluating the effectiveness of interventions for ULPSSI was not available for therapists. This provided the rationale for the Cochrane systematic review that forms Chapter 3 of the thesis (Doyle, Bennett, Fasoli & McKenna, 2010). The systematic review found single RCTs with positive effects for (1) mirror therapy for improving detection of light touch, pressure and temperature pain; (2) a thermal stimulation intervention for improving rate of recovery of sensation; (3) intermittent pneumatic compression for improving tactile and kinaesthetic sensation. Single RCTs also reported statistically significant results but inadequate data to calculate effect sizes for (1)
repetitive peripheral magnetic stimulation, (2) early intensive task-oriented training, and (3) graded sensory retraining.

The literature review in Chapter 5 also highlighted the limited understanding of the current practice patterns of occupational therapists when addressing ULPSSI. This was the rationale to undertake a qualitative study to increase our understanding of therapists’ CDM and practices when addressing ULPSSI. This qualitative descriptive study (Chapter 4) of a convenience sample of 12 occupational therapists was the first that described the multiple factors therapists utilised in their decision-making. Therapists also expressed considerable uncertainty in this area and used their experience, those of their peers as well as reasoning by analogy as a strategy to support their CDM but only infrequently described searching for research evidence to support their CDM. Therapists reported using interventions for which they lacked confidence regarding their effectiveness and very few identified using interventions for which the Cochrane systematic review had located individual studies evaluating their effectiveness. There was considerable uncertainty regarding ULPSSI management and therefore it was suggested that training therapists to increase their understanding of CDM, especially in areas of uncertainty, may assist therapists in being more aware of their potential for bias and error and to manage the influence of the myriad factors influencing their decisions.

The information gained from the qualitative study informed the design of the questionnaire for the survey study (Chapters 5 & 6) intended to further explore therapists practice patterns with a larger population of therapists. The majority of the 145 respondents reported frequently measuring sensory impairments but did not use any of the standardised sensory measures that were available. Respondents most commonly assessed ULPSSI to determine the impact on occupational performance and guide choice of interventions, and most commonly did not undertake assessment if clients reported having no sensory impairment or were unable to participate in testing. The interventions that were most frequently reported as being provided were passive sensory stimulation followed by compensatory strategies. Most therapists provided patient/caregiver education about safety. Clients’ cognitive status, severity of ULPSSI, and time since stroke influenced therapist’s choice between compensatory or remedial approaches. Therapists
cited lack of knowledge and skills, patients’ short length of stay, and lack of time as barriers to utilising interventions. Prior experience, effects seen when trialling interventions, and consulting other therapists most commonly influenced specific intervention choice. While therapists reported using theories or models to provide information regarding ULPSSI very few reported using clinical practice guidelines (which as noted in Chapter 2 had made recommendations for ULPSSI assessment and intervention), research studies and systematic reviews and cited the lack evidence available as a barrier to providing interventions for ULPSSI. While there was no clear summary of the evidence for the effects of interventions for ULPSSI available prior to the Cochrane systematic review which therapists could refer to, there were still single RCTs that had been published as well as recommendations for practice in national practice guidelines.

The majority of therapists reported not being up to date with current research and requested continuing education to support practice, nominating numerous different topics regarding ULPSSI on which they wanted further education. Given that the evidence for ULPSSI interventions comes from individual RCTS or non-randomised studies, therapists may also benefit from information and guidance about CDM in areas of uncertainty and how to think about research which is limited to these types of studies. Further information about using standardised sensory measures and how to evaluate their practice would be beneficial. The results of this study informed the rationale to undertake an educational intervention to support therapists CDM when addressing ULPSSI.

Another important source of information for CDM comes from the client themselves. Very limited information was available to describe the impact of ULPSSI from the perspective of the stroke survivor prior to this thesis and this provided the rationale for the fourth study that forms this thesis. This qualitative descriptive study of 16 stroke survivors was the first that sought to describe the impact of ULPSSI from the survivors’ perspective. Three themes emerged from the information provided by the participants in this study: 1) What happened to my hand?; 2) I was only just getting started; and 3) If I work hard then maybe someday.
The first theme provided a description of the significant impact of sensory impairments on survivors’ roles and participation in valued occupations. Survivors described the impact not only in terms of potential risk of injury and the difficulties with controlling the upper limb in functional activities but also the resulting physical and cognitive fatigue from having to monitor the upper limb position due to the lack of sensory awareness and the emotional response related to these impairments. Recovery of lost sensation was valued by stroke survivors, though at times second to motor recovery in the upper limb.

The second theme described how survivors felt the remediation of the upper limb generally and ULPSSI in particular were ignored in rehabilitation and described being left on their own to devise their own rehabilitation strategies. While stroke survivors had both positive and negative memories of their interactions with rehabilitation professionals, they frequently felt that therapists had low expectations for their recovery. The conflict between the survivor’s focus on recovery and the perceived focus of rehabilitation on compensatory skills was noted as well as the conflict between the timing of rehabilitation services and when the stroke survivor felt ready for and needing therapists’ guidance. Generally stroke survivors felt that by the time they were focused on upper limb rehabilitation including addressing ULPSSI they generally no longer had access to rehabilitation professionals.

Stroke survivors continued to value focusing on recovery and not giving up and this is described in the third theme. Participants were not always sure what specific activities seemed to lead to sensory return; they felt that stimulation, increased movement, constantly trying to use their arm did help. While hope for future recovery was important, hope appeared at times to have come from a restructuring of their life story, with survivors describing developing a sense of a new normal. Many survivors also described contributing to the family and community providing hope and a sense of meaning for their lives after stroke.

Information from this study is important for therapists’ CDM when working with stroke survivors and should also inform the development of services to meet stroke survivors’ needs.
The preceding studies provided the rationale for the final study which evaluated the feasibility and effects of a theory-based CPE on therapists’ knowledge, attitudes and intended behaviours regarding ULPSSI management. The eight hours long CPE workshop was designed utilising the Theory of Planned Behaviour and aimed to provide background information about ULPSSI, information about the best available evidence for ULPSSI management strategies, and discussion of CDM strategies and SDM. The theory-based CPE has the potential to increase a broad range of evidence-based knowledge supporting therapists CDM when addressing ULPSSI. The CPE also has the potential to impact therapists’ attitudes, perceived behavioural control and intentions regarding ULPSSI management, SDM and strategies for CDM in areas of uncertainty. Recommendations regarding improvements of recruitment strategies, study design and usefulness of the outcome measures for further studies were made.

9.2. Implications
While stroke survivors form one of the largest groups who receive occupational therapy services (National Board for the Certification of Occupational Therapy, 2004; Woodson, 2008) they also provide a challenge for occupational therapists’ CDM especially with regard to incorporating research evidence into practice (Gustafsson & Yates, 2009; Welters, 2011). Previously little was known of about how occupational therapists chose to manage ULPSSI when working with stroke survivors even though it has been demonstrated that impaired sensation in the upper limb impacts a majority of stroke survivors (Acerra, 2007; Sullivan & Hedman, 2008; Tyson et al., 2008) with significant consequences including diminished upper extremity functional use, motor control, as well as decreased outcomes including fewer discharged home and lower levels independence and participation (Desrosiers et al., 2003; Nowak et al., 2007; Tyson et al., 2006; Tyson et al., 2008; Welmer et al., 2008). The research that is outlined in this thesis has provided new and valuable insights into ULPSSI management, therapists’ CDM, and the stroke survivors’ perspective. What follows is a discussion of some key implications from the findings from this thesis.
9.2.1. Utilising standardised sensory measures.

The initial steps of CDM involve gathering data from multiple sources and interpreting that data (Smith et al., 2008). Using standardised measures provides therapists with valid and reliable data for CDM. Therapists frequently reported using client self-reporting of not having ULPSSI as a reason for not further evaluating for ULPSSI (Chapters 5 & 6). Research has demonstrated that stroke survivor self-reporting of impairment is not a good indicator of impairment (Acerra, 2007). Given the high incidence of impairment in both limbs after stroke it is recommended that therapists evaluate all stroke survivors for ULPSSI and be cautious in utilising the ipsilateral upper limb as the control.

Therapists value and frequently test for ULPSSI but do not appear to utilise currently available standardised assessment measures (Chapters 4, 5 & 6). The literature review for this thesis (Chapter 2) and the final study (Chapter 8) summarised the research evidence regarding the reliability, validity and clinical utility of the available standardised sensory measures. While this literature review and a later systematic review by Connell and Tyson (2012) have identified a few standardised sensory measures available for therapists’ use, one of the key findings of the practice patterns survey (Chapter 5) was that therapists were typically not utilising the standardised sensory measures that were available. This low use of standardised by occupational therapists has significant implications for therapists’ CDM, the ability to identify outcomes for occupational therapy services, and how therapists manage CDM in areas of uncertainty.

The initial step in CDM involves identifying the functional problem facing the client and forms the basis for formulating goals and an intervention plan. Standardised measurement tools with good psychometric properties provide therapists with information that is the best available and accurate evidence on which to base these decisions (Potter, Fulk, Salem, & Sullivan, 2011). Using standardised measures increases the accuracy of the occupational therapy diagnosis and potentially allows comparison with norms for that behaviour or attribute, improves the targeting of the specific intervention strategies to the functional abilities of the client, as well as assisting with identifying the specific level for the goals being set (Velozo & Woodbury, 2011). Therapists in the survey study identified some of these reasons as reasons why they assess sensory impairments. The low level of
utilisation of standardised measures may be due to difficulties relating the results from these assessments to these key components of intervention planning and CDM (Velozo & Woodbury, 2011). This concern was expressed by therapists in the qualitative study (Chapter 4) who described difficulty understanding the relationship of the sensory measures and functional use of the upper limb and intervention planning. Velozo and Woodbury (2011) proposed that measurement developers consider these concerns and demonstrated improving the ability of the FMA to assist therapists with daily clinical decisions related to goal setting and intervention planning using new approaches to measurement development based on Item Response Theory. Further development of currently available sensory measures and recommending developers of new sensory measures incorporating these methods can potentially increase their utilisation.

Not only are standardised measures important when designing intervention plans, standardised measurement tools should also be used to monitor the effectiveness of interventions (College of Occupational Therapy, 2013). Professional organisations such as the College of Occupational Therapy (2103) call for the use of evidence-based outcome measures as a key component of EBP. With the current climate in healthcare that values cost effectiveness, the ability to demonstrate the effectiveness of occupational therapy interventions is essential (Wales, Clemson, Lennin, & Cameron, 2012) with Unsworth (2011) voicing concern that only those services demonstrating effectiveness will continue to be funded. Therapists must be aware of the implications of using non-standardised measurement tools which may include decreased accuracy, impact ability to demonstrate outcomes, loss of professional credibility and potential impact on the client (College of Occupational Therapy, 2013). The quality of the data obtained during the evaluation process also impacts the therapist's CDM.

In areas where there is limited or slow development of research evidence, Unsworth (2011) stresses that using standardised outcome measures provides data that therapists can use to evaluate the effectiveness of their specific interventions and also potentially allows sharing of data that could potentially be used in research about these interventions. This may be potentially helpful for therapists who are experiencing considerable uncertainty regarding the effectiveness of the interventions they are using for which a
body of research evidence does not exist such as those therapists described using in survey study (Chapter 5). Therapists’ ability to use standardised measures in this manner needs to be evaluated as only a few therapists mentioned using sensory measures to monitor clients’ sensory return in the qualitative study (Chapter 4) and while the majority of therapists in the survey study (Chapter 5) reported using sensory measures during the initial assessment phase only two thirds report using sensory measures at discharge. In the survey study (Chapter 5) therapists reported using sensory measures to select/guide interventions (34.5%), determine the impact on occupational performance (32.5%) with few reporting using the measures to monitor progress (8.1%). This is concerning given the need for the therapists to document outcomes for their interventions and also to reflect back on the effectiveness of the interventions that they used for this client especially when using interventions with limited research support.

The lack of use of standardised measures is consistent with findings by Robertson and Blaga (2013) in a study of 70 New Zealand occupational therapists in an acute care setting, who found that informal assessments were commonly used to provide information about a variety of areas including upper limb function. Stapleton and McBrearty (2009) also reported low rates of use of standardised measures by 109 occupational therapists in a range of physical disabilities practice settings in Ireland. Two hundred and fifty three Canadian occupational therapists working in inpatient rehabilitation centres were surveyed by Holmqvist, Kamwendo, and Ivarsson Menon-Nai, (2009) about their practice patterns regarding the management of unilateral neglect with a total of 27% of respondents reported using standardised measures. Korner-Bitensky, and Ogourtsova, (2007) completed a qualitative descriptive study of 12 occupational therapists who worked in a community setting with clients with brain injury. Therapists in this study described a reluctance to use standardised assessments. Wales, Clemson, Lennin, and Cameron (2012) summarised the literature related to assessments used by occupational therapists with older adults and concluded that therapists favour using non-standardised measurement tools. The reasons most commonly cited for the lack of uptake in using standardised measures include the therapists’ readiness and skills, motivation, self-confidence, lack of management support, therapists’ values and beliefs and lack of knowledge (Wales, Clemson, Lennin, & Cameron, 2012). In the final study (Chapter 8) therapists in the elicitation questionnaire identified lack of assessment skills and
knowledge regarding assessments, lack of availability of assessments and difficulty relating the test scores to function as reasons for not utilising standardised sensory measures.

The lack of use of standardised measures is a major obstacle to occupational therapy becoming the science-driven, evidence-based profession (AOTA, 2006) and potentially to ongoing funding for occupational therapy services (Unsworth, 2011). Methods to increase the uptake of standardised measures in occupational therapy practice need to be evaluated with the use of standardised sensory measures being one example. Cooke, McCluskey, and Bowman (2007) found that an educational intervention regarding standardised outcome measures for persons with pain significantly increased occupational therapists’ use of these measures up to four months after the intervention. The final study in this thesis (Chapter 8) showed some potential for a theory-based educational intervention to increase therapists’ intent to use standardised sensory measures. This study needs to be further expanded and the components of the education intervention that address behavioural change i.e. increasing use of standardised sensory measures by therapists may need to be combined with other elements that have been shown to have been effective for changing practice behaviours e.g. practice audits and feedback, reminders (Novak, Russell, & Ketelaar, 2013) and the participants followed to see if there were actual changes to their practice behaviours and if these changes were sustained.

Another issue regarding sensory measures raised by this thesis is the lack of a “gold standard” measure. In the 14 studies identified in Cochrane systematic review (Chapter 3) evaluating the effects of interventions for ULPSSI there were 36 different sensory outcomes measures used. Having a large number of measures contributes to the significant diversity and limits the ability to compare or synthesise the outcomes from research studies as in the case of the systematic review. Having a “gold standard measure” would increase the ability of therapists to share information, communicate with team members, and increase efficiency between team members by reducing unnecessary replication of measurement of the same impairment using different measures. Burton, Tyson, and McGovern (2013) studied 84 health care professionals and 12 managers in stroke centres in the United Kingdom. They reported that while there was an increase in
use of standardised measures at least at one time in the survivor’s plan of care, multiple measures were used and there was little consistency in the tools used consistent with the findings of the survey study in this thesis. Diagnostic test accuracy reviews to look at the effectiveness of measures for sensory impairments, especially related to the impact on upper limb function and functional performance and participation after stroke would also be a priority, providing therapists, managers and researchers with evidence for decision-making and may potentially identify key measures.

Increasing therapists’ awareness of the psychometric properties of measurement tools, how this impacts the results obtained and ongoing support for resources of summarised measures such as Rehabmeasures.org and reviews such as Connell and Tyson (2012) may provide therapists with tools to navigate this complex area.

Persons who have had strokes identified impairments related to force pressure and dropping objects or objects slipping as significantly impacting their functional use of the upper limb (Chapter 7). There are no measures available to clinicians that address these issues. There are also no measures related to the clients’ perspective including issues regarding visual monitoring of tasks, ease and flow of tasks, and fatigue levels (Chapter 7). The College of Occupational Therapy (2013) recommends that therapists use measures that not only measure the functional status of the client but also the client’s feelings and attitudes. Development of measures that address these concerns within the context of upper limb recovery after stroke is in the very early stages but steps need to be taken to incorporate the impact of ULPSSI on the clients’ experience. It is imperative that reliable, valid and sensitive measures demonstrating good clinical utility are developed and available for clinicians to use, with their relationship to functional upper limb use established.

Therapists in the qualitative study (Chapter 4) expressed concerns regarding how to relate the results of sensory measures to functional outcomes and occupational performance. Approximately one third of the therapists in the survey study (Chapter 6) reported using sensory measures to determine the impact of ULPSSI on occupational performance. While clearly improved measures that focus on occupational performance, participation and the clients’ perspective are needed and could potentially inform CDM, occupational
therapists must also decide if the evidence provided is congruent with the basic tenets of the occupational therapy profession. Gustafsson, Moulinex and Bennett (2014) propose that occupational therapists’ professional reasoning is the process through which the evidence used for CDM is integrated with the core paradigms or philosophies of the occupational therapy profession and that as the profession moves back to the focus on occupation and away from the biomedical paradigm, therapists will need to screen evidence used for CDM based on the congruency with these core tenets. In the studies forming this thesis, occupational therapists have appeared to struggle with using measures focused on impairments or biomedical factors to provide information related to occupational performance and then how to use the information provided by these measures to design intervention plans. A survey of 142 American occupational therapists that worked in short term rehabilitation regarding EBP, reported that 57.7% of therapists in their survey agreed that not enough research is available that is relevant to occupational therapists and provided a significant barrier to the use of EBP in CDM (Lopez et al., 2008). Potentially, some of the struggle could be due to the mismatch between the biomedical paradigm and the occupation paradigm. The studies in this thesis did not explore this area but further exploration of how this mismatch may impact therapists’ CDM especially in the area of ULPSSI is warranted. The development of methods to aid clinicians in this CDM process as well as the development of measures and intervention strategies that meet these needs and are congruent with the occupation paradigm would be an important focus for future research for the profession.

In summary, therapists relied on the stroke survivors’ report of impairment as an indication of the need to use sensory measures and when they did decide to measure ULPSSI they did not utilise the standardised sensory measures that were available. This significantly impacts the information available for therapists' CDM both related to identifying the presence of ULPSSI and evaluating the effectiveness of the therapy provided. While it appears that educational interventions may increase the use of standardised measures by therapists further studies are needed to verify the usefulness of a theory-driven CPE. Further development of sensory measures that address the concerns raised by stroke survivors, are related to functional use of the upper limb, and linked to intervention strategies are warranted.
### 9.2.2. Interventions for ULPSSI.

One of the key contributions of this thesis is the Cochrane systematic review that synthesises the effectiveness of interventions for ULPSSI. The results of the Cochrane Systematic Review have also been re-published in Stroke (Doyle, Bennett, Fasoli, & McKenna, 2011) and incorporated into Evidence-based Reviews of Stroke Rehabilitation (Foley, Teasell, Jutai, Bhogal, & Kruger, 2012) providing wider dissemination. The Cochrane systematic review found evidence from single RCTs reporting positive effects for three interventions for ULPSSI with potentially three others showing positive effects but lacking sufficient data to calculate effect sizes. Since the systematic review was completed there have been several further studies published that evaluate the effects of interventions for ULPSSI. An updated literature search for the evidence was completed for the final study in this thesis and results of these new studies together with those from the Cochrane systematic review are summarised in Table 8.1. It is likely that new studies have been published since this work and it is clearly time to formally update the Cochrane systematic review. There is a need for further well designed studies with larger numbers of participants to increase the amount, quality and strength of the evidence available for these interventions.

The nature of evidence currently available to guide clinicians’ CDM regarding ULPSSI management raises the question about the when there is sufficient evidence to make recommendations for changes in routine practice. Grimshaw, Eccles, Lavis, Hill and Squires (2012) argue that this decision should be based on good quality systematic reviews or synthesis of research. When constructing clinical guidelines for making routine practice recommendations the Agency for Healthcare Quality and Research (Agency for Healthcare Quality and Research, 2014) now requires that the guidelines be based on a systematic review with an evaluation of the quality of the evidence using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) standards (GRADE working group, 2014). The GRADE working group was established to address the inconsistency between appraisal methods for research evidence in healthcare. These recommendations apply to the development of guidelines and broad recommendations for routine practice. Given the increasing numbers of RCTs evaluating the effectiveness of interventions for ULPSSI it is time for the Cochrane systematic review on this area of practice to be updated and for new studies to be considered in updates of clinical practice.
guidelines. Whether there is sufficient evidence available to make recommendations for routine practice could then be reassessed.

While currently clear recommendations for routine practice change may not be able to be made due to the lack of recommendations from a systematic review, EBP advocates therapists use the best available evidence for CDM regarding intervention choices for individual clients. This is the recommendation from the Sicily statement on evidence-based practice, in which Dawes, Summerskill, Glasziou Cartabellotta, Martin, Hopayian et al. (2005) contend that EBP requires clinical decisions to be based on the systematic retrieval of the “best available, current, valid and relevant evidence” (p.1). The best available evidence many times is from a single RCT (Gray, 1997). While there are potentially risks associated with using single RCTs, RCTs still are viewed by many experts in EBP as providing strong evidence related to the effectiveness of interventions (British Medical Journal, 2014; Centre for Evidence Based Medicine, 2014; Duke University, 2014). Clearly therapists must be trained in evaluating the risks of bias and strength of evidence provided in individual RCTs when using the results to inform CDM (Mahtani, 2013) as well as how to integrate this information with their clinical expertise and the client’s goals and values. A number of methods for evaluating the level of evidence or strength of the evidence to support individual therapists’ CDM have been developed. In the final study (Chapter 8), the level of evidence for interventions was evaluated using the Stroke Engine Rating System (McGill University, 2011). Based on this scale, strong evidence exists for an intervention if there is a high quality systematic review or at minimum two high quality RCTs demonstrating positive effects for a specific intervention and moderate evidence exists if there is at least one high quality RCT demonstrating positive effects for a specific intervention. Evaluating the evidence utilising this system is consistent with the approach taken by the Evidence Based Reviews of Stroke Rehabilitation Research Group (2014), who provide appraised and summarised evidence for therapists to use in CDM.

As the body of research grows therapists need to have methods for updating their knowledge as well as the skills to understand and interpret the research findings. Systematic reviews represent a summary of the appraised, available evidence regarding
specific clinical questions and need to be updated regularly but therapists also need to be aware of and use sources that locate these reviews as well as newly published RCTs. Ideally websites such as OTSeeker (Bennett et al., 2003), which aims to locate and appraise systematic reviews and RCTs relevant to occupational therapy practice, Stroke Engine (McGill University, 2011) and Evidence Based Reviews of Stroke Rehabilitation (EBRSR Research Group, 2014), which aim to provide an up to date review of the research evidence in stroke rehabilitation, provide therapists with a time efficient method of staying up to date and are freely accessible. Therapists in the qualitative study (Chapter 4), the survey study (Chapter 5 & 6) and the final study (Chapter 8) did not appear to be aware of these resources or how to access them to inform CDM. When provided with these resources in the final study (Chapter 8) several participants commented on now having access to resources that would help them stay current and up to date.

Potential changes in initial professional education to increase the level of research knowledge (such as the move to master’s degrees as the entry level qualifications in the USA) and the incorporation of training in EBP into the curriculum (ACOTE, 2011) was proposed to increase therapists’ skills and utilisation of EBP. Although in the survey study only 45% of the respondents reported having an entry level Bachelor’s degree and the majority reported having higher levels of qualifications, there was still limited use of EBP strategies such as searching for evidence and using standardised measures. Research that explores other factors that may contribute to this lack of use of these skills and how to overcome them has been explored in other areas of occupational therapy practice. CPE has been identified as one potential means of doing so and the final study of the thesis (Chapter 8) demonstrated some potential for a theory-driven CPE to change therapists behaviours but further well designed studies are warranted. Further research utilising the TPB model to explore the attitudes, norms, barriers, and perceived control of occupational therapists within different settings may identify barriers to EBP that can be then addressed.

Therapists in the survey study (Chapter 5) reported the biggest barriers to utilising interventions for ULPSSI as being lack of knowledge (51.8 %), client’s short length of stay (51.8%), lack of time (48.9) and insufficient evidence to support their use (32.8%). We
have addressed some concerns regarding insufficient research evidence in the discussion above and issues related to lack of knowledge and making decisions when there is uncertainty exists are discussed in the next section. The issues related to client’s length of stay and the therapists’ lack of time have been raised in previous studies (Bennett et al., 2003; Upton, Stephens, Williams, & Scurlock-Evans, 2014). Only limited numbers of therapists (9.8 %) in the survey study nominated making more time available as potentially increasing their use of ULPSSI interventions. Although the reason for this was not explored in this survey, perhaps prioritising use of time and more efficient use of available time, rather than having more time for intervention could be considered. McCluskey (2004) noted that there were inefficiencies in time use in implementing EBP strategies in the population of 114 Australian occupational therapists involved in a study evaluating the impact of EBP training. McCluskey (2004) concluded that competent therapists demonstrated less use of these inefficient strategies such as procrastination, prolonged searching, being reactive rather than proactive, poor understanding of the task and decreased skills. Potentially increasing therapists’ knowledge, skills and confidence may increase their efficiency for choosing and using standardised measures and ULPSSI interventions as was similarly proposed with reducing time barriers to utilising EBP skills such as searching and evaluating evidence (McCluskey, 2004). The development of decision-making aids as well as increasing the stroke survivor and or caregiver/family involvement with such areas as self-management and home programs may decrease the therapists’ time demands (Barker & Brauer, 2005; Kuipers & Grice, 2009). Evaluation of the effectiveness of these methods needs to be undertaken.

9.2.3. Using experience in CDM and strategies for managing uncertainty.

Consistent with previous studies, in the qualitative study (Chapter 4) and survey study (Chapters 5 & 6) therapists reported relying on their experience and that of their peers when making intervention choices and when evaluating the effectiveness of an intervention. However clinical experience can also be potentially fraught with bias and hence experience must be combined with mechanisms for learning and reflection for therapists to develop expertise and reduce bias (Jensen, Resnik, & Haddad, 2008; Kempainen, Migeon, & Wolf, 2003). Years of experience alone do not develop expertise. For example, Resnik and Jensen (2003) found that expertise in physiotherapists was not
related to years of experience or specialty certification. Rassaffiani et al. (2009) also concluded that years of experience was not associated with attributes of expertise such as consistency of decision-making and the ability to be able to discriminate between cases when they studied occupational therapists’ CDM in the context of paediatric cerebral palsy cases. Reliance solely on clinical experience as a basis for CDM may result in errors in CDM with potentially poor outcomes for the client.

It is therefore important that clinicians are taught to minimise bias in clinical reasoning (Kempainen, Migeon, & Wolf, 2003). In EBP clinicians are encouraged to incorporate clinical expertise in their decision-making but very few models exist on how to actually do this in practice (Copely & Allen, 2009). When studying occupational therapists who worked in a paediatric setting, Copely and Allen (2009) found therapists reported testing what they learned in their professional program and the research evidence they located against the evidence from their experience. Therapists in Copely and Allen’s study proposed that the evidence generated from experience, which they called practice-based evidence, should be evaluated to reduce the bias using systematic peer-review, evaluation of outcomes including the client’s perspective, setting wide data collection, and setting wide evaluation of the outcomes. When therapists trial interventions, a process akin to ‘trial and error’, they need to use adequate observation and reflection to avoid bias (Jensen, Resnik, & Haddad, 2008; Kempainen, Migeon, & Wolf, 2003). One potential approach in these situations is utilising the N-of-1 trial or single system design studies testing the effects of an intervention on an individual (Backman & Harris, 1999). Higgs et al. (2008a) proposed teaching therapists to use cross checking, critiquing, and verifying practiced-based knowledge to reduce the biases involved in CDM based on experience. Jensen, Resnik and Haddad (2008) concluded that experts demonstrate ongoing learning that results in well-structured practice knowledge but achieving this is very dependent on metacognition and reflection. The effectiveness of these methods has not been evaluated and further studies exploring the use of these methods would be helpful.

Tonelli (1999, 2010) not only proposed that clinical expertise could inform clinician’s CDM but can also inform researchers by identifying potential adverse effects, inform the context of clinical research, identifying clinically relevant research projects, and identify potential factors that impact the suitability of an intervention for particular clients. Further research exploring CDM regarding ULPSSI management aimed at identifying expert clinicians and
exploring the specific client factors that impact their CDM may provide useful directions for further research.

Research about CDM needs to extend beyond surveys and standard qualitative research methods and could use approaches that capture CDM in the “moment” such as videotaping, think aloud techniques, retrospective and explanation protocols may provide more insight into these factors and the reasoning processes used (Arocha & Patel, 2008; Unsworth, 2008). Kuipers and Grice (2009) used a repertory grid to identify further sources of information or factors identified by clinical experience that an expert occupational therapists used in CDM regarding upper limb management after traumatic brain injury. Using this method might further clarify and provide quantitative analysis of clinical expertise in ULPSSI management and may provide further information to inform research and education. Rassafiani et al. (2009) used Cochran–Weiss–Shanteau statistical methods with hypothetical cases to identify expert occupational therapists who worked with clients with cerebral palsy. Expertise was defined by Rassafiani et al. (2009) as consistency in decision-making as well as being able to discriminate between important stimuli in the case and is domain specific. As this thesis identified factors therapists consider when making decisions regarding ULPSSI management, this would be a suitable next step for research in this area, allowing for quantitative analysis of the impact of practice knowledge or clinical expertise, such as client factors, that expert therapists use in CDM regarding ULPSSI management. These results would be useful to inform further research to evaluate the impact of these factors as well as providing information that may be used for training student and entry-level clinicians to improve their CDM.

The associations between clinicians’ personality traits and their practice behaviours have been studied and may provide further insight into how therapists respond when facing uncertainty (Korner-Bitensky et al., 2007; Wyszewianski & Green, 2000). Korner-Bitensky et al. (2007) studied the relationship between 117 physiotherapists and 126 occupational therapists in a stroke rehabilitation setting and reported an association between personality traits and the reasons for choosing assessments and interventions. It could be hypothesised that these same personality traits would impact how therapists responded in situations of uncertainty, and further studies, with adequate power, to explore this
association are warranted. Wyszewianski and Green (2000) also proposed tailoring interventions to increase the use of EBP skills to clinician’s personality traits. While the TPB provided some information related to structuring interventions to change practice behaviours, some of which are similar to those described by Wyszewianski and Green (2000) combing these methods may potentially increase the effectiveness of these interventions and build on the information gained from the studies in this thesis.

Interestingly, while therapists in the qualitative study (Chapter 4) and survey study (Chapter 5 & 6) reported using their experience as a basis for choosing interventions and evaluating their effectiveness, they also reported not being up-to-date with their knowledge and expressed considerable uncertainty regarding CDM for ULPSSI management. Higgs and Jones (2008) reported that being a professional often involves decision-making when there is uncertainty, but few studies have described uncertainty in occupational therapy. While one other study (Kuipers & McKenna, 2009) identified occupational therapists’ uncertainty and lack of confidence in CDM, even by therapists with considerable experience, the qualitative study in this thesis was the first study that described the reasoning strategies occupational therapists used when reasoning in areas of uncertainty. Given the limitations of the qualitative study, and that it did not primarily focus on uncertainty in CDM, further exploration of the concept of uncertainty is needed to further understand uncertainty in CDM and to potentially identify ways to best support therapists’ CDM.

Therapists in the survey study (Chapter 5) requested further education and research to support their CDM. The final study (Chapter 8) described the effects of a pilot study of a theory-based education intervention on knowledge, attitudes, and perceived control which demonstrated potential to increase knowledge and perceived control (both of which may be linked to uncertainty). While the theory-based educational intervention was evaluated using a pilot study and further development to a RCT is recommended, evaluation of how this intervention impacted therapists' uncertainty in CDM regarding ULPSSI management is also warranted.
While education is one approach for supporting therapist’s decision-making, other approaches must also be considered. Kuipers and McKenna (2009) recommended the use of evidence-based decision-making protocols that differentiated where decisions were based on propositional knowledge versus practice-based or non-propositional knowledge, and that guidelines for reflective practice to guide CDM be developed. This could be evaluated in the context of ULPSSI management, where the decision-making aid or protocol incorporates the best available evidence covering the wide range of clinical decisions, identifies evidence gaps and provides information on reflective practice and methods for reducing bias when using experiential knowledge. This would be a potential extension of the educational intervention trialled in the pilot study (Chapter 8), which while it updated scientific knowledge, presented available standardised evaluation tools, summarised the best available evidence and included a section on decision-making in areas of uncertainty and reducing bias, the workshop did not present a decision aid as outlined by Kuipers and McKenna (2009).

In summary, therapists rely heavily on their clinical experience which is frequently prone to bias and often report considerable uncertainty in CDM regarding ULPSSI management. Future research is warranted that focuses on the following topics: 1) developing methods to increase therapists' awareness of the bias in reasoning based on clinical experience and how to reduce this bias particularly in areas with limited research evidence, 2) development of a decision-making aid for ULPSSI management, and 3) further study of uncertainty in occupational therapy CDM, effective strategies for the management of uncertainty as well as how therapists' personality traits influence how they make decisions.

9.2.4. Understanding the client’s perspective: Implications for sharing decision-making, timing and content of occupational therapy services.

The definition of EBP proposes that therapists incorporate the client’s values and goals in the CDM process (Sackett et al., 2000). This is consistent with recommendations from professional groups and accrediting agencies for occupational therapists to practice from a client-centred perspective and involve the client in shared decision-making (Bright et al.,
Stroke survivors reported significant changes in sensation that impacted their upper limb functional use and safety. Altered sensation and often a lack of sensation were seen as leading to less awareness and use of the upper limb and often survivors described an overall sense of detachment. This is consistent with studies demonstrating the association between ULPSSI and decreased spontaneous upper limb use (Rand et al., 2001). Difficulties using the upper limb in functional activities due to impairments in controlling the amount of force used in grip as well as identifying object movement or slip within the hand were concerns raised by stroke survivors (Chapter 7). It is concerning that there are currently no standardised, reliable or valid measures of these skills available to clinicians. While potentially therapists could use skilled observations to identify these problems in functional tasks, the development of a standardised measure would provide reliable information for CDM and to evaluate the effectiveness of potential intervention strategies. Therapists should be aware of these concerns and take steps to identify and address ULPSSI when working with clients who have had a stroke.

Stroke survivors reported that the amount of mental effort required to compensate for ULPSSI contributed to their fatigue levels (Chapter 7). The aetiology of post-stroke fatigue is multifactorial and often unclear and while fatigue due to mental effort has not been frequently identified in the literature (McGeough, Pollock, Smith, Dennis, Sharpe, Lewis, at al., 2010; Daniels, Winding, & Borell, 2002), fatigue specifically related to compensating for ULPSSI has not been previously mentioned. This study identified a potential role that additional mental effort plays in adding to the overall post-stroke fatigue burden. Post-
stroke fatigue has been associated with poorer functional outcomes especially in younger stroke survivors (Maaijwee, Arntz, Rutten-Jacobs, Schaapsmeerders, Schoonderwaldt, van Dijk, & de Leeuw, 2014). Only recently has attention been given to interventions for post-stroke fatigue with a number of RCTs testing a range of different interventions for managing fatigue, concluding that more attention to find effective interventions is necessary (McGeough, Pollock, Smith, Dennis, Sharpe, Lewis, et al., 2010). While attention has focused on improving physical endurance, addressing depression, energy conservation and pacing as methods for improving fatigue (Stroke Association, 2012) potentially remediation of and effective compensation for ULPSSI may also reduce fatigue levels.

Stroke survivors (Chapter 7) reported wanting to focus on remediation of sensory impairments but reported that therapists predominantly focused on compensation if they addressed ULPSSI. This divergence between the stroke survivors’ goals and the therapists’ focus has been described previously in a qualitative study with occupational therapists working in stroke rehabilitation (Daniels, Winding, & Borell, 2002). Daniels et al. proposed that one way of addressing this difference might be to take an occupation-based approach to therapy as it could provide an alternative focus potentially sitting between remedial and compensatory approaches. Daniels et al. (2007) stressed the importance of the client being able to make meaningful choices in order to increase their sense of autonomy. Using SDM would also potentially facilitate stroke survivor’s sense of autonomy so they might be more equally participating in directing the therapy process. However many stroke survivors (Chapter 7) reported that they were not ready for this level of involvement in planning their care initially and relied on the expertise of the therapists at this stage. This appeared to change the further along the recovery process the survivor was and they described gradually wanting to increase their involvement in the decision-making process. Training for therapists in SDM that incorporated skills to coach stroke survivors in SDM may improve the stroke survivors’ satisfaction with therapy, adherence to therapy recommendations, and improved adjustment to stroke as has been demonstrated in other areas (van Til, Drossaert, Punter, & Ijzerman, 2010). The final study (Chapter 8) demonstrated the potential for a theory-driven educational intervention to impact therapists’ attitudes and intended behaviours regarding SDM but further well-designed studies are needed.
One of the other key concerns raised by stroke survivors in the qualitative study (Chapter 7) was the timing of therapy services. While a number of survivors reported being ready to address ULPSSI relatively soon after their stroke, many felt they were not ready until later, some of them even six months or more following stroke. This is consistent with the conclusions of Barker and Brauer (2005) in a qualitative study of stroke survivors’ experience of upper limb recovery who recommended the development of therapy services to support stroke survivors from onset of stroke until end of life. With very few stroke survivors receiving services after the initial hospitalisation it is little wonder that they felt left on their own to devise their own rehabilitation plans. In the USA there has been limited referral to outpatient services for stroke survivors, though recent changes to Medicare guidelines may potentially allow for further services for persons with chronic illnesses (Fisher & Friesema, 2013) but this will also require therapists to development new models of service delivery. Development of research evidence and clinical practice guidelines to support therapists in these emerging areas of practice is warranted.

In Britain, the Department of Health recommends that chronic stroke survivors receive a multidisciplinary rehabilitation team assessment at six weeks, six months and then annually after stroke to re-evaluate the survivors’ needs and provide services as necessary (Department of Health, 2010). Opportunities are also provided for self-referral providing the stroke survivor with greater opportunities for self-management and these services can focus on increasing participation in valued roles and community activities (Department of Health, 2010). Barker and Brauer (2005) recommended that self-management programs focus on strategies and information to prepare stroke survivors to navigate the many dimensions of stroke recovery. The development of programs focused on self-management for persons with chronic stroke is only in the early stages though a few studies have identified improvements in self-efficacy, self-management behaviours, and improved quality of life (Damush, Ofner, Yu, Plue, Nicholas, & Williams, 2011).

Stroke survivors (Chapter 7) reported little attention was paid to their upper limb and almost no attention to ULPSSI management and reported feeling left on their own to develop or manage interventions for ULPSSI as well as having little input into decisions
related to the management of their care. Potentially improving stroke survivors’ self-management skills could address these concerns and further development and evaluation of these programs would be helpful not only to therapists but also to stroke survivors. Having increased skills to manage their own care and rehabilitation immediately after stroke may be potentially reduce the sense of isolation, lack of services, and lack of involvement in decision-making. Evaluating the timing of this approach will be important as survivors reported varying levels of readiness shortly after their stroke and the unique characteristics of each survivor, the therapist, and the setting would need to be considered in future research.

The majority (79.8%) of therapists in the survey study (Chapter 5) reported providing education to the stroke survivors and this education focused on safety issues (35.71%), followed by education about sensory stimulation or re-education programs (n=38, 14.86%), and a home program (12.78 %). These topics could potentially be associated with self-management strategies by increasing survivors’ knowledge of their impairments, the implications for safety and provide strategies they can follow at home not only to reduce safety risks but also to carryover strategies aimed at remediation. While therapists reported frequently providing education regarding issues related to ULPSSI, few stroke survivors recalled having therapists address ULPSSI. Further improving the educational components of the current occupational therapy interventions may also provide more support in this area for stroke survivors and increase the efficacy of this intervention. Development of educational materials and trials of effectiveness of delivery methods may provide evidence to guide therapists’ CDM as they incorporate new intervention strategies.

In summary, concerns were raised by stroke survivors regarding the lack of attention to upper limb rehabilitation, particularly ULPSSI, as well as the timing of rehabilitation services, the focus of those services and their involvement in the decision-making process. Providing training for therapists in SDM so that they can include the stroke survivor in the decision-making process at a level they are comfortable with, providing training in self-management strategies, and developing other models of service delivery that extend beyond the current time-frames need to be further investigated.
9.3. Limitations

The studies described within this thesis contain some strengths and limitations, which have all been recognised within each of the individual Chapters that address the studies and are summarised below. The preconceived ideas and beliefs of the thesis candidate may have potentially impacted the design and implementation of the research projects that form this thesis. These initial beliefs were outlined in a statement at the beginning of the research process and were reviewed with the thesis advisors during the design and analysis of the therapists’ qualitative study and again reviewed by the thesis candidate during the process of summarising the overall thesis in this Chapter. A summary of the reflexivity statement is provided below.

The thesis candidate’s clinical experience with two particularly memorable clients, who experienced significant sensory impairments but only minimal motor impairments after stroke, triggered her interest in ULPSSI and potentially influenced the degree of significance that was associated with ULPSSI and the perceived impact of upper limb functional use. The thesis candidate initially believed that most therapists would state that they used a neuro-developmental treatment approach, would focus on remediation of ULPSSI until the client was 6 to 12 months post-stroke, would utilise research evidence as a means of determining effective interventions, and would search for research articles to find effective interventions for their clients. This was also influenced by the belief that there was some evidence to support interventions for ULPSSI though there was no preconceived ideas regarding what interventions would be supported by that evidence with the exception of some exposure to the work of Yuketiel (2000) on graded sensory re-education.

This thesis delivered a much-needed, comprehensive, systematic review of the effects of interventions for ULPSSI providing clinicians with a concise summary of the available evidence regarding interventions for ULPSSI. The utilisation of the Cochrane Collaboration methodology for this systematic review, seen as strong methodology for systematic reviews, strengthened the design and hence the validity of the results. This systematic review has provided a basis for the advancement of further studies evaluating
the effects of interventions for ULPSSI and has highlighted other areas for future research. The Cochrane systematic review methodology limited the inclusion of research designs of the studies to RCTs and this may have limited the overview of emerging evidence or studies for different or novel interventions that may indicate important areas for future research.

The first studies that described occupational therapy practice choices and CDM when addressing ULPSSI were also undertaken as part of this thesis. These studies have not only provided information to inform further research studies but also to inform CDM. In the second study, the qualitative study of therapists’ practice choices and CDM with regard to ULPSSI management, there were several limitations. Understanding CDM and the factors that influence CDM is a complex research undertaking. Study findings were based on interviews and are limited by the participant’s ability to recall and verbalise their thoughts about CDM. Ideally, being able to videotape interactions between the therapist and client has been used and provides an opportunity for the researcher and participants to discuss their CDM immediately after it occurred (Unsworth, 2005). It was not possible to use this process in this study due to pragmatic reasons although it may be a fruitful approach to use in the future. While some attempt to stimulate recall and CDM was attempted using cases, the details provided were limited and the factors that varied in the cases were time since stroke and severity of stroke. Further studies that incorporate other factors and greater details of cases may provide further richness in the data by stimulating recall and triggering changes in CDM. A larger number of participants would also have provided a richer source of data with regards to CDM and practice choices regarding ULPSSI. The primary researcher’s preconceived ideas potentially impacted the wording of the questions in the structured interview and the interpretation of the results. These were recorded in a reflexivity statement at the beginning of the research project and were reviewed during the thematic development process to evaluate their impact with the co-investigators.

Several limitations impacted the generalizability and validity of the conclusions regarding clinical practice choices and CDM based on the survey study. Subjects were randomly selected from the AOTA’s Physical Disabilities Special Interest Subsection (PDSIS) and may not be representative of all occupational therapists treating stroke patients as not all
occupational therapists are members of AOTA or the PDSIS. The response rate of 37% is consistent with research of response rates for mail surveys (34.6 - 39.6%) though lower than research for mixed (mail and online) methods (60%) (Greenlaw & Brown-Welty 2009), hence the respondents reflect a small proportion of the sample. The AOTA’s PDSIS is not focused solely on stroke rehabilitation but on therapy for a wide range of diagnostic groups including hand therapy and hence some members who were sent surveys did not respond as they did not treat stroke patients. Future studies might be able to utilise licensure board mailing lists to incorporate a boarder range of occupational therapists but may potentially have similar problems related to identifying therapists that solely or predominantly treat clients post-stroke and limitations regarding geographical location.

There are limitations when using survey methods for studying CDM. Therapists’ recall hinders gathering accurate information about CDM that might be better achieved through observing and questioning therapists ‘in the moment’ where they might explain their reasoning. Although qualitative methodologies may be informative, use of more rigorous quantitative methods to determine factors influencing decisions may also be valuable. In particular, use of social judgement theory which incorporates the relative importance of factors and their relationship to clinicians’ judgments may be fruitful (Harries & Harries, 2001b; Rassafiani et al., 2009; Wigton, 1996). The use of head mounted camera’s to describe CDM in the moment (video-assisted recall) is another methodology that may reduce some of the limitations related to recall, distance, and the need to provide socially acceptable responses that may be encountered by the survey that asks for self-report and has been used in previous studies on CDM (Unsworth, 2008). Another possible limitation is the potential impact of the primary researcher’s preconceived ideas not only the wording and content of the questions in questionnaire tool used in the survey study but also the data analysis itself. Attempts to reduce the potential bias were made by using sample questions from other survey questionnaires, using the data obtained from the qualitative study, frequent reference to the reflexivity statement, input from co-investigators and piloting of the questionnaire. No attempts were made to address the reliability or validity of the questionnaire used and further development of the use of tools to identify different types of CDM processes therapists use and factors that trigger using different CDM processes are warranted.
Given the limited studies regarding ULPSSI in the literature when compared to motor impairments, the qualitative study of stroke survivors’ perspective on ULPSSI has added another voice to the importance of this area. Not only did it illustrate the difficulties they experienced as a result of ULPSSI, but raised some important issues regarding delivery of rehabilitation services and SDM. The participants in the stroke survivors’ qualitative study were drawn from Stroke Support Groups. Survivors who attend stroke support groups do not necessarily represent the stroke survivor population in general as they may be more active in their pursuit of recovery, more active in general and more likely to seek support and information about stroke recovery than other stroke survivors. These stroke survivors also volunteered for this study and hence may have different attitudes and experiences than those survivors who did not volunteer. Additionally, survivors self-reports may also not truly reflect what actually occurred in therapy due to issues of recall and distance in time since receiving therapy and this should be considered when interpreting the findings in this study. This study did not verify the presence of ULPSSI at the time of participation and it is unclear how many of the participants were relying on recall versus their current experiences. This may have impacted how they perceived or interpreted the experience. Participants also were not tested for the presence of hemianopia or for unilateral neglect or asked about experiencing this neglect after their stroke. The presence of hemianopia or unilateral neglect may have altered their experiences or the interventions which they received. Response bias or the survivors’ reports possibly being influenced by the need to provide socially acceptable answers or answers that they feel the researcher wanted may have impacted the study.

The feasibility study of a theory driven, evidence-based educational intervention is the first study testing the impact of this intervention on occupational therapists’ knowledge, attitudes, perceived behavioural control and intended behaviours with respect to ULPSSI management and SDM. This is an important contribution because it demonstrates how theory might be used to design interventions that facilitate supporting occupational therapists’ CDM, including their use of evidence for CDM, and hence increase EBP while also addressing the needs and concerns that therapists identified in the previous studies in this thesis. The small convenience sample in the pilot study was a significant limitation to the generalizability of the results of the final study, as was the limited geographical area
from which the participants were recruited, however this was primarily a feasibility study. Measures of actual behaviours of interest versus self-reporting both pre and post workshop would also have improved the accuracy of the study. Following therapists for a period of time after the educational intervention, reviewing chart notes and interviewing therapists and clients are potential methods for identifying actual behaviour change that could be incorporated into future study designs. The study design was a pre and post-test single group design which also limited the strength of the results, therefore use of a RCT design is recommended.

9.4. Conclusion
Stroke survivors form the largest number of adults with disability in the developed world with the numbers predicted to grow. Sensory impairments of the upper limb impact a majority of those survivors, reducing upper limb functional use and affecting their participation in meaningful activities and life roles. The studies in this thesis sought to explore the decision-making about the management of ULPSSI by occupational therapists. An appraised and synthesised summary of the evidence provides key information for CDM and this thesis provided the first Cochrane systematic review that evaluated the effects of interventions for ULPSSI. This thesis also provided the first account of occupational therapists’ practice patterns when addressing ULPSSI in the USA as well as the first published study to describe the stroke survivors’ perspective on the impact of ULPSSI and their rehabilitation experience.

When addressing stroke survivor’s ULPSSI, occupational therapists appear to struggle due to lack of awareness and knowledge about ULPSSI, their management and associated research, and the constraints of the current rehabilitation system. Therapists reported high levels of uncertainty, expressing a lack of confidence in decision making regarding ULPSSI. Stroke survivors clearly articulated the significant impact of ULPSSI on upper limb functional use and described their recovery process as extending years beyond the current rehabilitation time frames, requiring considerable work that was often on their own. In response to the outcomes of the above studies in which therapists indicated they would like further education in this area, a study evaluating the feasibility of an innovative, theory-driven educational intervention to change knowledge, attitudes,
perceptions and intended behaviours of occupational therapists related to ULPSSI management demonstrated the potential to support their decision-making in this area.

Occupational therapists should be encouraged to use standardised sensory measures, consider the best available evidence when making decisions regarding interventions for ULPSSI, incorporate the stroke survivor in decision-making regarding therapy services, use methods to evaluate their practice and CDM to reduce bias and manage uncertainty, and develop service provision models that extend beyond the current framework of stroke rehabilitation to address the concerns raised by stroke survivors including increasing emphasis on self-management.
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Appendix 1: Ethics Approval Study Two

THE UNIVERSITY OF QUEENSLAND
Institutional Approval Form For Experiments On Humans
Including Behavioural Research

Chief Investigator: Ms Susan Leicht Doyle
Project Title: Occupational Therapists' Reasoning Process And Use Of Evidence Based Practice When Addressing Recovery Of Motor And Sensory Function In The Upper Extremity After Stroke -23/05/2008 - AMENDMENT
Supervisor: Dr Sally Bennett
Co-Investigator(s): Dr Sally Bennett, Dr Susan Fasoil
Department(s): School of Health and Rehabilitation Sciences, Division of Occupational Therapy
Project Number: 2005000264
Granting Agency/Degree: PhD
Duration: 31st December 2009
Comments:

Name of responsible Committee:-
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:-
Dr Jack Broerse
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Date 27/05/08 Signature

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February 26, 2008

Susan Doyle, MS, OTR/L, BCN
Southwest Washington Medical Center
P. O. Box Vancouver, WA 98668.

RE: Occupational therapists’ reasoning process and use of evidence based practice when addressing recovery of motor and sensory function in the upper extremity after stroke.

Dear Ms. Doyle:

At the Institutional Review Board meeting held on February 20, 2008 the study titled: Occupational therapists’ reasoning process and use of evidence based practice when addressing recovery of motor and sensory function in the upper extremity after stroke, including the Informed Consent documents were reviewed and granted approval for a period of one year (03/13/08 to 03/12/09).

Copies of the stamped/approved Continuing Review application and Informed Consent documents are enclosed.

PLEASE NOTE: PER CMS AND JOINT COMMISSION REGS THE TIME HAS BEEN ADDED TO CONSENT DOCUMENTS. THIS IS REFLECTED IN THE ATTACHED/APPROVED FORMS.

Please make sure that the enclosed SWMC IRB approved documents are used in your study.

Please be advised that you should inform the SWMC Institutional Review Board of any changes in your protocol, if any problems emerge, or if serious or unexpected adverse patient experiences have been observed. Please note that IRB approval is granted for one year; however, the subjects’ progress and your needs as principal investigator will continue to be re-evaluated on an as-needed basis.

If we can be of further assistance, please do not hesitate to contact Sylvin MacWilliams in the IRB office at 360-514-6100 or smacwill@swmedctr.com.

Sincerely,

Shaun Harper, MD
Chair Institutional Review Board

SH:scm
Appendix 2: Ethics Approval for Study Three

THE UNIVERSITY OF QUEENSLAND
Institutional Approval Form For Experiments On Humans
Including Behavioural Research

Chief Investigator: Dr Louise Gustafsson
Project Title: Sensory Retraining Of The Upper Limb Post Stroke:
Practice Patterns And Clinical Reasoning Strategies Of
Australian And American Occupational Therapists
Supervisor: None
Co-Investigator(s): Sue Doyle, Dr Sally Bennett, Sally Hatch
Department(s): School of Health and Rehabilitation Sciences, Division
of Occupational Therapy
Project Number: 2010000150
Granting Agency/Degree:
Duration: 31st March 2011

Comments:
Expedited review on the basis that data collection is by means of an anonymous
survey.

Name of responsible Committee:-
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the National Statement on
Ethical Conduct in Human Research and complies with the regulations governing
experimentation on humans.

Name of Ethics Committee representative:-
Dr Jack Broerse
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Date 16/02/10 Signature

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Appendix 3: Copy of Participant Information Sheet and Questionnaire for Study
Three

THE UNIVERSITY
OF QUEENSLAND

School of Health and Rehabilitation Sciences
Division of Occupational Therapy
HEAD OF DIVISION
Dr Sylvia Rodgers

Project Title: Sensory retraining of the upper limb post stroke: practice patterns of Australian and American occupational therapists.

Lay Title: Treatment approaches and clinical reasoning used by occupational therapists within Australia and America to improve the sensation of affected upper limbs in stroke clients.

Investigators:
Dr Louise Gustafsson, Lecturer
Mrs Susan Leicht Doyle, Doctor of Philosophy Student
Dr Sally Bennett, Lecturer
Miss Sally Hatch, Master of Occupational Therapy Student,

Division of Occupational Therapy
School of Health and Rehabilitation Sciences, The University of Queensland
St Lucia, 4072 Queensland, AUSTRALIA

What is the purpose of the study?
With the growth of research evidence regarding sensory retraining, we are interested in exploring the current clinical practice and reasoning of Australian and American occupational therapists in the field of stroke care and rehabilitation. The specific aim is to determine whether clinical practice reflects the recommendations of the Guidelines for Rehabilitation and Recovery, published by the National Stroke Foundation (NSF) and identify the key components of therapist reasoning strategies.

By identifying the most widely used and accepted post-stroke sensory retraining strategies within Australia and the USA, the proposed research study may facilitate more effective treatment interventions, or guide the development of new clinical guidelines.

How can I participate?
Your participation in this research is completely voluntary and involves the completion of a questionnaire, which should take approximately 15-20 minutes. The questionnaire can be completed online at [insert link]. Completing the questionnaire online requires you to mouse click on one or more responses. Once you have completed the questionnaire, please press the submit button and your responses will be filed for us. The written questionnaire can be completed by choosing or writing your answers as directed.

If you are in Australia and unable to complete the survey online, please complete the attached questionnaire. This may be returned to Louise Gustafsson by email (l.gustafsson@uq.edu.au), fax ((07) 33651622) or post - Division of Occupational Therapy, University of Queensland St Lucia 4072.

If you are in the USA and unable to complete the survey online, please mail the completed questionnaire to: Sue Doyle MS OTR/L, P.O. Box 822873 Vancouver, WA 98682. If you have any questions please email sue10@hotmail.com or phone (360) 903 3720.
Please note that the completion of the online survey or return of the questionnaire by post to the research investigator implies that you have provided informed consent.

How will my involvement in this research be of benefit?
Although you will not directly benefit from the specified research study, outcomes are predicted to provide benefits to both occupational therapists and their prospective clients in the area of post-stroke rehabilitation.

Are there any risks involved?
No. This questionnaire can be completed in the privacy of your own home, and does not have the potential to cause any physical or psychological stress or discomfort.

Will my confidentiality be protected?
Yes. The questionnaire is completely anonymous and therefore your data can’t be identified. Any identifying information returned with the questionnaire will be immediately destroyed. Data will be stored in a locked filing cabinet in a secure office at The University of Queensland or password protected computer file.

Will I receive feedback once the study is completed?
Upon request, research investigators will release a report of the study’s findings once data has been appropriately analysed. If you are interested in receiving a report, please contact the research investigators listed at the top of this information sheet.

Who can I contact if I need support or have further questions?
Should you have any questions or comments about this study please contact either Louise Gustafsson (Australia) on 07 3365 2926 or Sue Doyle (America) on (360) 903 3720. This study adheres to the Guidelines of the ethical review process of The University of Queensland. Whilst you are free to discuss your participation in this study with project staff (contactable on +61 7 33651622), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924 or by email on m-tse@research.uq.edu.au.

Sincere thanks for your interest in this research study.
Occupational Therapy Practice  
People with sensory impairment following stroke

We are interested in understanding more about the current practice of occupational therapists working with people with sensory impairments following stroke.

We appreciate your time in completing this questionnaire.

<table>
<thead>
<tr>
<th>What to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Please complete the questionnaire which takes about 20 minutes either by completing the attached written copy included in this package or by going online to: <a href="http://www.surveymonkey.com/s/YCW9RD3">http://www.surveymonkey.com/s/YCW9RD3</a></td>
</tr>
<tr>
<td>- Please ensure that questions on each side of the pages have been answered.</td>
</tr>
<tr>
<td>- Please either submit the questionnaire online, fax or post the completed questionnaire in the envelope provided to:</td>
</tr>
</tbody>
</table>

**In Australia:**  
Dr Louise Gustafsson  
Division of Occupational Therapy  
School of Health and Rehabilitation Sciences  
The University of Queensland  
Brisbane, Qld, 4072  
Ph: (07) 3365 2926 | Fax: (07) 3365 1622 | Email: l.gustafsson@uq.edu.au

**In United States of America:**  
Sue Doyle MS OTR/L  
PO Box 822875  
Vancouver WA 98604  
Ph: (360) 903 3720 | Email: sue10@hotmail.com

Please complete the questionnaire by: **14th March, 2010**

All information supplied is anonymous. Individual therapists cannot be identified and will not be able to be identified in any publications arising from this survey.

Thank you very much for your assistance.
A Survey of Occupational Therapy Practice
For people with sensory impairment following stroke

1. Please circle your highest occupational therapy educational qualification.
   1. Diploma
   2. Bachelor Degree
   3. Entry Level Masters
   4. Entry level Clinical Doctorate
   5. Postgraduate Coursework (Certificate/Diploma/Masters)
   6. Postgraduate Research Degree (Masters/PhD)
   7. Other

2. Please circle the option that best reflects the area where you practice.
   1. Metropolitan region (pop'n >150,000)
   2. Regional /Rural region (pop'n 10,000-99,000)
   3. Remote region (pop'n <10,000)
   4. Other

3. Please indicate which state/territory you work in:

4. Please indicate how many years you have practiced as an occupational therapist: ________ Years

5. Please indicate how many years you have worked with stroke patients: ____________ Years

6. Please circle the option that reflects your primary practice setting.
   1. Acute Hospital- inpatients
   2. Outpatient Services or clinic
   3. Inpatient rehabilitation service
   4. Community agency e.g. Blue Care
   5. Community health centre or Home Health Agency
   6. Day therapy centre
   7. Private practice
   8. High care facilities/ skilled nursing homes
   9. Retirement village/supported residential facility/ hostel/ Assisted Living Facilities
   10. Mixed (please specify)________________________
   ➢ Other (please specify)__________________________

7. Please indicate the percentage of your clinical caseload that is comprised of stroke patients. _______

8. Please indicate how many people with stroke you personally work with on average each week. ________

9. Please circle the option that best reflects the average time since stroke for your client population.
   1. 0 – 6 weeks
   2. 6 weeks – 3 mos
   3. 3 mos – 6 mos
   4. 6 mos – 1 year
   5. > 1 year

The following questions ask about your experience with people with sensory impairments of the upper limb following stroke.

10. Please indicate how frequently, in your practice, your client’s upper limb functional use after stroke impacted by sensory impairments. (Circle the most relevant number)

<table>
<thead>
<tr>
<th>Always</th>
<th>Often</th>
<th>Half of the time</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

(Please continue on the next page.)
11. Please indicate **how frequently** you assess sensation when treating a patient who has had a stroke. (Circle the **most relevant number in each row**)

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Often</th>
<th>Half of the time</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Assessment</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Reassessment</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Discharge</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

12. Please list the reason(s) you **complete** a sensory assessment of the upper limb with a stroke patient.

________________________________________________________

13. Please list the **most frequent** reasons you would have for not completing a sensory assessment of the upper limb of a stroke patient.

________________________________________________________

14. Please list the sensory assessments you **most frequently** use.

________________________________________________________

15. Please indicate **how frequently** you include interventions that specifically target sensory impairments when implementing an intervention plan for a patient who has had a stroke. (Circle the **most relevant number**)

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Often</th>
<th>Half of the time</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

16. If you **answered 3, 2, or 1** in Question 15, please indicate the reasons you do **not include, or only sometimes use** specific interventions aimed at sensory re-education of the upper limb after stroke in a plan of care. (Choose all that apply)

   a. There is no evidence that any interventions are effective
   b. Unaware of specific interventions to use
   c. There is no time to address this issue
   d. Sensory re-education is adequately covered by intervention strategies for motor impairments
   e. Clients need to focus on motor return prior to sensory return
   f. Not the client’s priority
   g. Other

17. Please list the 3 specific intervention strategies that you **most frequently** use to address sensor impairments in the upper limb after stroke.

________________________________________________________

18. Please indicate how many intervention sessions would you **typically** utilize for a person with sensory impairments. (Circle one response):

   1. One
   2. 2-3
   3. 4-6
   4. 7-10
   5. Other (please indicate how many)

19. Please indicate **how frequently** you provide education to clients with sensory impairments that is specifically related to their sensory impairments. (Circle the **most relevant number**)

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Often</th>
<th>Half of the time</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
20. Please list the components you frequently include in a clients' education program directly related to their sensory impairment.


21. Please indicate how frequently each of these factors impact on your decision whether to improve sensation versus compensate for sensory impairment in clients after stroke. (Circle the most relevant number for each option)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Almost Never</th>
<th>Some times</th>
<th>Half the time</th>
<th>Often</th>
<th>Most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since stroke</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Age of client</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Cognitive status of client</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Time available</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Stroke clinical guidelines</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Familiarity with intervention techniques</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Effectiveness of intervention techniques</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Dominant vs non-dominant arm</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Client goals or motivation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Level of motor return</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Severity of the sensory deficit</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

22. Please indicate how frequently each of the following factors impacts your choice of intervention with a specific client. (Rank all of these reasons in order of most frequently used (1) to least frequently used (11).)

- Personal prior experience with similar clients
- Results of the assessments used
- Techniques learned while attending continuing education course
- Consultation with other therapists
- Expert opinion
- Knowledge from entry level occupational therapy education
- Reading an article in a practice magazine
- Reading a research article
- Searching on the internet
- Effects seen when trialled with that client
- Other (please specify)

23. Please indicate the sources of information that you are aware of that support the use of sensory interventions after stroke. (Circle all that apply)

1. None
2. Personal Observation
3. Colleagues
4. Expert opinion
5. Practice theories or models
6. Case studies
7. Pre Post studies (no control group)
8. Literature reviews
9. Clinical trials (with control group)
10. Systematic reviews
11. Clinical guidelines
12. Continuing education courses

Other: 
(Please continue on the next page.)
24. Please indicate what you consider to be the most important outcome measure to determine the effect of interventions for a client who has sensory impairment after stroke. (Circle one)
   1. Improved sensation as measured on your assessments
   2. Improved motor control in the arm
   3. Improved grip in the hand
   4. Increased safety and awareness
   5. Improved functional use of the hemiparetic arm
   6. Other: Please Specify ___________

25. Please indicate if you consider that you are up to date with current research evidence about the effectiveness of sensory interventions for people with sensory impairments following stroke.
   1. Yes
   2. No

26. Please indicate how effective you perceive sensory interventions for clients after stroke to be. (Circle the most relevant number)

<table>
<thead>
<tr>
<th>Very effective</th>
<th>Moderately effective</th>
<th>Effective Half of the time</th>
<th>Only a little bit effective</th>
<th>Never effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

27. Please rank the following methods based on how beneficial they would be to increase your use of interventions for sensory impairment.
   (Rank these in order of most beneficial (1) to least beneficial (7))
   _ Continuing education workshop
   _ Written protocols or clinical practice guidelines
   _ Expert spending time at your practice setting
   _ Improved research that demonstrates the effectiveness of specific interventions at improving sensation
   _ More time in your practice
   _ Other: ___________

28. Please list topics you would be most interested in receiving training for related to sensory impairment of the upper limb after stroke.

29. Please circle the main barriers impacting your ability to utilize sensory interventions with your clients following stroke? (Circle all that apply)
   1. Costs too much to deliver
   2. Role restrictions designated by facility (please explain below)
   3. Distance you or client needs to travel
   4. Your lack of knowledge/skills in this area
   5. Lack of time
   6. Insufficient evidence to support it
   7. Client’s length of stay too short
   8. Lack of therapy resources
   9. Not a priority for the client
   10. Not a priority in the treatment plan
   11. Other. Please specify ___________

   Explanation: ___________

30. Please comment on the delivery of sensory assessment or interventions for this client group.

   ___________

(Please continue on the next page.)
31. Please circle the number that best indicates the extent to which you agree with the following statements when making decisions about sensory interventions for your clients:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I make decisions based mainly on my previous experiences</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I don’t make judgements about my choice of intervention until I have sufficient data</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I think in terms of comparing and contrasting information about a client’s problem and proposed solutions to them.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I ask for the client’s viewpoint</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>When there is conflicting information about a clinical problem I make assumptions underlying the different views</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I use clinical protocols for most of my interventions</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>If there is good research evidence for a particular intervention but is my experience it hasn’t worked, I would not use it</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>If there is no clear research supporting the effect of a particular intervention, and my experience suggests it does not work, but my client wants to receive that intervention, I would provide the intervention anyway explaining my concerns.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I am confident judging the value of different types of information when making a decision about whether to use an intervention and how to use it.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I feel confident in explaining my reasoning about why I think an intervention might (or might not be) good to use with a particular client.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I regularly think back over specific client sessions and ask myself how well did that work and what could I do differently.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I feel confident about my ability to find information about new treatments for a client with sensory impairments.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Thank you for your assistance with this research.
Appendix 4: Ethics Approval Study Four

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**THE UNIVERSITY OF QUEENSLAND**
Institutional Approval Form For Experiments On Humans Including Behavioural Research

---

**Chief Investigator:** Ms Susan Doyle

**Project Title:** Impairment Of The Upper Limb After Stroke: The Survivors' Experience

**Supervisor:** Dr Sally Bennett

**Co-Investigator(s):** Dr Brian J. Dudgeon

**Department(s):** Occupational Therapy, School of Health and Rehabilitation Sciences

**Project Number:** 2010000589

**Granting Agency/Degree:** Phd

**Duration:** 30th June 2011

---

**Comments:**

---

**Name of responsible Committee:-**
Medical Research Ethics Committee
This project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research and complies with the regulations governing experimentation on humans.

**Name of Ethics Committee representative:-**
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

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Date: 15 - 7 - 2011
Signature: [Signature]

---
Ms Sue Doyle  
c/o Dr Sally Bennett  
Division of Occupational Therapy  
School of Health and Rehabilitation Sciences  
The University of Queensland, Qld. 4072.

August 10th 2011

Dear Ms Doyle,

Re: Ethics application approval #2011SHRS-OT004

I am pleased to advise that your project ‘The impact of an educational program on therapists knowledge, confidence in clinical decision making skills, and shared decision making in an area of uncertainty: Sensory impairments after stroke’ (#2011SHRS-OT004) has been approved.

Yours sincerely,

[Signature]

Laura Desha PhD BOccThy(Hons)  
Senior Lecturer and Research Committee Representative  
Division of Occupational Therapy  
School of Health & Rehabilitation Sciences  
The University of Queensland 4072
Appendix 6: Study Five Elicitation Questionnaire

Upper Limb Post-stroke Sensory Impairment

Attitudes and Beliefs Questionnaire

Instructions: Please take a few minutes to tell us what you think about the particular assessment and intervention issues below for people who have Upper Limb Post-Stroke Sensory Impairments (ULPSSI). There are no right or wrong responses; we are merely interested in your personal opinions. In response to the questions below, please list the thoughts that come immediately to mind. Write each thought on a separate line.

Sensory Assessments:

1. What do you see as the advantages of using standardized or function based assessments (eg Nottingham Sensory Assessment) with people who have ULPSSI when appropriate?

2. What do you see as the disadvantages of using standardized and/or function based assessments (eg Nottingham Sensory Assessment) with people who have ULPSSI when appropriate?

3. Please list the types of individuals or groups who would approve or think you should use standardized and/or function based assessments (eg Nottingham Sensory Assessment) with people who have ULPSSI when appropriate.

4. Please list the types of individuals or groups who would disapprove or think you should not use standardized and/or function based assessments (eg Nottingham Sensory Assessment) people who have ULPSSI when appropriate.

5. Please list any factors or circumstances that would make it easy or enable you to use standardized function based assessments (eg Nottingham Sensory Assessment) with people who have ULPSSI when appropriate.

6. Please list any factors or circumstances that would make it difficult or prevent you from using standardized function based assessments with people who have ULPSSI when appropriate.

7. Are there any other issues that come to mind when you think about using standardized function based sensory assessment for ULPSSI?
**Sensory Interventions:**

8. What do you see as the **advantages** of using graded sensory retraining interventions for specific ULPSSI when appropriate (in addition to compensatory techniques and education)?

9. What do you see as the **disadvantages** of using graded sensory retraining interventions for specific ULPSSI when appropriate (in addition to compensatory techniques and education)?

10. Please list the types of individuals or groups who **would approve or think you should use** using graded sensory retraining interventions when appropriate (in addition to compensatory techniques and education).

11. Please list the types of individuals or groups who **would disapprove or think you should not use** graded sensory retraining interventions when appropriate (in addition to compensatory techniques and education).

12. Please list any factors or circumstances that would **make it easy or enable you** to use graded sensory retraining interventions when appropriate (in addition to compensatory techniques and education).

13. Please list any factors or circumstances that would **make it difficult or prevent you** from using graded sensory retraining interventions when appropriate (in addition to compensatory techniques and education).

14. Are there any other issues that come to mind when you think about using graded sensory retraining interventions for ULPSSI?

**Client involvement:**

15. What do you see as the **advantages** of involving clients in making decisions about interventions for ULPSSI if they have the cognitive capacity/interest to be involved?

16. What do you see as the **disadvantages** of involving clients in making decisions about interventions for ULPSSI if they have the cognitive capacity/interest to be involved?
17. Please list the types of individuals or groups who would approve or think you should involve clients in making decisions about interventions for ULPSSI if they have the cognitive capacity/interest to be involved?

18. Please list the types of individuals or groups who would disapprove or think you should not involve clients in making decisions about interventions for ULPSSI if they have the cognitive capacity/interest to be involved.

19. Please list any factors or circumstances that would make it easy or enable you to involve clients in making decisions about interventions for sensory impairments if they have the cognitive capacity/interest to be involved.

20. Please list any factors or circumstances that would make it difficult or prevent you from involving clients in making decisions about interventions for sensory impairments if they have the cognitive capacity/interest to be involved.

21. Are there any other issues that come to mind when you think about involving clients in decisions about interventions for ULPSSI?

Updating your knowledge:

22. What do you see as the advantages of updating your knowledge of current research about the effects of interventions for ULPSSI on a regular basis (e.g., once a month)?

23. What do you see as the disadvantages of updating your knowledge of current research about the effects of interventions for ULPSSI on a regular basis (e.g., once a month)?

24. Please list the types of individuals or groups who would approve or think you should update your knowledge of current research about the effects of interventions for sensory impairment post stroke on a regular basis (e.g., once a month).

25. Please list the types of individuals or groups who would disapprove or think you should not update your knowledge of current research about the effects of interventions for sensory impairment post stroke on a regular basis (e.g., once a month).

26. Please list any factors or circumstances that would make it easy or enable you to update your knowledge of current research about the effects of interventions for sensory impairment post stroke on a regular basis (e.g., once a month).
27. Please list any factors or circumstances that would make it difficult or prevent you from updating your knowledge of current research about the effects of interventions for sensory impairment post stroke on a regular basis (e.g. once a month).

28. Are there any other issues that come to mind when you think about updating your knowledge of current research about the effects of interventions for ULPSSI?
Appendix 7: Study Five Pre Workshop questionnaire

Sensory Impairment after stroke

This questionnaire is anonymous and will not be linked to any identifying information. Please complete this questionnaire prior to the commencement of the course and place in the box at the back of the room.

Demographic Information
1. Please give your age in years: _______ years

2. Gender (check one): ___ Male ___ Female

3. Please circle your highest occupational therapy educational qualification.
   1. Diploma
   2. Bachelor Degree
   3. Entry Level Masters
   4. Entry level Clinical Doctorate
   5. Postgraduate Coursework (Certificate/Diploma/Masters)
   6. Postgraduate Research Degree (Masters/PhD)
   7. Other

4. Please circle the option that best reflects the area where you practice.
   1. Metropolitan region (pop n>100,000)
   2. Regional /Rural region (pop n 10,000-99,000)
   3. Remote region (pop n <10,000)
   4. Other____________________

5. Please indicate how many years you have practiced as an occupational therapist. _______ Years

6. Please indicate how many years you have worked with stroke patients. ______________________Years

7. Please circle the option that reflects your primary practice setting.
   1. Acute Hospital- inpatients
   2. Outpatient Services or clinic
   3. Inpatient rehabilitation service
   4. Community agency e.g. Blue Care
   5. Community health centre or Home Health Agency
   6. Day therapy centre
   7. Private practice
   8. High care facilities/ skilled nursing homes
   9. Retirement village/ supported residential facility/ hostel/ Assisted Living Facilities
   10. Mixed (please specify) ______________________
   11. Other (please specify) ______________________

8. Please indicate the percentage of your clinical caseload that is comprised of stroke patients. ______% 

9. Please indicate how many people with stroke you personally work with on average each week. _______

10. Please circle the option that best reflects the average time since stroke for your client population.
    1. 0 - 6 weeks
    2. >6 weeks - 3 mos
    3. >3 mos - 6 mos
    4. >6 mos - 1 year
    5. > 1 year

11. Have you previously attended a course or workshop specifically on sensory impairment after stroke?  
    Yes ___ No ___

(Please continue on the next page.)
12. The following questions ask about your experience with people with sensory impairments of the upper limb following stroke.

<table>
<thead>
<tr>
<th>Please indicate how often the following applies:</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The majority of my clients functional use of the upper limb after stroke has been impacted by sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I frequently use sensory assessments when I complete my initial evaluation with stroke patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I frequently use sensory assessments when completing my discharge evaluation of a stroke patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I frequently use interventions specifically targeted to remediate sensory impairments in the upper limb for stroke patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I usually provide information to my clients about interventions for their sensory impairment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I frequently use interventions specifically targeted to compensate for sensory impairments in the upper limb for stroke patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Prior to finishing rehabilitation with my client I usually confirm they know what to do in future to either continue working on sensory impairment issues or know how to get further help for this</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I usually ask my clients what their preferences are about being involved in decisions about interventions that might be used for their sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I read or look for research articles related to the management of sensory impairments after stroke regularly (ie. every month or two)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have reviewed electronic research databases regularly in the past 6 months to help inform my practice about sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

13. Please circle a number to indicate the degree to which you agree with each of the following statements in relationship to sensory impairments after stroke

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel confident treating patients with sensory impairments after stroke</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am confident deciding on the best assessment for sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am comfortable explaining how the results of the sensory assessments relate to the functional use of the arm</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am sure about the options for general intervention approaches available for use with people with sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am confident explaining the reasons and benefits of different options for sensory interventions to my patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am confident choosing specific interventions that are the most effective for remediation of sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall I think that providing interventions for sensory impairments is beneficial</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall I think that providing interventions for sensory impairments is good practice</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>It is expected of me that I provide interventions for people with sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Other therapists think I should provide interventions for people with sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel under pressure to provide interventions for people with sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am confident reading or looking for research articles related to intervention for sensory impairments after stroke</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
14. Please indicate if you consider that you are up to date with current research evidence about the effectiveness of sensory interventions for people with sensory impairments following stroke.

Not at all | Not very | Uncertain | Somewhat | Definitely
--- | --- | --- | --- | ---
1 | 2 | 3 | 4 | 5

15. Please indicate how effective you perceive sensory interventions for clients after stroke to be. (Circle the most relevant number)

Very effective | Moderately effective | Effective Half of the time | Only a little bit effective | Never effective
--- | --- | --- | --- | ---
5 | 4 | 3 | 2 | 1

**Knowledge Questionnaire**

16. Sensory Impairment of the contralateral upper limb occurs in what percentage of patients after stroke?

a. Approximately 50%
b. Less than 25%
c. Up to 94%
d. Approximately 37%

17. Sensory impairments have been observed in what percentage of the ipsilateral or “unaffected” arm?

a. The ipsilateral arm is not affected by the stroke
b. Less than 10%
c. Up to 26%
d. Up to 51%

18. Which of the following describes the type of sensory impairment seen in the upper limb after stroke?

a. Changes in sensory threshold
b. Altered nature of the sensation
c. Delayed perception
d. All of the above

19. Which order should you train sensory skills in?

a. Perception, discrimination, detection
b. Detection, discrimination, perception
c. Discrimination, perception, detection
d. Detection, perception, discrimination

(Please continue on the next page)
20. Which of the following interventions has been shown by research to possibly be effective in retraining detection of light touch?
   a. Weight bearing
   b. Rice bucket activities
   c. Electrical Stimulation
   d. Mirror Therapy

21. Which intervention has been shown by research to possibly be effective to increase the rate of sensory return?
   a. Electrical stimulation
   b. Thermal stimulation
   c. Weight bearing
   d. Active or Passive Movement

22. Which of the following interventions has been shown by the research to possibly be effective in improving sensory discrimination?
   a. Neuro-mobilizations
   b. Electrical stimulation
   c. Active or passive movement
   d. Weight bearing

23. Sensory bombardment or exposure has been demonstrated to be an effective intervention for sensory impairment after stroke.
   a. Agree
   b. Disagree

24. Weight bearing has been supported by the research as being an effective intervention tool for proprioceptive retraining.
   a. Agree
   b. Disagree

25. There is some evidence that sensory discrimination after stroke can be improved by which of the following:
   a. Weight bearing
   b. Rice/Bean bucket tasks
   c. Graded sensory retraining program
   d. Electrical stimulation

(Please continue on the next page)
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I question how, what and why I do things in practice</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I ask myself and others questions as a way of learning</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I don’t make judgements until I have sufficient data</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Prior to acting, I seek various solutions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Regarding the outcome of proposed interventions, I try to keep an open mind</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I think in terms of comparing and contrasting information about a client’s problems and proposed solutions to them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I look to theory for understanding a client’s problems and proposed solutions to them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I look to Frames of reference for planning my intervention strategy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I try to understand clinical problems by using a variety of frames of reference</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>When there is conflicting information about a clinical problem I identify assumptions underlying the differing views</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>When planning intervention strategies, I ask “What if” of a variety of options</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I ask for colleagues ideas and viewpoints</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I ask for the viewpoints of clients’ family members</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I can function with uncertainty</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I regularly hypothesise about the reasons for my clients problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I must validate clinical hypotheses through my own experience</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I clearly identify the clinical problems before planning the intervention</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I anticipate the sequence of event likely to result from planned intervention</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Regarding a particular intervention with a particular client I determine whether it worked</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I use clinical protocols for most of my treatment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I make decisions about treatment based on my experience</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I use theory to understand my intervention strategies</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

(Please continue on the next page.)
## 27. Patient Practitioner Orientation Scale (Adapted)

<table>
<thead>
<tr>
<th>Description</th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The therapist is the one who decides what gets addressed during a therapy session</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Although health care is less personal these days, this is a small price to pay for medical advances.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>The most important part of the standard therapy visit is the physical evaluation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>It is often best for patients if they do not have a full explanation of their deficits.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Patients should rely on their therapists’ knowledge and not try to find out about their conditions on their own.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>When therapists ask a lot of questions about a patient’s background, they are prying too much into personal matters.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>If therapists are truly good at evaluation and treatment, the way they relate to patients is not that important.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Many patients continue asking questions even though they are not learning anything new.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Patients should be treated as if they were partners with the therapist, equal in power and status.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Patients generally want reassurance rather than information about their impairments.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>If a therapist’s primary tools are being open and warm, the therapist will not have a lot of success.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>When patients disagree with their therapist, this is a sign that the therapist does not have the patient’s respect and trust.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>A treatment plan cannot succeed if it is in conflict with a patient’s lifestyle or values.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Most patients want to get in and out of the therapy clinic as quickly as possible.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>The patient must always be aware that the therapist is in charge.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>It is not that important to know a patient’s culture and background in order to treat the person’s illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Humor is a major ingredient in the therapist’s treatment of the patient.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>When patients look up medical information on their own, this usually confuses more than it helps.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

THANK YOU VERY MUCH       YOUR PARTICIPATION IS IMPORTANT
Appendix 8: Study Five Post Workshop questionnaire

The same measures were used as in the Appendix 7 Pre Workshop Questionnaire with the following changes.

1. Demographic data was not collected at the end of the workshop.
2. The wording on the second set of questions was changed as follows to measure intended behaviours. These changes are included below.
Sensory Impairment after Stroke

Post-Course Questionnaire

1. Please answer the following questions about how you intend to practice now that you have completed this course.

<table>
<thead>
<tr>
<th>Please indicate how often the following applies:</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The majority of my clients functional use of the upper limb after stroke has been impacted by sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to frequently use sensory assessments when I complete my initial evaluation with stroke patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to frequently use sensory assessments when completing my discharge evaluation of a stroke patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to frequently use interventions specifically targeted to remediate sensory impairments in the upper limb for stroke patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to usually provide information to my clients about interventions for their sensory impairment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to frequently use interventions specifically targeted to compensate for sensory impairments in the upper limb for stroke patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Prior to finishing rehabilitation with my client I intend to usually confirm they know what to do in future to either continue working on sensory impairment issues or know how to get further help for this</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to ask my clients what their preferences are about being involved in decisions about interventions that might be used for their sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to read or look for research articles related to sensory impairments after stroke regularly (ie every month or two)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I intend to reviewed electronic databases regularly in the next 6 months to help inform my practice about sensory impairments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. Please indicate if you consider that you are up to date with current research evidence about the effectiveness of sensory interventions for people with sensory impairments following stroke.

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Not very</th>
<th>Uncertain</th>
<th>Somewhat</th>
<th>Definitely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

(Please continue over the page. Thank you)
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Jun 03, 2012

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