Community-Based Stroke Information for Clients with Stroke and Their Carers: Is There Congruency Between Actual and Recommended Practice?

Sally Eames, Tammy Hoffmann, Kryss McKenna, and Linda Worrall

Purpose: Information provision is an integral part of poststroke care, and there is a need to identify how to provide it most effectively. Intervention details, such as content, delivery style, format, and timing, are infrequently reported in the literature. This project describes in detail the provision of information to clients with stroke and their carers by community services in Brisbane, Australia, and compares these to current recommendations in the literature. Method: Fifty-seven metropolitan-based community services were surveyed regarding the content, delivery style, format, and timing of information available to clients with stroke and their carers, using a telephone-administered questionnaire designed for this study. Results: Services provided information using a range of formats and delivery styles. The most frequently provided topics were information on services and benefits available and practical management strategies. Less than 75% of services provided written information to most of their clients and/or carers. Less than 40% of services considered client and carer input when designing written information materials. Conclusion: Community services surveyed in this study demonstrated congruency with some, but not all, of the current content, format, and delivery style recommendations in the literature. Areas for improvement are discussed. Key words: cerebrovascular accident, consumer health information, health education, patient education, stroke, teaching

Stroke is a leading cause of death and disability in the Western world, with up to two thirds of stroke survivors living with some level of disability. The provision of information is recognised as a key feature of poststroke management for clients with stroke, their carers, and their families and it can improve client and carer knowledge, reduce client depression, and increase some aspects of client satisfaction. However, details of postdischarge information provision for community-dwelling stroke clients and their carers have received little attention in the literature. This article begins with a discussion of the recommendations from the literature regarding the content, format, delivery style, and timing components of information provision about stroke. Where stroke-specific recommendations do not exist in the literature, general health education recommendations are provided. A study that explored the way in which services provide information to community-based clients with stroke and/or their carers is then described and the literature recommendations are subsequently compared to the results of the study.

Content of Information Provision

As clients with stroke transition from inpatient care to the early post hospital-discharge phase, their need, and that of their carers, for clinical...
information (such as the causes, risk factors, and treatment of stroke) is often surpassed by their need for information regarding the consequences of stroke, practical management strategies, and available services and benefits.\textsuperscript{5–14} This mix of information needs typically continues into the chronic or community-based stage of living with the consequences of stroke.\textsuperscript{15–18} A fear of recurrence of stroke and the subsequent need for information regarding secondary prevention is particularly strong for community-based clients with stroke and their carers.\textsuperscript{10,11,14,15,17,18} Therefore, information about a wide range of topics, including clinical information but with a focus on the consequences of stroke, practical management strategies, available services and benefits, and secondary prevention, should be available to people living in the community after stroke. It is crucial to regularly assess clients’ and carers’ information needs\textsuperscript{10,19–21} and to tailor the information provision to these needs.\textsuperscript{21–26}

**Format of Information Provision**

Format variables to consider when providing information include the number of people present, the setting where the information is provided, and the media used. The presence of carers or family members when clients are receiving information is important\textsuperscript{6,14} as it provides the carers with an opportunity to become informed and may also enable them to assist clients with decision making and recalling information.\textsuperscript{26} Depending on the content of the information being provided, small groups can be more time-efficient than one-on-one sessions and have the potential advantages of encouraging discussion and providing peer support.\textsuperscript{21,27} However, group sessions may limit the extent to which participants’ individualised needs are able to be addressed,\textsuperscript{26,27} which is an important requirement for effective information provision.\textsuperscript{21,28} This suggests that information sessions should be conducted, where possible, with both the client and carer together or in small groups, but one-on-one sessions with the health professional should be offered as appropriate for the content being discussed or to accommodate variation in clients’ and carers’ preferences.\textsuperscript{29,30}

Studies of educational interventions for people living in the community after stroke have evaluated the effectiveness of providing the information in participants’ homes,\textsuperscript{31,32} at community-based centres,\textsuperscript{32–36} and over the telephone.\textsuperscript{37} Even though there can be some restrictions to providing information via the telephone (such as limited use of nonverbal cues), clients with stroke and their carers have reported a desire to receive\textsuperscript{29} and satisfaction with receiving\textsuperscript{38} telephone support when it is a supplement to or follow-up component of face-to-face information provision. In-home information provision may be more contextually relevant\textsuperscript{21} and can overcome travel and transport barriers that clients with stroke can have, although it can be time-consuming and resource intensive for health professionals. Currently one setting has not been identified as superior to another when providing clients and carers with information. Therefore, flexibility in providing information in the setting or combination of settings that best meets the needs of clients and their carers is important.\textsuperscript{21,30–41}

Media options for providing information include verbal (either face to face or over the telephone), written, audiovisual, or computer-based materials. Compared with verbal provision, written material can reduce the burden on health professionals and resources and reach large numbers of clients.\textsuperscript{42} Although the provision of only written information has not been found to be an effective means of informing clients with stroke and their carers,\textsuperscript{43} it is strongly recommended as a supplement to information provided verbally\textsuperscript{6,14,21,26,44–46} and is preferred by clients and carers.\textsuperscript{9,10,12,14,47,48} However, written materials must be designed appropriately if they are to be of use to clients and their carers. Detailed recommendations for the design of written health information materials have been discussed elsewhere.\textsuperscript{26,47–54} In summary, modified layout features (such as appropriate font size, increased use of white space, illustrations, and bullet points) should match clients’ reading abilities and take into account the possible effect of stroke-related impairments such as those in cognition, vision, and communication. Tailoring written material can enhance its effect\textsuperscript{55} and has resulted in some positive outcomes when used with people who have had a stroke.\textsuperscript{56,57}

Although many clients with stroke and their carers may prefer to receive information via verbal
or written methods, rather than through alternative media such as audiovisual, computer-based, or online materials,\(^9,14\) there are circumstances where alternative media can be useful. For example, the use of audiovisual formats is often desired by people with complex communication needs\(^9\) or aphasia.\(^9\) Examples of alternative media used to provide information to clients with stroke and their carers include videos as part of group information sessions,\(^60\) stroke-related Web sites,\(^61\) telehealth,\(^62\) and tailored computer programs.\(^63\) However, the effectiveness of these alternative media has not yet been conclusively demonstrated.

**Delivery Styles Used in Information Provision**

There are various ways in which clients and carers can be provided with information, including didactic or lecture-style, a combination of written and verbal information, interactive discussion, demonstration and practice of skills, role playing, goal setting, and problem solving.\(^19,26,45,64\) The use of an interactive style and demonstration and practice are recommended in preference to a didactic style to maximise the comprehension and retention of information.\(^21,26–28,65,66\) However, interactive styles can be more time-intensive.\(^19,26\)

Often accessed through a group setting, peer support is another way of sharing information\(^21,23,39,67,68\) and has been shown to have benefits for some clients with stroke and their carers.\(^14,22,30,31,69\) Involving clients with stroke and their carers in goal setting is recommended\(^5,21,28,39\) but this process can be complex and needs to be in collaboration with the treating health professionals.\(^70,71\) Problem-solving training is also recommended in general health education literature\(^21,39,67,72\) but has had inconclusive results when used with stroke populations.\(^73,74\) Role playing can provide clients with the opportunity to practise new skills and develop self-efficacy,\(^19,21,26\) but it tends to be used in combination with other teaching styles, for example, as a part of a self-management program. These programs have resulted in positive outcomes in nonstroke populations,\(^44,75,76\) and there is promising preliminary research into the use of self-management programs with people with stroke.\(^77,78\)

**Timing and Frequency of Information Provision**

There is clear evidence in the literature that health information should be repeated and reinforced\(^8,9,39,79,80\) As clients with stroke and their carers can continue to need information years after a stroke,\(^15,18,41\) there is strong support for ensuring that information provision is available to community-based clients.

In summary, it is recommended from the literature that information for clients with stroke and their carers be provided across a range of topics and formats, using well-designed written information material to supplement verbal information, an interactive delivery style, demonstration and practice, goal setting, self-management, and reinforcement of information. The way in which community services in Brisbane, Australia, provide information to clients with stroke and/or their carers will now be compared to these recommendations.

**Method**

**Recruitment**

Community-based services (\(n = 119\)) from the greater area of Brisbane, Australia, were identified from government directories. Only services that provide direct interaction with the public, and those for which clients with stroke and/or their carers were eligible, were included. Services providing allied health services, nursing services, respite, domestic or practical support, or education and/or advice were included. Services solely providing transport, meals, home modifications or equipment, social-only or non-stroke-specific group support were excluded, as were interstate, national, and international-based services unless they had a locally based program.

In addition, snowball sampling was used. On completion of the questionnaire, participating service providers were asked to suggest other services in their area that they felt would be suitable for the researcher to contact. If eligible, these suggested services were approached.
Questionnaire

A telephone-administered questionnaire was designed for this study. The questionnaire used a multiple-response format and contained four sections: service demographics and details of verbal, written, and alternative methods of information provision. Service demographics included asking a representative from the services whether the services provided were stroke-specific, brain injury-specific, or general. The section on provision of verbal information asked the service representative to identify to whom and in what setting verbal information was provided in addition to the frequency, content, and delivery styles used. Questions about content were informed by previous research and used five categories: medical and/or background information of stroke, consequences and impact of stroke, practical tips and/or help for managing at home after discharge, services and benefits available, and healthier lifestyle issues and cardiovascular disease risk factors.

The third section asked the service representative to identify the frequency of provision and the proportion of clients and/or carers receiving written material in addition to its source. If written materials were produced by staff within the service, they were asked whether they considered the needs of the intended audience (such as visual ability, reading ability, potential aphasia, or other stroke-related impairments) or used consumer feedback or tailoring when designing the material. The fourth section asked the service representative to identify the type of alternative media used to provide information and the proportion of clients and/or carers accessing it. All questions that requested service representatives to indicate a proportion of clients and/or carers used a five-point Likert scale that ranged from “none or a few” to “nearly all or all.” A copy of the questionnaire is available from the authors on request.

Procedure

Service managers or other senior staff were contacted via telephone and asked whether clients with stroke and/or their carers were eligible for their service. Following a verbal explanation of the study, they were invited to participate in the research and offered a copy of the questionnaire. If agreeable, this was sent with an information sheet and consent form and a suitable time was made for the researcher to contact them to complete the telephone questionnaire. Responses were recorded by the researcher and were collated and reported in aggregate form using descriptive statistics. Ethical approval was received from the University of Queensland’s Behavioural and Social Sciences Ethical Review Committee.

Results

Participants

One hundred and nineteen services were initially identified, with an additional 27 services identified from snowball sampling. Of the total 146 services contacted, 22 were deemed ineligible, 67 declined or were unable to be contacted, and the questionnaire was completed on behalf of 57 services, resulting in a response rate of 46%. Details about the types of services that participated are provided in Table 1. Only 9 (15.8%) of the participating services were stroke- or brain injury-specific services.

Content of information provision

The topics that service providers addressed when providing verbal information to clients and carers are presented in Table 2.

Delivery style

Staff at the services used a range of teaching styles to impart verbal information, as shown in Table 3. An interactive style was used by the highest proportion of services, followed by a combination of verbal and written information.

Format of information provision

Face-to-face verbal information was offered to individuals by 80.7% of services, to groups by 78.9% of services, and to the client and carer together by 71.9% of services. Verbal information was provided in the service’s own
facility for 66.7% of services, in the client’s and/or carer’s home for 64.9%, over the telephone by 57.9%, and at another community facility for 31.6% of services. Most services used multiple settings to provide verbal information, but one service (a community-based allied health service) provided only individual face-to-face information and five services (one respite service, one stroke support group, and the three education programs) provided only group face-to-face information. No services provided information only by telephone.

### Written materials

The written materials provided were reported to be either stroke-specific (provided by 44.4% of the stroke- or brain injury-specific services and 10.4% of the general services), general (provided by none of the stroke- or brain injury-specific services and 37.5% of the general services), or a mixture of both stroke-specific and general information (provided by 55.6% of the stroke- or brain injury-specific services and 52.1% of the general services). Less than three quarters of all services (66.7% of the stroke- or brain injury-specific services and 72.9% of the general services) provided written information to “nearly all/all” or the “majority of” their clients and/or carers.

Three quarters (75.4%, n = 43) of services reported that they produced their own written materials to use with clients. Table 4 shows the proportion of services that considered various features when designing written materials.

Twenty-six services (45.6%) reported tailoring or individualising written information for their clients. Specific methods of tailoring included producing information for a particular client and

### Table 1. Details of the participating services

<table>
<thead>
<tr>
<th>Type of community-based service</th>
<th>Description</th>
<th>Number of services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public nursing services</td>
<td>Public: Coordinated by government body Nursing services with or without allied health and/or practical/domestic services</td>
<td>Stroke-or brain injury-specific (n=9) General (n=48)</td>
</tr>
<tr>
<td>Private nursing services</td>
<td>Private: Coordinated by nongovernment organisations (can access government funding) Nursing services with or without access to allied health and/or respite services</td>
<td>0 5</td>
</tr>
<tr>
<td>Rehabilitation day hospitals</td>
<td>Public (coordinated by government body) or private (coordinated by nongovernment body) Outpatient rehabilitation services including allied health, medical, and nursing</td>
<td>0 6</td>
</tr>
<tr>
<td>Community health centres</td>
<td>Public; covering defined geographical area Allied health and nursing services and practical/domestic assistance (also act as central intake for a wide range of other services/programs, e.g., child health, mental health)</td>
<td>0 7</td>
</tr>
<tr>
<td>Community-based allied health services</td>
<td>Public or private May include physiotherapy, occupational therapy, speech pathology, social work, dietetics, and/or podiatry</td>
<td>2 9</td>
</tr>
<tr>
<td>Respite-only services</td>
<td>Public or private Centre-based and/or in-home respite</td>
<td>0 6</td>
</tr>
<tr>
<td>Culturally specific services</td>
<td>Public or private Nursing, practical/domestic services targeting clients with a specific cultural background (with or without access to allied health)</td>
<td>0 5</td>
</tr>
<tr>
<td>Stroke support groups</td>
<td>Support groups for clients with stroke and carers; coordinated by the Stroke Association of Queensland</td>
<td>4 0</td>
</tr>
<tr>
<td>Independent or advisory services</td>
<td>For example: Stroke Association of Queensland</td>
<td>2 1</td>
</tr>
<tr>
<td>Educational programs</td>
<td>For example: Chronic Disease Self-Management program</td>
<td>1 2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>57</strong></td>
<td></td>
</tr>
</tbody>
</table>
“cut-and-pasting” or “tick-and-flicking” sections from generic written material. Five services (8.8%) described developing written material that targeted certain client and/or carer groups, such as particular cultural groups. Five services (8.8%) reported that they “tailored” their provision of written information by selecting various materials to provide to individual clients, for example, selecting only the information that is relevant to a particular client from a generic information package.

**Alternative media**

Thirty-two services (56% overall; 88.9% of the stroke- or brain injury-specific services and 50% of the general services) reported using media other than written or verbal formats to provide information. Details of these are shown in Table 5. Over half of the 32 services (50% of stroke- or brain injury-specific services and 58.3% of general services) reported provision to “only a few” or “a small proportion” of their clients and/or carers.

**Timing and frequency of information provision**

One third (33.3%) of services reported that they provided verbal information to clients and/or carers on a single occasion and 14% provided written material on a single occasion. Of the 29 services (50.9%) that reported providing regular verbal information, most of them reported providing it

<table>
<thead>
<tr>
<th>Table 2. Percentage of services that addressed, via verbal information provision, various poststroke topics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Services and benefits available</td>
</tr>
<tr>
<td>Practical tips and/or help for managing at home after discharge</td>
</tr>
<tr>
<td>Healthier lifestyle and/or cardiovascular disease risk factors</td>
</tr>
<tr>
<td>Consequences and impact of stroke</td>
</tr>
<tr>
<td>Medical and/or background information</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 3. Percentage of services that used various delivery styles for verbal information provision</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Style</strong></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Interactive (e.g., discussion, question and answer)</td>
</tr>
<tr>
<td>Combination of verbal and written information</td>
</tr>
<tr>
<td>Goal setting</td>
</tr>
<tr>
<td>Didactic (e.g., lecture-style)</td>
</tr>
<tr>
<td>Demonstration and/or practice of skills</td>
</tr>
<tr>
<td>Peer support</td>
</tr>
<tr>
<td>Problem solving with health professional</td>
</tr>
<tr>
<td>Training in problem-solving skills</td>
</tr>
<tr>
<td>Role playing/talking through scenarios</td>
</tr>
<tr>
<td>Combination or specialist (e.g., self-management program)</td>
</tr>
</tbody>
</table>
being services and benefits available and practical management strategies. Over 20% of services reported that they did not provide information about risk factor awareness and secondary prevention, which is of concern as it is particularly important that community-based clients receive information about these topics.\textsuperscript{10,11,14,15,17,18}

### Format of information provision

As discussed earlier, providing information sessions for the clients with stroke and their carer together, where possible, is recommended in the literature. In this survey, providing information to

#### Table 5. Percentage of services that used formats other than verbal or written information to provide information

<table>
<thead>
<tr>
<th>Alternative media</th>
<th>Percentage of total services (n = 32)</th>
<th>Percentage of stroke- or brain injury-specific services (n = 8)</th>
<th>Percentage of general services (n = 24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet-based information</td>
<td>40.6%</td>
<td>37.5%</td>
<td>41.7%</td>
</tr>
<tr>
<td>PowerPoint presentations</td>
<td>12.5%</td>
<td>0%</td>
<td>16.7%</td>
</tr>
<tr>
<td>Internet information sourced for clients</td>
<td>6.3%</td>
<td>0%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Audiovisual:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Videotapes and/or DVDs</td>
<td>50%</td>
<td>75%</td>
<td>41.7%</td>
</tr>
<tr>
<td>Audiotapes and/or CDs</td>
<td>6.3%</td>
<td>0%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Both video and audio</td>
<td>6.3%</td>
<td>0%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Library resources that clients could borrow:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Books</td>
<td>25%</td>
<td>37.5%</td>
<td>20.8%</td>
</tr>
<tr>
<td>Videotapes and/or DVDs</td>
<td>25%</td>
<td>37.5%</td>
<td>20.8%</td>
</tr>
<tr>
<td>Audiotapes and/or CDs</td>
<td>6.3%</td>
<td>12.5%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Media not specified</td>
<td>3.2%</td>
<td>0%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Sourced alternative media resources from other service providers for clients (e.g., borrowed a DVD from another service)</td>
<td>15.6%</td>
<td>12.5%</td>
<td>16.7%</td>
</tr>
</tbody>
</table>
both the client and carer occurred less frequently than group sessions or one-on-one information provision with only the client. Just over half of the services reported using the telephone to provide verbal information, but this was reportedly always used as a supplement to face-to-face verbal information provision. However, the questionnaire did not investigate whether the information provided over the telephone was new information or reinforcement of information that had previously been provided to clients and/or their carers.

Health education literature recommends that written material be provided as a supplement for verbal information. Fewer than three quarters of all services reported providing written information to “nearly all or all” or “the majority” of their clients and/or carers. It is possible that the clients and/or carers who did not receive written materials did not wish to be given written materials, however it is also possible that health professionals at some services may not have provided written materials to certain clients because they perceived it to be an inappropriate format for them. There is some evidence that health professionals may withhold information because of certain client characteristics – such as older age, having English as a second language, and/or the presence of a cognitive or language impairment. However, health education literature recommends that the presence of characteristics such as these should result in extra effort being placed on information provision for these clients.

The need for written materials to be designed according to the needs and abilities of its target audience has been well documented in the literature. In this survey, over half of the services reported considering the visual needs and reading ability of their target audience when designing written material. However, only a minority of services reported considering other impairments (such as aphasia), which is of concern given the range of stroke-related impairments that may affect the person’s ability to use written materials. Less than 40% of services considered client or carer input when designing written materials. Discrepancies between what stroke clients want to know and what health professionals think they want to know have been found. Designing materials according to clients’ and/or carers’ needs, rather than according to what health professionals think clients want to know, is one of the principles of developing effective health information materials.

Given the extremely poor rates of awareness of aphasia, it is surprising that 42% of services reportedly considered the possible impact of aphasia or used “aphasia-friendly” principles when designing their written materials. It could be assumed that stroke-specific services would have had higher rates of awareness of this impairment and strategies to address it, but there was similarity in the proportions of stroke-specific and general services that reported considering this when designing written materials. This finding may be a result of participants from both service types being unaware what would constitute an aphasia-friendly feature or even failing to recognise the term aphasia. For example, one service reported that they did consider both aphasia-friendly principles and stroke-related impairments, stating that clients were “asked at initial assessment what the best format is for them (i.e., written or verbal).” Even with 42% of services considering possible language impairment when designing their written information materials, it appears that clients with aphasia may have difficulty accessing appropriate written material.

**Delivery styles used in information provision**

As reported in the introduction, the literature recommends the use of an interactive style and demonstration and practice in preference to a didactic style. The combination of written and verbal information and the use of goal setting and self-management are also supported.

Styles of information provision used by the surveyed services matched these basic recommendations, with the most frequently reported styles being interactive, a combination of verbal and written, and goal setting, although over half of the services reported using a didactic style. Time required, the recent emergence of stroke-specific self-management programs, and the predominance of non-stroke-specific services in this survey may be reasons for the low proportion
of services that reported using a “specialist” style (such as self-management).

Timing and frequency of information provision

Despite literature recommendations about the importance of repeating and reinforcing information that is provided, up to one third of services that provided verbal information reported providing it on a single occasion. This may reflect a lack of awareness of the need to reinforce verbal information or limited resources that prevent services from providing reinforcement of information.

Limitations

Results of this questionnaire cannot be generalised to areas outside of Brisbane, Australia. The questionnaire did not explore the rationale of staff at the services for their current practice, such as their reasons for providing or not providing particular educational interventions. Although this was not the focus of the study, interpretation of the results would be enhanced if this information was available. Finally, as the perspectives of clients and carers who used these services were not obtained, it cannot be determined if their needs were met by the information provided by the services that were surveyed.

Future Research

Suggested areas for future research include exploration of both consumer and service providers’ perceptions of the benefits of, and barriers to, providing information using different delivery styles, formats, and variations in the timing of information provision.

Conclusion

There is congruency with current recommendations and preferences found in the literature in the following areas: provision of information about practical management strategies and services and benefits available, use of group and one-on-one settings, use of a range of settings, and use of an interactive delivery style, a combination of written and verbal information and goal setting. Areas where current service provision does not meet literature recommendations include the following: the provision of information about secondary stroke prevention, the provision of written material, the design of appropriate written material (in particular strategies for addressing language impairment and/or aphasia-friendly principles and incorporating client and carer input and feedback), and the repetition and reinforcement of information. It is important to ensure that information is available and appropriate to the needs of clients and carers living in the community after stroke.

Acknowledgments

Ms Eames was in receipt of an Australian Postgraduate Award (APA) scholarship while this research was undertaken. The authors would like to thank all service providers surveyed for their time and interest in this project.

REFERENCES

40. Thomas C, Parry A. Research on users' views about stroke services: towards an empowerment research paradigm or more of the same? *Physiotherapy.* 1996;82(1):6–12.
69. Printz-Feddersen V. Group process effect on the


86. Tse S, Lloyd CA, McKenna K. When clients are from diverse linguistic and cultural backgrounds In: McKenna K, Tooth L, eds.  *Client Education: A Partnership Approach for Health Practitioners.* Sydney, Australia: UNSW Press; 2006:307–266.

