International Journal of Narrative Practice (IJNP)

Introduction

This new journal is an eclectic publication that draws on different uses of narratives in research, education and practice. As such, it is not confined to any one area or discipline. Submissions from practitioners and academics in any discipline are encouraged and it is planned to have guest editors and single theme issues. The publication will come out four times a year (Spring, Summer, Autumn and Winter) and the first and second issues will be devoted to presentations and papers from the 2nd International Narrative practitioner Conference, held at Glyndŵr University in June 2008.

The journal will initially be published as an online journal but it is planned to develop it as an academic journal, published in hard copy.

Vision

Much of human life is conducted through narrative accounts of events and experiences. Many of our social institutions are comprised almost entirely of opportunities for telling and re-telling stories, for sharing the narratives that constitute our lives. We have all had experience of relating to and living vicariously inside the stories that are told by others, whether they are stories about their own lives or stories of the kind that we encounter in literature and film, that writers create, using elements of their experience. Narratives, therefore offer a method of teaching and communicating with one another about professional matters.

The aims of the journal are:

To engage participants in a multidisciplinary dialogue around the use of narratives in research education and practice

To facilitate ongoing collaboration in the development of narrative communities

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Journal Format
The Journal will accept both empirical/research based and theoretical articles

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Much of life is conducted through narrative accounts and experiences.
The International Journal of Narrative Practice (IJNP)

Welcome and Introduction

I want to welcome you to the 2nd edition of the journal. The International Journal of Narrative Practice (IJNP) is for anyone, in any context, who uses narratives in any way. We welcome narratives from fields as diverse as the Arts, Humanities, Social Sciences, Philosophy and Ethics as well as from professionals in any area. The journal has been substantially late in making this appearance and I apologise for that. Due to technical and resource issues, our planned publication date has been delayed for two months. These problems have now been resolved and we plan to produce a further winter edition in January 2011. If you have any narrative based work, either conceptual or empirical, we would be happy to review it.

This year’s conference was a one day event on June 21st at Glyndŵr University. The title of the conference was ‘Capturing the patient’s story’ and reflected a growing interest in narratives in health and social care. A report of the conference will appear in the next edition of the journal. Next year’s conference will take place in North Wales at Glyndŵr University in June 2011. We hope you will join us (www.thenarrativepractitioner.co.uk). We are hoping to attract a number of national and international speakers.

This edition of the journal contains a variety of interesting articles that displays different understandings and uses of narratives. The first paper reflects the theme of the 3rd International Conference which took place at Keele University, UK in 2009. This was a very successful conference, hosted by Michael Murray. We are all very grateful to Michael and Sally and the team for such a fantastic venue and arrangements. The second paper from Kathryn Hunt relates the personal and professional use of narratives in a particular cultural context. Andrew McKie’s paper suggests that a reading of literature and its narratives can help to raise ethical awareness among nursing students. Richard Dover’s paper explores the relationship of a general standard, the archetype, to a particular narrative reading. Cassie Ogden’s paper concludes this edition of the journal by exploring the way that narratives could help to widen our definitions of what counts as a good quality of life.
These papers are superficially different but all share an interest in the way that narratives can help us to understand a little clearer. I hope you will enjoy them and respond to them by engaging in the conversation which this journal supports.

Alex Carson (Chief Executive Editor)

The 5th International Narrative Practitioner Conference
Glyndwr University, Wales, UK
June 20-21 2011
Speakers include to be announced

For more details visit www.thenarrativepractitioner.co.uk
Narrative, Health and Social Justice
Alexander M. Carson

Abstract
All health and social care professionals are interested in health and social justice. This paper will explore the relationships between health and social justice through the use of narratives. The paper outlines a particular method of working with narratives and clients. Based on the work of Gadamer, the paper suggests that narratives show the need for a more conversational approach to issues of health, illness and social justice. In this paper conversations are defined as attempts to understand ourselves and others. As such, they provide opportunities for both professionals and clients to learn from each other. The paper is presented as a conversation between different views of what health and social justice are. The idea is that through conversations, and this paper is an example, we can get a clearer view about what health and justice could be.

Key Words: Narrative, Health, Social Justice, Culture, Conversation

Introduction
This paper reflects the title of the 3rd International Conference called ‘Narrative, Health and Social Justice’. It seems appropriate then if I structure my paper around the relationship that I see between these three; narrative, health and social justice. What they all have in common is that they are all essentially social practices. By this, I mean that I do not see health or justice or narrative in terms of theories about narratives or health or justice. All three are practices that might structure themselves around particular theories or concepts. Of course, all practice makes a claim for itself as something good or worthwhile. We can use this idea as a method of evaluating the practice itself. It is in the gap (theoretical, at least) between what a practice claims for itself and what it actually is, that the narrative practitioner can work.
I work with narratives as they represent at all times a view from the ground up. Narratives are about people not about anything else. By keeping close to the narrative, we keep close to the person behind the narrative. Much of the research in the human sciences gets too far away from its objects of study. In this paper I want to explore how the notions of narrative, health and social justice are constitutive features of the paper. I see the paper as a conversation between us that could result, for me and you, in a gain in self-understanding. I want to begin by teasing out some of the issues around narrative, health and social justice.

**Narrative, Health and Social Justice**

I’ll begin with looking at a narrative that I recently came across in a magazine. It’s a woman talking about a problem she has:

“I came down with ... a year after my marriage and then, alas, my husband caught it. We now spend all day every day sitting on the couch eating KFC, and watching TV while hoping for news of a breakthrough cure.”

This woman is, of course, talking about her obesity. This is an interesting narrative on a number of fronts. In the rest of the paper, I want to look at this story from a number of possible perspectives. Two questions that we can immediately put to this narrative might be: Is it healthy or is it just? For some of course, even these two questions might be going too far. I am thinking here of our post modern friends who would want to leave this woman alone to live her life as it appears to her. There is an ethical argument around autonomy that would want to say that everyone is and should be masters of their own fate: this woman’s definition of the situation is the only game in town. Our notion of the dignity of each and every person also underwrites this view. This woman, like all of us, is entitled to live her life as she sees it; if she wants to live like this she is entitled to. On this view, she is ‘doing her own thing’ and many see this as healthy and just. I am not so sure and to tease out some of the main threads of the argument, I will use the idea of personal responsibility as it is a key idea in any discussion of health and social justice.
Personal responsibility in health

As we moved away from the political consensus after the Second World War that accepted that society had an overarching responsibility for providing security and welfare for its citizens, individual personal responsibility has begun to assume a greater emphasis. We saw this particularly in the eighties with Thatcherism, where this consensus was finally laid to rest. Since there was ‘no such thing as society’ it was assumed that people should be encouraged to take personal responsibility for ‘their’ problems. This was continued with the development, in the 1990s, of a ‘third way’, where responsibility became a shared concern. Citizens are now expected to do what they personally can and society or the state is expected to ‘top up’ any gaps. In the context of health, this has meant that people are expected to take responsibility for their own health. This includes things like eating properly, taking exercise and abstaining from ‘bad’ things such as cigarettes, drugs, alcohol and fatty foods. There has been a large amount of comment in recent years about how much responsibility society has for people who continue to do bad things and fail to do good things. Obesity is a good example where personal and societal views on responsibility meet.

Is this woman acting in a responsible way? Well, she thinks so. There she is waiting patiently and hoping for a cure. What more can she do? The sick role, as articulated by Talcott Parsons lays out some key responsibilities for people who wish to claim to be ill (Parsons 1970). These include seeking competent medical advice as well as wanting to get better. So she qualifies as ill. But is she really ill? She certainly thinks so. One might be tempted to prescribe a few sessions of health promotion for her; getting her to see that she is eating the wrong kind of food and doing the wrong kind of activity. But this does not answer the woman’s more basic difficulty in that she could agree with this view but go on to point out that it’s the disease that causes her to engage in these unhealthy activities and that she cannot be blamed. She still needs a cure. In a recent article, a nurse makes the point that:

The British Medical Association wanting obesity reclassified as a ‘lifestyle’ problem is very alarming. If it succeeds, obesity will no longer be a medical problem and the NHS will no longer be required to treat people for it. It’s a lifestyle problem, so it’s the persons fault. (Payne.D Nursing Times 2008)
Here is the dilemma for us to consider. This person wants the NHS to ‘treat’ this woman and this woman would certainly want to agree. Justice, for her, would be getting the appropriate medical treatment and she is doing her part, waiting and hoping. What would health be for this woman? For her, it would be a cure from the disease that causes her to simply wait and hope. What would justice be? A cure would be what she might consider to be what she deserves. She ‘came down’ with it and so it was not something that she considers that she deserves; it seems to be bad luck or an accident of nature. As such, she bears no personal responsibility for catching it and is acting responsibly by waiting and hoping. We all know that obesity is not good for you and can cause serious health problems such as diabetes, arthritis, heart disease and so on. What should we do? For many of us, we see this woman as operating with a misunderstanding. We see that she is, at least partly, the cause of her own misfortune and that she might be able to do something about it? We might want her to co-operate in her own cure. But how can we get her to see that she herself can do something and that eating KFC and leading a sedentary life are potentially unhealthy activities.

What counts as health in modern society can be difficult to specify. For the various schools of European Philosophy and social/critical theory, such as postmodernism and post-structuralism, health can be seen as a normative concept that aims at homogenising and dominating our lives. We are all encouraged to live healthy lives by taking exercise and eating ‘healthy’ foods including fruits and fibre. Foucault would certainly want us to resist this idea and this woman could be considered a resistance fighter. She does her own thing, oblivious to the possible consequences of her ‘lifestyle’ choices. For her, it’s not her but the disease that is making her do these things. If later on, she develops heart disease or diabetes, would we want to say that this was a just outcome in that she deserved her fate? Would it be fair enough?

**Justice as Fairness**

Recently, there has been a great deal of discussion about the funding of health and welfare provision and the realisation that the state cannot continue to limitlessly tax its citizens to fund this so-called ‘bottomless pit’. Part of this has been carried on as a process of ‘rationing’ scarce resources. In this context, justice comes to play an important role. John Rawls defines justice as fairness where all members of society cooperate in producing and apportioning social goods. In deciding what each is entitled to, Rawls invents an ideally neutral position to view these social
goods such as health and justice; calling it the ‘original position’. The original position, for Rawls, can allow us define:

“..the most appropriate principles for realizing liberty and equality once society is viewed as a fair system of cooperation between free and equal citizens (Rawls, 2005:22).

Rawls wants to establish a method for evaluating social goods such as health and justice. His original position is a kind of thought experiment, where we are to imagine how an impartial judge, with no history or pre-conceptions, would make fair judgements in different situations. However, we define them, these social goods, such as health and justice, are measured against the twin standards of liberty and equality. Personal autonomy or liberty is the key standard of any decision we might make. On this view, this woman is acting freely and it might be unfair if we co-erced her into eating what we would consider a healthy meal. As far as she is concerned, she is co-operating by waiting and hoping for a cure. This presents a difficulty for Rawls’ theory. Is it just and fair to leave this woman to define the situation in her own way? Would this leave health and social care professionals with nothing to do, till she develops a more socially recognized disease such as diabetes or heart failure? For Rawls, a deciding influence would be what he calls ‘public reason’. Now the question might be better put in terms of this woman’s ‘reasonable’ behaviour. Is it reasonable? Well, yes and no. On the one hand, we might want to point out that she is causing some of her own problem by taking no exercise and eating unhealthy foods. But is it unreasonable? After all, there are many citizens who act like her and would consider her behaviour reasonable and normal.

For many cultures, being overweight was a social signal of prosperity. Certainly Victorian novelists saw a lack of food for the poorer classes as a social problem: the Dickensian workhouse is still used as a metaphor for these times. Being overweight was a privilege restricted to the rich. Rationing of food continued in the 1950s. For good or ill, the rise of the supermarkets through the 70s till the present day has resulted in cheap food being available to everyone. The rise in the availability of cheap food in supermarkets has seen the development of a ‘take-away’ culture, with largely fatty foods on the menu. In the last ten years obesity has moved from being exclusively a health and social problem to being a social ‘epidemic’. While cookery programmes proliferate and thin models are criticised for providing poor role models to young woman, we castigate supermarkets for selling
readymade food. Public rationality has equally undergone a change, where eating what one could get has been replaced by an ethic of responsible eating as the reasonable thing to do. While many would want to agree with this new rationality, there is a danger that we can slip into a new form of authoritarianism, crudely characterized as ‘Health Fascism’. While we would all agree that notions of health are constitutively linked to notions of rationality, this might be an example of what Michael Waltzer calls the ‘insolence of office’ (Waltzer 1995). This is where one feature or part of social or professional life comes to colonize other areas. Critics of ‘Health Fascism’ argue that matters of health should be limited by individual freedom and responsibility. The question that we need to ask, in this woman’s case, is to what extent we are willing to take responsibility for her actions. Is it reasonable for us to leave her to her own devices or should we impose a rational action plan on her?

**Health and Justice as a Virtue**

Alasdair MacIntyre is a writer who sees a justice and rationality as being constitutively related. He sees both as arising historically from the social context or form of life in which they are situated. In our natural state, there would be no need for health and justice as concepts. In a state of nature, people would take what they could get. This is his distinction between nature and convention. What counts for MacIntyre is the social context, which establishes the standards for health and justice. There can be no appeal to ‘criteria’ outside this social context to settle arguments and justice. The problem, for MacIntyre, is that there is no rational way, today, of adjudicating between competing versions of health or justice. He asks:

How ought we to decide among the claims of rival and incompatible accounts of justice competing for our moral, social, and political allegiance (2001:2)

MacIntyre wants to show that the Enlightenment, in its search for universal rules or prescriptions, has failed to develop a sufficiently rational account of justice which could provide a strong enough justification for us all. He situates justice in its historical context by looking at a number of traditional models of justice and their rational foundations in their particular historical context. For MacIntyre, the Enlightenment abolished this tradition and has found nothing suitable to replace it. This tradition, for MacIntyre, was a historical development that been built over the whole of our history. Developments were possible as each new epoch tried to remedy the defects of previous
versions of justice and public rationality. For MacIntyre, there have been diverse versions of justice and rationality, which for him personally, reached its pinnacle before the advent of the Enlightenment and modern liberalism. He sees himself as an ‘Augustinian Christian, which seems to be a synthesis of Aristotle and Christianity. MacIntyre thinks that the Enlightenment, in its attempts to repudiate the previous tradition, has thrown the baby out with the bathwater and is now left with no consensually agreed account of public rationality.

This woman, in her view, is acting rationally while others might see her behaviour as irrational. She could take MacIntyre’s advice and adopt an Augustinian Christian version of rationality but would she not be adopting one version of rationality for another? What would be her justification for this change? Is she not simply adopting one coercive model of rationality, the disease is making me do it, for another, I do what I do because I am an Augustinian Christian? This seems to be a narrowed down version of how we understand ourselves. It narrows our freedom of action and takes away much of our personal responsibility. MacIntyre thinks that since we have no consensually agreed way to proceed with this woman, we have no rational way of helping her but I think that he is wrong.

I think that aside from problems in practice, narratives by Rawls and MacIntyre are what could be called monological. Rawls suggests that we should begin with principles that can then be applied in practice. However, these principles are generated in a context free zone, the original position, which, of course, exists nowhere. As has already been indicated, Rawls version of justice as fairness might be in conflict with his principles. MacIntyre is monological in that he limits discussions about justice and health to the social context, our own particular background understandings, and this seems to leave no room for personal responsibility or self development: you just do what your particular rationality demands of you. Using Rawls’s or MacIntyre’s versions of justice and rationality, health and social care professionals would be left with two options; either leave her alone or impose a more rational form of healthy behaviour on her. However, I think that there is a more rational way to proceed, that could lead to a better understanding for health and social care professionals and their clients.
In *Truth and Method* (1989) Gadamer develops, following Plato, a method for developing our self-understanding. If we listened to this woman’s story, we might initially think that she was labouring under a misapprehension. Part of the reason for this initial response is that when we hear a story, we often already ‘understand’ it. We assimilate this other understanding into our own world view and consider this woman to be sadly mistaken. In anthropology, this hearkens back to the days when the behaviour of strange people in strange cultures was understood simply as gibberish or witchcraft or some such label. This was because, so they say, our white European ethnocentric rationality could only make sense of foreign cultures in terms of their ‘irrational’ behaviour. So the first part of the method outlined by Gadamer could be summed up saying that when we are confronted by any narrative, we should begin by ‘resisting the obvious’. In this narrative, we need to resist jumping to the obvious conclusion that this woman has got the wrong end of the stick.

Gadamer’s model is structured around our ordinary everyday practice of engaging others in conversation. We begin by resisting the obvious move of assimilating other views into our own world view. What we have in this situation is two different self-understandings, ours and this woman’s. We presume that, since we already know that this woman is irrational, she needs help that makes her act in a more rational way. Here the judgement and correction come too soon. We presume, because we implicitly privilege our knowledge that this woman is acting irrationally; we already understand. Gadamer sees this kind of judgement as being unreflective as it avoids trying to validate its own position. He constructs a conversational model that opens up both positions to critical scrutiny as they engage in an authentic conversation.

We can think of a conversation as something that ‘we’ share: it is not mine and it is not yours. It’s a very hot day and I am thirsty. I go into a café to order a cold drink. While waiting to be served, someone at the next table turns to me and says ‘it’s hot’. I know it’s hot and my new interlocutor knows that I know that it’s hot. Here conversation is defined as not so much a communication method but as a way of creating a social space that we share. In a similar way, Gadamer’s conversation is designed to create a new space that we can share in conversation and that is neither exclusive to either of our self-understandings but inclusive of both. To get to this point,
Gadamer’s ‘fusion of horizons’ or ‘common mind, requires that we engage seriously in trying to include both understandings. Charles Taylor puts it very well when he states that:

...the image of the conversation conveys how the goal is to reach a common language, common human understanding, which would allow both us and them undistortively to be... The aim is fusion of horizons, not escaping horizons. The ultimate result is always tied to someone’s point of view (1995:151)

The conversation is inclusive as it tries to collect all points of view to try and reach a new understanding that we both share. All parties to this conversation can learn from each other. An assumption of anyone who engages in conversation is that their view is one view among a number of possible views. In encounters between health and social care professionals this conversation can begin with each sharing their narratives of how they see the situation. This provides an inclusive model of practice that help each to reflect on their own stories; both professional and lay narratives.

Engaging this woman in conversation would begin with not assuming that this woman was simply mistaken. We could note that the narrative and woman are not very self reflective. The narrative excludes any other possibility for her obesity; it’s simply a disease. As a professional trying to ‘help’ this woman to help herself, we need to engage this woman and persuade her that there are explanations that could account for her obesity. This woman has first of all got to see for herself and then convince herself before she can change and retain her self-respect.

Narratives and conversations, as I outlining them here, are respectful of persons. They do not work with external criteria or principles that decide things in advance. They are inclusive of all interlocutors’ narratives as they engage each narrative in this conversation. They do not distort or try to overcome any particular narrative but aim to develop an inclusive language that allows each narrative or interlocutor to be. The gain for each participant can be a better understanding of both themselves and the other participants in the conversation and that would be both healthy and just.

It might be the case that sharing narratives will allow this woman to see that she can play a part in reducing her weight. However, even if she does come to see this, she may decide that she does not want to do anything about it. Engaging this kind of conversation will have helped her to see that her
problems are not solely related to an outside force but are more a choice that she is making and this will be a gain for her in understanding herself. Equally, a professional, engaging with her in this kind of conversation, could come to see that her initial assumptions about this woman were wrong and helped her to develop a more reflective model of decision making.

Conclusion

In this paper, I have tried to show that narratives are where we should begin if we are to talk about health and justice. I have also tried to show that justice and health are social practices and that justice and health are realized in the conversations that we have with each other. These conversations are inclusive, valuing each other’s point of view. Conversations, as I am outlining them here are self reflective practices that begin and end with openness and incompleteness. Narratives allow us to speak in a common language and we might, if we are fortunate, understand ourselves a little better at the end.

Health and social care researchers and practitioners who use a narrative approach engage in what I would call self reflective conversations with clients and each other. It aims to provide the best possible account of a situation that could be sustained by the situation itself. Using narratives ensures that all parties to the conversation are immediately sensitive to the context. As a research method, it allows new understandings to emerge and be recognized. The researcher brings himself or herself and all their experiences to the research. The narrative researcher aims to engage the participants in a conversation about the topic of the research. Equally the participants have their own story to tell which can be missed if they are asked pre-set questions or themes/questionnaires. The practitioner who engages clients in these narrative conversations is treating clients with respect. It can be difficult for professionals to give up the idea that their own story is not automatically the better one. Sharing narratives in a conversation, while empowering for the client, can seem disempowering for professionals. However, I think that the opposite is true.

Narratives and their use can help researchers and practitioners to develop themselves from the ground up. Rather than practicing with a pre-determined model of practice, narratives can allow health and social care professionals to develop and their clients can play their part in helping them
to develop. Using narratives can bring the rhetoric of service user and carer involvement in the development of services much closer to reality and that would be just and healthy for all.

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A Kenyan story about the needs of vulnerable children

Kathryn Hunt
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Abstract
This paper offers findings that indicate the perceived benefit to 3 separate groups of twenty caring professionals of a brief training in Child-centred play therapy. All African course participants have adult counsellor qualifications and work with vulnerable children in East Africa. These include children in crises in children’s homes, residential schools, hospitals and street children. The courses were delivered and data collected in three separate cities: Nairobi; Kisumu; and Mombasa in Kenya, East Africa in July and August 2007. Qualitative research methods included: ethnographic material gathered in field diaries, pre and post –training questionnaires and semi-structured interviews with Kenyan co-tutors. Findings suggest that regardless of Kenyan/Ugandan tribal or geographical differences there appears to be a need for an accessible generic training for counsellors trained to work with adults to build on existing therapeutic understanding to adapt their knowledge and skills to be able to offer counselling support to children. Specific training in relation to tribal and geographical location was not considered to be necessary. Unexpected findings suggest high levels of sexual abuse, neglect and general lack of respect for the rights of the child in Kenyan society. Kenyan counsellors’ who were the course participants and tutors, spoke in their stories of child abuse of the need for a political and ideological shift in thinking to bring the Kenyan child to the centre stage of policy makers and those who are responsible for the welfare of Kenyan children. Until Kenyan society recognises its responsibility to meet the child protection and well-being needs of its most vulnerable members then counsellors will inevitably end up containing the avalanche of need and ‘patching’ children up to return them into a society that will continue to perpetuate and ignore the obvious neglect and abuse.

Key words: Africa, play therapy, safeguarding children, HIV/AIDS

Introduction
In 2001 I was part of a research team looking at the suitability of applying a western psychologically –based model of counselling training in contexts where the social and cultural conditions differ from mainstream Western societies (McGuiness et al, 2001) Interview data was analysed to provide
a tentative answer to the question of the appropriateness in a Kenyan cultural milieu of a humanistic counselling training model developed in the UK. It was concluded that such application is possible and desirable, if it is undertaken as shared and respectful learning between trainers and trainees.

Some time later, I was approached by the Chief Executive of the NGO we had collaborated with to undertake the counsellor training in Kenya and invited to offer play therapy training for qualified counsellors. With a colleague, Dr. Maggie Robson I accepted the challenge, with some reassurance from the preceding successful research project and designed and offered such training in 2004. I published the results of research relating to this project evaluating the perceived benefit to a group of thirty caring professionals of a brief training in Child-centred play therapy. The course was delivered in Nairobi, Kenya, East Africa. Questionnaires provided qualitative data. Key findings included pre-training prevalent feelings of inadequacy to meet the needs of vulnerable children using adult style counselling; post training perceived raised awareness of the therapeutic power of play with positive impact on professional and personal lives; perceived increase in therapeutic play skills and increased ease in establishing therapeutic rapport. Training was largely beneficial increasing confidence, knowledge and skills of the course participants. (Hunt, 2006) In 2006 I returned to Kenya to work alongside Kenyan counsellors in delivering the play therapy training in Kisumu, in the Rift Valley area of Kenya. A local infection and a stay in hospital prevented me from returning until 2007 when I undertook the same training in three different geographical areas over a period of two months. These include Nairobi, Kisumu and the new addition of Mombassa. I wondered if the generic training was meeting the needs of each group of trainee play therapists. I also wondered whether geographical location and the consequent cultural groupings, for example, tribal differences, changed the training needs of the student groups. These were my research questions.

Method

I kept a field diary during my 6 weeks of travelling and teaching and learning in Kenya. I spoke with many people and I conducted interviews and spoke informally with my Kenyan Co-tutors in each area. In addition, I invited the course participants to give consent to take part in the research.
project by signing a consent form agreed by the University ethics committee where I was employed. Each participant was given an information sheet about the project also approved of by the same committee. They were then offered pre and post training questionnaires to record their experience of the training. I listened daily to stories in our self development groups which was a major part of the training. The focus of the group was to consider the experience of being a child in Kenya. I gathered all these kind of stories.

THE STORIES PEOPLE TELL
HAVE A WAY OF TAKING CARE OF THEM.
IF STORIES COME TO YOU, CARE FOR THEM. AND LEARN TO GIVE THEM AWAY WHERE THEY ARE NEEDED.
SOMETIMES A PERSON NEEDS A STORY MORE THEN FOOD TO STAY ALIVE.
THAT IS WHY WE PUT THESE STORIES IN EACH OTHER’S MEMORY.
THIS IS HOW PEOPLE CARE FOR THEMSELVES.

Dr Tom Janisse, Editor in Chief of the Permanente Journal, which contains art and stories from the medical world, includes the above quote at the beginning of his book ‘Soul of the Healer’. He tells us that physicians and nurses encounter many dilemmas in their practice: moral, ethical, legal, social, human rights, religious, economic, and personal values. He maintains that stories help us to find solutions. Stories integrate and organize complicated situations. (Janisse, 2005)

‘Giving language to what we witness lifts into personal and, sometimes, public consciousness the otherwise unarticulated existential dimensions of experience that permeate our work- whether we name them or not. Consciously narrating these accounts illuminates more of our collective lives as patients and physicians (or counsellors and clients/ students*), expanding our felt understanding of human frailty, compassion, strength, love, fear, hatred and ill will’. (Scannell, K. 2002)

*The bold indicates the author of this paper’s addition to the text.
Recently, I heard a story that moved me, a story of pain, courage, compassion and parental love. This story which has been told for some years in steel works in Corby in England.....

A father and his son worked alongside each other in the steel works at the mouth of furnace filled with molten iron. One day the son slipped and fell into the furnace, but not completely. The father grabbed his son and with split second timing pushed him further into the furnace. (Given, J. 2008)

It is not hard to see that this story lifts into personal and public consciousness an otherwise unarticulated existential dimension of this experience and illuminates our felt understanding of human frailty, compassion, strength, love and fear inherent in it. For those who continue to work in the steel works and for those of us who know what it is to love someone so much we would sooner see them dead than to suffer in indescribable pain the story is powerful.

All therapies are narrative therapies. 'Whatever you are doing, or think you are doing as a therapist or client can be understood in terms of telling and re-telling stories'. (McLeod, 1997, p.x) As counsellors we intend to give the client the freedom to tell his/her story. McLeod (1997) elucidates on the work of Jerome Bruner (1983) who writes of the gap between knowledge obtained through stories and science. Bruner clarifies the essential nature of both a paradigmatic way of knowing (scientific propositional knowledge) and a narrative knowing (through stories recounted about experiences). Narrative knowledge can be dismissed as vague, irrelevant and not legitimate (McLeod, 1997) The narrative approach to knowledge is growing in respectability and some ten years or more later there is a wealth of literature and interest in this area of human endeavour. McLeod (1997) ends his chapter on Narrative Knowing, by describing it as a powerful, complex and subtle medium for conveying meaning.

For the above reasons I am adopting a narrative perspective in offering my Kenyan research to present the findings and discussion from my study. I am consciously narrating in the hope of offering illumination to others of the issues for vulnerable children in Kenya and how training in play therapy is developing to meet their many needs. I heard many stories in Kenya as I worked as a volunteer for an NGO training counsellors to work therapeutically with children both infected and affected by HI/AIDS amongst other issues for children in East Africa. One of the great things about
being involved in collecting research data in counselling is the opportunity it brings to gather stories.

Results and Discussion

My Story

The road from the airport in Mombasa at night was very dark, coal black sticky dark. The bends in the road were accentuated by the driving style. The driver, high on amphetamines, swayed the car recklessly from one side of the road to the other with no particular regard for the designated side for travellers. His eyes stared hard at me as I approached him at the airport and he talked excitedly back to his car. Two police men with AK47 rifles poked and coerced him for more money to let us pass. He had already paid once and now the revelation that he was in fact a taxi driver encouraged a further demand for protection monies. In Swahili they argued and he smiled and he spoke quickly, explaining to me later that he had told the police that I owned the car and that he was using it to collect me as his friend from the airport. This arrival onto the coastal port of Mombasa marked the beginning of a fearful time. A hotel where strangers knocked on my door in the night announcing ‘room service’ when none had been asked for, a sullen and self-absorbed centre manager who stole the only play therapy book in the library the day I donated it to support her own studies at the expense of those students she held responsibility for. Welcome to Kenya! Jambo! A warm and colourful city with smells and tastes of the east meeting west in this amazing and beautiful country with sunsets that snap close rather than slip away. I love Africa. I fear Africa. I oscillate between hope and despair in Africa. The days and nights I have spent in fever with retching and clasping my body and finally sinking down to find myself on a concrete hospital floor covered in my own bodily fluids and too weak to move, add up to too many.

Amongst this chaos, fear and danger I find a warm and loving people who have shown me love, wiped my mouth and held me when naked and too sick to care, a people who love their children and weep at the injustice of UN charters that do not translate into child protection. I find mothers who have taken in orphaned children and loved them as their own, sisters, grannies, aunties who care for the thousands of children ripped apart from mothers and fathers by HIV/AIDS.
‘No it doesn’t matter where you are in Kenya all the children are connected as are all the people. Children are bought and sold and travel from Kisumu in the west to Mombasa in the east to provide for the sexual pleasure of the paedophile tourists who inhabit the pleasure zones. Children watch television. We are a global village. It is true.’

There are so many mobile phones. In a village without fresh water children collect water everyday from the lake, infested with malaria carrying mosquitoes and yet in that same village there is a small hut with a grass roof selling mobile phone cards. Mobile phones are seen glinting in the brightness of the day all over Kenya. The latest models are held in the manicured hands of young women with elaborate western style hair of all colours and styles. Hiding under these nylon wigs are beautiful African curls rejected and scorned as being African.

We pray to God to take care of the children and to keep them safe. One family were devastated by HIV and the house was rented and the landlord came to the house which was now occupied by two small boys aged 8 and 10 years and he told them pay the rent or out you go. Of course they could not pay the rent and they were evicted into the street.

A priest sets up a play therapy room in his parish, a gentle catholic priest with a heart the size of a rugby ball. He laughs he smiles he sits in dignified and calm quietness and speaks in a wise and loving voice. She cries inside when she tells the group of her sadness at the abuse she has witnessed in children. There is frustration that even though we know that sexual abuse takes place we cannot stop it. The police do not stop it and the children continue to suffer. A young woman of the cloth tells of a mercy dash to hide a young victim in another town. Close your legs! It was your fault little girl you should learn to close your legs. !!!

Beatings and beatings, harsh beatings pile up in all our groups. ‘I was beaten and I mean beaten’ ‘I was so badly beaten and I was beaten for playing when I should have been working and I was beaten for playing football and I was beaten for disobedience’. Some children have been so beaten that they died at the hands of their teachers.
Violence towards children both physical and sexual is prevalent in all places. A psychology of development is a revelation for one. ‘I didn’t know that children had similar feeling to adults until I read that book’.

What is your tribe of origin? Are you a Kikuyu? Are you a Maasai? Are you a Luo? I don’t know. ‘Most young people today do not even know their tribe’. Not so, when some months later when the women and children of the one tribe were burned to death trapped in a church by youth from another. They knew for certain the tribe they belonged to then.

The large slums of Nairobi are like tinder boxes of seething poverty and deprivation which breeds anger and resentment waiting to boil over and flood onto the populace at a moment’s notice.

Beautiful white teeth, beautiful eyes and skin the colours of toffee apples, dates, sandy brown suede, black bordering on midnight blue. The graceful movements and the clothes that hang on people not out of place on a Prada catwalk pass us in the heated pot-holed streets. Children tend goats and clean, scrub, shop, care for babies, walk to school in perfect turn out. Children seen not heard, so perfect that the military would tick them off as graduates.

Town mouse and country mouse
In the rural areas there is no expression for the children it is taboo to mention sex. If there was abuse it could not be talked about. There are no facilities to support children there. In town it is different there are lobby groups and hospitals and institutions a disclosure can happen there. In the deep, deep rural areas there is less openness there.

Tribe
Cultural practices are different based on ethnicity.
Navasha so quiet, silent abuse
Go over board with secrecy.
Things happen in Kikuyu society that rarely happen in the Luo.

Overtly sexual Swahili people teach young girls how to move to excite a man. Children traded here from 9 years upwards. In Mombasa the children are abused for income (some don’t till the land and
sell the children instead out of idleness) and in Nairobi and Kisumu taken mostly for lust, she told me.

Some women freely trade in communal sex without controls. Some women learn that their husband has HIV and they lead separate lives. He then takes the child for gratification. Some men believe it safer to have sex with a child than to risk HIV with a strange woman.

Traditional doctors told us have sex with a virgin and you will be cured of AIDS. This has happened all over Africa in different parts. In a few cases women abuse the boys. Boys are being abused more frequently in the coastal regions.

Lobby groups shout ‘castrate him’ and ‘put him in prison for life’. ‘Is he a homosexual? Then get him before he hurts more children’. Fuzziness between homosexual and paedophile prevails in ignorance.

My mummy died. My daddy died I have been taken to live with relatives. I am 10 years old. I take care of the animals. I till the land I look after the chambra (vegetable garden). Sometimes I sell second hand clothes even though primary school is free I do not want to go because of the beatings. I prefer to work

Oh Kenya, your children are treasure. They are the dawn they are the freshness and the hope. Across the country following the railway line from port to rural city you know that they are precious. Amazing courage and generosity abounds and counsellors enter the metaphoric worlds of hurt and pain of loss and sadness with toys and sand.

Yes she tells me, ‘There are commonly shared issues for our children wherever they live but cultural practices my trigger some behaviours and make it less easy to protect our children. A generic training in play therapy is fine if we are aware of the cultural nuances of the lives of our children’.

**Conclusion**

Whilst it became clear that geographical region or tribal identity did not require separate specific education and training courses for counsellors to convert their therapeutic knowledge and skills to
work with children in play therapy I conclude that the groups I taught unanimously agreed that societal attitudes to the rights of children and safeguarding children from abuse was a prerequisite to the healthy development of therapeutic services for children in East Africa. Many felt that therapeutic intervention would merely put dressings on psychological wounds knowing that in many cases those children offered such support would very likely continue to experience a high risk of abuse. Those children living in the cities were more likely to receive the kind of protection needed, although this is unevenly scattered. In the rural areas ignorance and exploitation alongside a repressive approach to discussions about sexual matters conspire to create a societal norm where disclosure of abuse is not common. Many counsellors working with children in play therapy in Africa face a difficult task of influencing government policies and procedures in the area of safeguarding children. However, I am heartened by the dedication and serious application of the course participants to these matters and hope that the counselling body in East Africa, which is growing and developing at a rapid pace, will be powerful in its influence. The stories the group participants brought to the training in play therapy are rich and have a way of taking care of them. They gave them away generously in the group. Just as physicians and nurses encounter many dilemmas in their practice: moral, ethical, legal, social, human rights, religious, economic, and personal values, so too do play therapists in East Africa working with vulnerable and abused children. Janisse (2005) maintains that stories help us to find solutions. Stories integrate and organize complicated situations. It is suggested in the findings that the opportunity to tell stories, a major part of the play therapy training, may have help the participants to integrate and organise the complicated situations they find themselves in on a daily basis in seeking to develop their knowledge and skills in play therapy.
References


Mrs. Gamp is Still Alive!’ Exploring the contribution of reading literature toward a narrative ethic in nurse education

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Abstract
The place of narrative as one way of exploring ethics in nurse education is discussed in this paper. In particular, the role of literary fiction is examined for its potential contribution to a teleological, or intentional, ethic characterised by features of aspiration towards the ‘good’, working with others and recognising important contextual factors.

This is examined by considering key features of narrative in terms of plot, meaning and awareness of identity in narrator and reader. Narrative, viewed as a potentially helpful way of exploring the experiences of patients and nurses, is considered as another way of approaching ethics in clinical practice. Selected passages from two very different works of fiction explore this intentional ethic via discussing of aspirating towards the ‘good life’, relating to others and recognising the significance of social environments.

Although certain limitations of narratives are apparent, this paper nevertheless highlights the potential for narrative ethics to be seen as an alternative approach to other, more dominant, approaches in ethics education. Reading literary fiction, as part of an emerging dialogue between the humanities and professional health care education, can make a positive contribution.

KEY WORDS: ethics narrative reading fiction relationality aspiration

INTRODUCTION
In this paper, I seek to explore the potential contribution of reading works of literary fiction to the use of narrative ethics within nurse education. This shall be addressed, firstly, by examining the place of narrative itself and the role which it might play within ethical discourse and practice in professional health care environments. In the second part, the reading of literary fiction is explored in terms of its potential contribution to an intentional, or teleological, understanding of ethics via its use of the imagination and metaphor. This is demonstrated by exploring selected passages from
two novels: that of Elie Wiesel’s *Night* (1960) and Janice Galloway’s *The Trick Is To Keep Breathing* (1999). Finally, in a third part, I shall seek to draw some conclusions about the place of narrative ethics within current ethics discourse in nurse education.

PART ONE

INTRODUCING NARRATIVE

The place of narrative can be seen as a form of ‘causal thinking’ (Cooper, 2000) which seeks to provide a framework for understanding human experience itself. In its form of telling (and re-telling) of events, narratives seek to provide a sense of coherence, meaning and identity for those involved in the act of narration itself and, potentially, for those reading, or listening to, narrative themselves. Furthermore, although narrative finds its focus on recounting past events, it is the selection, choice, ranking and interconnection of events (the ‘plot’) that distinguishes narrative from other forms of discourse dedicated to understanding the past e.g. annals and chronicles.

The emphasis in the act of narration on events is on the telling of a ‘time-thing’ or ‘something that happens’ (Scholes, 1981: 205). This can also be described in terms of action, where to act may be understood in terms of ‘to take an initiative, to begin, to set something in motion’ (Arendt, 1958: 177). Such an emphasis on action gives intentional and purposeful, but not necessarily predictable, dimensions to narrative. According to Hauerwas and Burrell (1997: 178), the ‘field’ for a narrative is that of action (deeds or dreams) alongside, conversely, that of suffering in which a person (as character) becomes the focus of events (e.g. war, illness, pain or oppression) happening to him/her (literally ‘being- acted-upon’). This distinction between active and passive elements of a person’s narrative may not always, of course, be possible to maintain given the complex interplay of intention, contingency, purpose, opportunity, acting, failure and suffering that might reasonably be expected to comprise any one person’s experience. Nevertheless, such a distinction may be a helpful way to understand the various underlying elements of a ‘narrative structure’ and to help in the process of discern meaning in, and through, narrative.

In addition, considering narrative in action terms as practice suggests provisional and tentative features or, as Carson (2009: 7) states it, narratives ‘cannot say it all ...’
The transmission of narrative can take many different forms. This can include literary fiction (novel, short story, novella), drama, poetry, history, memoir, journalism, autobiography, film and oral narratives (Charon, 1994). This multiplicity of genres that may in part account for the current interest in narrative as an important means of sourcing and transmitting knowledge in the human sciences and in practice disciplines, in particular (Bruner, 1991; Holloway & Freshwater, 2007; Carson, 2009).

The current versatility in the use of narrative in professional health and social care contexts is noteworthy. This can include the writing of ‘life-stories’ with people with learning disabilities to overcome ‘disabled authorship’ (Meininger, 2005: 108), typologies of patients’ illness experiences (Frank, 1997), understanding the therapeutic relationship (Brody, 2003; Sakalys, 2003) and aspects of the therapeutic relationship in psychotherapy (Polkinghorne, 1995). Where the issues of ethical discourse and practice are concerned, the use of narrative is often suggested as one, amongst several, alternatives to frequently used ethical models centring upon ethical theories (e.g. deontology, utilitarianism) and the use of ‘ethical principles’ (‘principlism’) (Beauchamp & Childress, 2009). Concerning the latter, the application of principles of autonomy, beneficence, non-maleficence and justice have been considered by way of application of rational, objective and universal ‘tools’ to help professional healthcare practitioners solve so-called ethical ‘problems’, or attempt to reconcile polar opposites in ethical ‘dilemmas’, as they arise in practice.

Amongst recent critiques of the use of ‘principlism’ as a method of promoting ethical discourse (McCarthy, 2003; Hedgecoe, 2004; Walker, 2009), Milligan and Woodley (2009: 133) highlight the limitations of a universalising and expert-led ‘sterile discourse’ which appears to underplay the influence of other, potentially salient, factors.

Although it remains segregated as a complex and expert discourse, it cannot facilitate the task of meaningful moral engagement. Moral understandings are always interpreted and deeply embedded in a particular time, history, and context, all of which create a unique, rather than universal, basis of meaning. As individual patients and practitioners are embedded in multiple layers of connectedness and understanding each person has a unique perspective. Hence, the
expectation that generic, universal principles should be presumed to equally apply to each individual is misplaced.

Nevertheless, it is important to be clear about the potential contribution which narrative might be able to make to ethical discourse and practice itself. Carson and Lepping (2009) caution against casual, or loose, adoptions of narrative as alternatives to principle-based modes of ethics in the practice of psychiatry. If the scope of narrative is not outlined carefully, then combining variants of principle-based ethics with, for example, virtue (character) ethics and/or narrative may only serve to preserve the dominance of distinctly professional narratives within therapeutic relationships. Rather, if the ‘ethic of helping people comes first’ (Carson & Lepping, 2009) within the ‘agenda’ of the therapeutic relationship, then it must be ensured that the narrative of the client is given co-equal status with the professional narrative within any therapeutic encounter.

Recognition of this, however, does not deny the legitimacy of professional narratives (e.g. medical model, nurses’ structured listening). What it may serve to do, however, is to deepen the exploration of the relationship between narrative and ethics. In particular, this might helpfully be stated as a question: what kind of ethics might be promoted by using the distinctive features of narrative?

One way of addressing this question may be to consider an ethic that moves ethical discourse and practice beyond an emphasis on solving ‘problems’ via the use of rational, objective and universal means of theory and ethical principles. One such approach deserving of consideration is a teleological, or intentional, ethic. This understanding of ethics has Aristotelian roots in the notion of a pursuit of the Good:

Let us now turn back again to the good which is the object of our search, and ask what it can possibly be: because it appears to vary with the action or art. It is one thing in medicine and another in strategy, and similarly in all the other sciences. What, then, is the good of each particular one? Surely it is that for the sake of which everything else is done. In medicine this is health; in strategy, victory; in architecture, a building – different things in different arts, but in every action and pursuit it is the end, since it is for the sake of this that everything else is done.
This emphasis on the end of actions is a distinguishing feature of a teleological ethic. For one advocate of such an ethic, Ricoeur (1992), this ethic is comprised of an exploration of, or quest towards, the ‘good’ and eschews any individualistic notions by incorporating wider relational and institutional dimensions within it. For Ricoeur (1992: 172), the “ethical intention” can be outlined as:

aiming at the “good life” with and for others, in just institutions

Two other features in Ricoeur’s exposition of this ethic of intentionality can be highlighted. The first is to note that any universalising, or abstract, notions of the Good are avoided by grounding it as ‘a question of the Good for us’ (Ricoeur, 1992: 172; original emphasis). This, then, may locate ethics in the pursuit of a ‘practical Good’, which gives ample recognition to the context and particularities of different types of actions. Secondly, by noting that ‘the good is rather that which is lacking in all things’ (Ricoeur, 1992: 172), the way is opened up for an ethic characterised by a seeking after the good in specific situations. In other words, in recognising the vicissitudes of everyday life (incorporating pain and illness), a teleological ethic may be considered to be one approach which seeks to find meaning and purpose (the ‘good’) within many diverse situations.

It is in these terms that it might be possible to identify the potential contribution of narrative to the ‘ethical aim’. Ricoeur (1992: 170) outlines an understanding of ethics by linking action and narrative. By locating the latter at the “crossroads” between description (action) and prescription (ethics), narrative can become a way of exploring these actions via the ‘imaginary space’ afforded by one type of narrative, namely that of fiction. The telling (and re-telling) of narratives with their features of coherence, meaning and identity, may then become a potential means of pursuing and exploring an ethic of ‘the Good’ based upon intentions, relationality and recognition of context. Several commentators explore this intentional ethic for its potential contribution to an understanding of ethics in nursing. Carson (2009: 7) outlines the way in which narrative, understood in terms of conversation (e.g. between an agent and others, objects and texts), can promote self-understanding (identity). Similarly, Fredriksson and Eriksson (2003) explore the ethics of the ‘caring conversation’ by transposing the three parts of Ricoeur’s outline into personal,
interpersonal and societal dimensions respectively. In the first, personal dimension, the pursuit of the ‘good life’ is explored in terms of how a nurse’s own self-esteem (identity) and understanding of the ‘good’ might be developed within the interplay of factors that impact upon one’s own life and the ‘ethical aim’ of alleviating the suffering of patients. As Ricoeur (1992: 179) states it:

for the agent, interpreting the text of an action is interpreting himself or herself

Nevertheless, such self-esteem should not be interpreted narrowly in self-development terms only or, by implication, viewing the pursuit of the ‘ethical good’ only in terms of the well-being of the nurse. By stating it in terms of ‘to say self is not say myself’, Ricoeur (1992: 180) moves the pursuit of the Good beyond individualistic and self-absorbing terms.

In the second, interpersonal, dimension, Fredriksson and Eriksson (2003) develop the ethical intention of the Good in relational terms (‘with and for others’) more fully. By acknowledging the inequality that a patient’s suffering may bring to the nurse-patient relationship, recognition is given to ways in which such approaches as solicitude, reciprocity, mutuality and similitude exchange may encourage the ‘ethical aim’ to become a genuinely shared experience in clinical practice (Ricoeur, 1992: 1990).

Alongside this, the third, societal, dimension (‘in just institutions’) gives recognition to the place of wider contextual factors (e.g. Codes of Professional Conduct, care setting procedures, clinical Guidelines) within which practice devoted to pursuing such an ‘ethical aim’ must necessarily operate (Fredriksson & Eriksson, 2003). Olthius et al (2006: 35) summarise this quest for the ‘ethical good’ in relational terms in this way:

..hospice nurses not give when they provide care, they also receive. Patients not only receive but they also give. Hospice nurses aim to contribute to the quality of life of dying patients. The patients contribute to the quality of life of their nurses through the positive effect of palliative care on the nurses’ self-esteem.

PART TWO

READING FICTION AS A FORM OF ACTION
The reading of literary fiction is part of an emerging dialogue between the humanities and professional health care education (Gallagher & McKie, 2010). In this section, the contribution that reading can potentially make towards a teleological ethic is explored. It is possible to identify an intentionality, or purpose, in reading which can encourage exploration and discovery. In engaging with a text, the reader can go beyond ‘micro’ attention to a text’s internal structure (e.g. sentence construction) to discern what a text is ‘about’. Reading can be seen as a form of two-way interrogation, or dialogue, between text and reader. As readers bring their own ‘biographies to the work’ (Hegge, 2008: 307), the text can address the reader by challenging long-held assumptions along the lines of Nussbaum’s (1990: 230) question:

“What is happening to them as they read?”

At the same time, the contribution of reading works of literary fiction to a teleological ethic deserves particular attention. Although the concept of narrative serves to link action and ethics, the particular issue of fictional texts requires to be addressed.

A real person, even if a stranger to others, may be present in real life. Characters in fiction, however, are part of what Ricoeur (1991: 170) terms as ‘images’ – ‘fictions that evoke not absent things but nonexistent things’. Wolterstorff (1997: 137) outlines this problem:

It is only persons who speak. Characters are mute. For characters are not persons but, so it seems to me, types of persons. And types of person do not speak (original emphasis).

One possible way of approaching this issue is to consider the role of the imagination in the act of reading. By locating imagination at the ‘crossroads’ between theory and practice, Ricoeur (1991: 174) defines imagination as:

the free play of possibilities in a state of non involvement with respect to the world of perception or of action

Reading fiction imaginatively (e.g. via the use of metaphor as an aspect of ‘semantic innovation’: Ricoeur, 1991: 171) can become a heuristic device, or a ‘free space’ (Meininger, 2005: 111), for
uncovering new meaning and understanding. Consider the potential use of metaphor by Rush (2006: 17) in enriching an understanding of the human experience of waiting in hospital:

Under that gown skulks your even more absurd carcass, entering its Prufrock stage. Your hair is grey ebb-tide, your teeth a lead-mine, your belly a sack of sand – not much left in the hour-glass either.

The specific contribution of reading literary fiction to a narrative ethic is addressed using the two novels of Wiesal (1960) and Galloway (1999). In considering passages from these novels, issues are explored from the stance of the character which, to follow Hauerwas and Burrell (1997: 178), can be viewed as the ‘cumulative source of human actions’. In particular, the selected passages indicate aspects of the complex dynamic between action and suffering underlying narrative itself. Night is the celebrated first novel of a trilogy written by the Hungarian-born Nobel Laureate Elie Wiesal. As a fifteen-year old Jew, along with his parents and younger sister, Wiesal was deported in 1943 from his Transylvanian hometown of Sighet to the Auschwitz and Buchenwald concentration camps in Poland. In this short novel, Wiesal, in narrating the events of his family’s deportation, camp ‘selection’ processes, mistreatment and torture on the part of camp commanders, the slow death of his father and his eventual liberation, seeks to explore the meaning and purpose behind the pain and suffering endured by his family, his people and himself. The novel’s title, Night, itself is pivotal towards understanding the use of narrative in this search for meaning:

so much had happened within such a few hours that I had lost all sense of time. When had we left our houses? And the ghetto? And the train? Was it only a week? One night – one single night?

(Wiesal, 1960: 47).

Aiming at the ‘good life’

In the following passage, Wiesal (1960: 30-31) demonstrates the way in which a sense of optimism or hope (no matter how unrealistic) can often act as a powerful motivation towards attaining the ‘good’ in situations where its absence is most keenly experienced.
On Holiday

At dawn, there was nothing left of this melancholy. We felt as though we were on holiday. People were saying:

“Who knows? Perhaps we are being deported for our own good. The front isn’t very far off; we shall soon be able to hear the guns. And then the civilian population would be evacuated anyway...’ On holiday!

It may often be the case that patients or nurses may be found searching for meaning and purpose during the course of a patient’s illness via expectations of hope which are eventually unfounded. This, however, may be considered to be more than mere ‘clutching at straws’. Hope, by way of its orientation towards an as-yet-unknown future, may be a sustaining power for good in particular moments of distress (Arman & Rehnsfeldt, 2007; Penz, 2008). In another passage, Wiesel (1960: 78) utilises protest as form of quest for the attainment of (some) good or purpose as a representative of his whole people. Here Wiesel explores a key tenet of his people’s religious faith, Judaism, namely belief in an all-powerful, knowing and merciful God, to ponder upon why thousands of children should be permitted to die in the camps’ gas chambers.

I Was The Accuser

This day I had ceased to plead. I was no longer capable of lamentation. On the contrary, I felt very strong. I was the accuser, God the accused. My eyes were open and I was alone – terribly alone in a world without God and without man. Without love and or mercy.

The recognition that spirituality is a significant element in nursing practice has received increased recognition in recent years (McSherry, 2000; Swinton, 2001). Nevertheless, nurses may not always immediately recognise that a patient’s expression of spirituality may include quests for meaning that might seriously challenge their previously accepted systems of belief and practice (Nelson, 2009). Indeed, in recognising their limitations in helping a patient, nurses may share in such questioning activities. This, however, may not be the end of the matter. In such situations, nurses may begin to co-create a therapeutic narrative by witnessing to, and standing alongside, their patients in their suffering, uncertainty and ambiguity (Sakalys, 2003). In so doing, they may help to create for the patient a renewed sense of meaning and purpose.
Relationality – With And For Others

A key theme running through Night’s narrative is the shared camp experience of Eliezer and his father following the ‘selection’ process. Several passages present situations where key ethical choices, or decisions, require to be made. These are explored by encouraging the reader to appreciate that the immediate context often contains contradictory motivations, as well as unclear, or unknown, articulations of the end of the ‘good life’ itself. These can be seen in two passages.

What Shall We Do, Father?

He was lost in thought. The choice was in our hands. For once we could decide our fate for ourselves. We could both stay in the hospital, where I could, thanks to my doctor, get him entered as a patient or a nurse. Or else we could follow the others.

“Well, what shall we do, father?”

He was silent.

“Let’s be evacuated with the others”, I said to him. He did not answer. He looked at my foot.

“Do you think you can walk?”

“Yes, I think so”.

“Let’s hope that we shan’t regret it, Eliezer”.

I learnt after the war the fate of those who had stayed behind in the hospital. They were quite simply liberated by the Russians two days after the evacuation. (p. 93)

Burning With Fever

‘He was burning with fever. Like a wild beast, I cleared a way for myself to the coffee cauldron. And I managed to carry back a cupful. I had a sip. The rest was for him. I can’t forget the light of thankfulness in his eyes when he gulped it down – an animal gratitude. With those few gulps of hot water, I probably brought him more satisfaction than I had done during my whole childhood.

“Have you had anything to eat?”

“No”

“Why not?”

“They didn’t give us anything ....’

I gave him what was left of my soup. But it was with a heavy heart.
I felt that I was giving it up to him against my will. No better than Rabbi Eliahou’s son had I withstood the test’. (p. 119)

Galloway’s novel (1999) is a powerful and subversive narrative centred around the theme of the experience of a twenty-six year old Scotswoman, Joy Stone, who suffers from depression. The narrative style itself (fragmentation, incomplete sentences, ‘disappearing’ text, repetition, blank pages and margin notes) may legitimately be considered as an overall commentary on the ‘good’ within Joy’s life itself. More particularly, however, the narrative is replete with examples of Joy’s quest for meaning, relational dynamics (friends, lovers and mental health care professionals) and the impact of care settings on the therapeutic relationship itself.

Aiming at the ‘good life’

A major theme of the novel is Joy’s exploration, or quest, to find her own identity amidst the vicissitudes of everyday life (Kornstein & Clayson, 2002). This can be shown in the following passage:

**Things Will Be Better**

I can’t decide what to do.
I used to spend a lot of time waiting. Women do. Women have this tendency to think things will be better if they wait longer ie when

- I get away from my mother
- when I live with the man-I-love
- when I get away from the man-I-love
- when my mother loves me more
- anyone loves me more
- when I finish the diet/buy new clothes/
get a haircut/buy new make-up/learn to
be nicer/sexier/more tolerant/turn into
someone else (p.193)

Such quest, or aspiration towards the ‘good’, may be considered to be a key feature of all therapeutic encounters which nurses engage in with their patients. Sakalys (2003: 234) describes
this in terms of ‘listening for the patient’s meaning’ within the dominant ‘clinical ‘metanarratives’ of nursing and medicine.

_Relationality – With And For Others_

_Coping_

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**HEALTH VISITOR**

So, how are you/how’s life, what’s been happening/anything interesting to tell me/what’s new?

**PATIENT**

Oh, fine/nothing to speak of.

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I stir the tea repeatedly. She picks a piece of fluff off her skirt.

**HEALTH VISITOR**

Work. How are things at work? Coping?

**PATIENT**

Fine. (Pause) I have trouble getting in on time, but getting better.

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I throw her a little difficulty every so often so she feels I’m telling her the truth. I figure this will get rid of her quicker.

**HEALTH VISITOR**

(Intensifying) But what about the day-to-day? How are you coping?

**PATIENT**

OK. (Brave smile) I manage.

**HEALTH VISITOR**

The house is looking fine.

**PATIENT**

Thank-you. I do my best.

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What are supposed to come here for? I said.

She just looked.

What’s it for? What are we supposed to talk about?

She said, I’m here to help you. To help you try to get better. I’m here to listen.

But I don’t know you from a hole in the wall. I can’t do it.

She said, You can tell me anything you like. I assure you it goes no further and I’ve heard it all before.

(pp.21-22)

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The potential of the ‘ethics of the caring conversation’ (Fredrickson & Erickson, 2003) may be demonstrated in this narrative by way of its relative, although not entire, absence. The narrator’s
ploy of presenting the health care professional’s list of indistinguishable openers in the therapeutic relationship is telling. Even if Joy is less than open in developing her own narrative (‘nothing to speak of’), one interpretation from reading this narrative may be that of a health care professional practising in a perfunctory manner (‘I’ve heard it all before’). Although the dialogue of many therapeutic relationships will most likely contain similar elements, an ‘ethical aim’ of attaining the good might accord ‘an ethic of help’ a high priority (Carson, 2005) to critique such a health care professional’s motivation and disposition.

Just Institutions

Of Course, You Can

I find my sea legs in the green and blue corridor. A man at the glass partition of the reception bay is filing little bits of buff card. I ask if it’s OK to go for a walk. He doesn’t look up, just keeps shuffling cards.
Of course you can. Of course, of course. (p.115)

Nothing Else Has Happened

Dear Marianne,

Please find enclosed one set of regulations so you can visit. Visiting is open everywhere in the hospital except here. This is because we need our rest. There aren’t many written rules. Most of them work on the landmine principle: they just let you loose till you trip on them. I’m not supposed to lie in or stay in the ward during the day. I have to get permission to go outside in case someone is looking for me. I’ve been for two walks round the grounds. There is nothing to see. Nothing else has happened. (p. 120)

In these two passages, the narrator addresses issues of the ‘ethical good’, or more precisely, its lack, within the wider context of the care setting. The atmosphere of Joy psychiatric ward is characterised by apathy, indifference and lack of stimuli, as demonstrated by the response of one staff member at reception to Joy’s simple request and to the staff member’s preoccupation with the trivial demands of bureaucracy.
In addition, Joy’s comments on the whole setting itself (‘nothing has happened’) are telling in themselves. At the same time, the care setting appears to function according to a set of unwritten rules, knowledge of which is only communicated to patients when they are breached. The potential of social institutions (e.g. political, family, religious, educational, welfare) to articulate common values and mores is a strong one. Nevertheless, the social history of care for people with mental health problems in institutional (e.g. hospital) settings provides many examples where rules, procedures and routinised practises may tend to predominate over aspirations to seek the ‘common good’ of all (Porter, 1987).

**PART THREE**

**CONSIDERING THE PLACE OF NARRATIVE ETHICS IN NURSE EDUCATION**

I want to preface discussion on evaluating the place of narrative ethics within nurse education with one of my own teaching narratives. In a recent literature workshop with a group of third-year nursing degree students, we were reading and discussing pre-selected passages from a range of literature sources. Amongst these passages, the account of Mrs. Gamp’s idiosyncratic style of nursing in Charles Dickens’ novel *Martin Chuzzlewit* (1844) was read out and discussed:

‘Why, highty tighty, sir!’ cried Mrs. Gamp, ‘is these your manners? You want a pitcher of cold water throw’d over you to bring you round; that’s my belief; and if you was under Betsy Prig you’d have it, too, I do assure you, Mr Chuffey’.

Perhaps it was the presence in a group of around ten students and myself of a visiting nurse-midwife from the States. But for a considerable period of the discussion time, the relevance and application of Dickens’ account of the nursing practice of Mrs. Gamp appeared to make little impression upon one young, but vocal, student in the group, Alison (name changed). Her note of scepticism continued until there appeared to be, for Alison, an ‘epiphanic moment’ in her reading of this particular passage of literature (Hawkins, 1984). It was that sudden insight arising from a vital connection being made between reading this particular passage of literature and her own experience of nursing practice within mental health nursing contexts: ‘Mrs. Gamp is still alive!’
I relate this narrative from my own teaching experience to illustrate the potential contribution of fiction to the development of narrative ethics within nurse education (Begley, 2003). Careful and sensitive reading of works of fiction may be able to provide ‘nonexistent’, but no less real, examples for helpful explorations of an ethic of the ‘good life’. Some of these may centre upon 30 examples of practice where the ‘good’ may be apparent by its absence, as in the case of Mrs. Gamp. In others, the ‘good’ may be more obviously present as in, for example, the character of Nurse Rooke in Jane Austen’s novel *Persuasion* (1818):

She always takes the right time for applying. Everybody’s heart is open, you know, when they have recently escaped from pain, or are recovering the blessing of health, and nurse Rooke thoroughly understands when to speak. She is shrewd, intelligent, sensible woman.

As the examples from Wiesal (1960) and Galloway (1999) indicate, literary fiction, in providing examples that are deeply contextual and complex, may invite careful and sensitive journeys of exploration, rather than providing clear and definitive ‘solutions’ to immediate problems or issues. This is not to deny that ‘solutions’ to problems are unimportant. Moreover, it may be objected that the examples cited trade in ambiguity rather than offering clear direction and insight. Nevertheless, it may be in the exploration of literary narratives themselves that contextual and embedded factors lying within practice may come to be more fully recognised and appreciated. There may exist a tendency to see narratives as permitting a more ‘natural’, or ‘open’, way to human experience than other forms of evaluating human knowledge (Paley & Eva, 2005).

Moreover, overusing narrative may obscure important boundaries between ‘common-sense’ accounts and a specific discipline (e.g. ethics) (Borisenkova, 2009). Nevertheless, by recognising the theoretical and conceptual dimensions of narrative alongside its contingent and contextual features, narrative can be received as one way, amongst others, of understanding the complexities of human experience and action.

Given these points, it may be possible to place narrative ethics alongside principlism as a valid source of ethical discourse and practice. This may be achieved by recognising parallels between
narrative’s structuring of events and the ‘rational’ selection of principles alongside the use of context in the application and use of generalised and ‘universal’ ethical principles (McCarthy, 2003).

To return to the contribution of relationality (‘with and for others’) to an ‘ethical aim of the ‘good life’, Carson (2005: 87) suggests that ‘an ethic of help’ should be a ‘core’ value within any caring relationship. Fredriksson and Erikson (2003), in developing an ‘ethic of the caring conversation’, suggests that the following criteria might usefully be used to evaluate a nurse’s narrative towards a client:
• what sort of person should a nurse be?

• how should a nurse engage in caring conversation with suffering clients?

In reading fictional narratives, a parallel process between the nurse and patient can be discerned in terms of the reader and the text (Daniels, 1986). In assessing the potential contribution of any literary work towards the development of a narrative ethic in nurse education, use of these same questions may helpfully be given a similar degree of prominence.

CONCLUSION

The reading of literary fiction has the potential to contribute towards an understanding of narrative ethics. Paralleling Carson’s (2009) notion of conversation as a form of narrative, reading literature can be considered as form of ‘conversational ethics’ characterised by features of intentionality, aspiration towards the good, relationality and the recognition of relevant social factors. These features can contribute towards an innovative alternative in ethics education in nursing.
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Dancing with the Wolf: Hesse’s *Steppenwolf* as a case study of Narcissism and Ego in relation to Archetypal Content

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Abstract

This paper is an exercise in literary psychology, or is it psychologised literature? The focus of the paper is the strange and enigmatic cult novel *Steppenwolf* (1927), a novel which, since its publication has intrigued, shocked, disturbed and delighted readers. The purpose of the presentation isn’t to “read” the novel, but rather to open out some intriguing and profound questions about reading and texts themselves, the ways in which reading can be both an allegorical and transformative process, and engagement with narrative as a basis for self-interrogation and self-transformation, an alchemical process, a notion of reading praxis based not on cognitive mastery of text but rather as dialectical engagement and relationship.

Key words: archetype, allegory, transformative

Introduction

This is nothing new, surely, for this is what case studies are all about, especially psychological case studies which, more often than not, draw us into narratives of psychopathology, subversion, dysfunction and abnormality, with the promise of drawing out lessons about what normality might mean. Narratives about people who have things wrong with them, those who are misfits or outsiders, “freaks” or oddballs, call for an interactive and self-interrogative reading and engagement within that narrative – am I like that? Could this be me? Are there parts of that narrative which mean something or apply to me? And what does it mean to be healed? What sort of “happy ending” can be desired or implied in that narrative? Do things work out alright? Is it a narrative of redemption? In the words of Van Morrison, “Did Yer Get Healed?”.

In what follows there’s also a preferred approach and agenda which will be declared from the outset. That agenda is Jungian, or rather post-Jungian, in its emphasis on archetypal or depth psychology, drawing on a vocabulary and discourse which seeks to open out fundamental aspects of the experience of the conscious ego and the relation with partially acknowledged but more often
latent archetypal patterns and dynamic relations. The value and significance will make more sense, hopefully, as I progress, but it is something which needs to be signalled from the start.

Steppenwolf, the narrative of a man with excessive ego-identification with the Wolf from the Steppes, is a particularly suitable narrative to approach from this post-Jungian perspective. I’ll assume no great familiarity with the narrative and hope to open out its underlying potential and complexities as I progress. It is a curiously lyrical, subjective, and poetic narrative, one that opens out and questions bourgeois normality and ordinariness in its portrayal of a schizoid and suicidal intellectual misanthrope, a socially ill-adjusted loner who has, yet, a love-hate relationship with bourgeois cleanliness and decency – the decency which is symbolised by the Araucaria (the equivalent of Orwell’s Aspidistra) which adorns the bourgeois landing of the guesthouse in which he resides. He appears to ring all of the bells in terms of the classic “Schizoid” type identified by Guntrip - introversion, withdrawnness, narcissism, self-sufficiency, a sense of superiority, loss of affect, loneliness, depersonalization, and regression (Guntrip, 1966).

Through the narrative this central figure, Harry Halle[r], undergoes a kind of psychedelic education, learns to do the foxtrot, do drugs, falls in love (lots of times, with men, women and himself), contemplates suicide (on a regular basis), communes with Mozart and Goethe, enters a sort of psychedelic “Magic Theatre”, which may or may not be a figment of his own imagining, and undergoes a kind of pre-EST dissolution of any notion of the solid bourgeois citizenly ego, to encounter and then live within himself the multiple possibilities of his own psyche and the plurality of the self. And, most importantly, he is instructed by the Immortals, learns to laugh, told to transcend his “romantics of atonement“, leave behind the “pathos and death-dealing!”, to “live and to learn to laugh.” Such an account gives some sense of this strange narrative, rendered as it is with the feel of the nightmarish cinema of German expressionism, a rehashed ‘Cabinet of Dr Caligari’. It might come as no surprise to learn that the novel was an indirect product of therapy sessions with one of Jung’s followers which Hesse underwent in the 1920s. No surprise also that Harry Haller is, at some level, a condensation of Hermann Hesse’s own crisis of belief and mental tortures and nightmarish dreams in which his psyche conjured up images of the “Wolf from the Steppes” who hunts alone, misunderstood and unloved, nomadic and nocturnal. And there are further lack of surprises about the novel, that its title should be memorialised in the name of the heavy rock metal band of the 1960s, “Born to be Wild”, and that the novel should be championed by no other than
Timothy Leary as a visionary anticipation of 60s acid counter culture. And no final surprise, that Hesse’s work should be banned and despised by the Nazi’s viewed as representing a degenerate, his works an assault on the bastions of the solid ego, loyalty to the State, Family and the Father Fuehrer.

For those who haven’t read the text this is intriguing stuff. Once opened it is an enchanting and heady brew – case study, treatise, intellectual allegory, weird fantasy and nightmarish dream, psychological confession, existential critique. It is also, like most case studies, told as multiple narratives, with the possibility therefore of irony and unreliability – whose dream or case study is it? The opening ‘Preface’ is told by the nephew of the landlady who lets one of rooms to a strange and lonely man, Harry Haller.

He really was a wolf of the steppes, as he called himself, a strange, wild, shy – very shy – being from another world than mine. (7)

For some reason, although he acknowledges the difference, there is something about this man, Harry, who intrigues and haunts him (“I often dream of him at night, and the mere existence of such a man has had a thoroughly disturbing and disquieting effect on me, although I have come to like him”), seeing him as unhealthy and ailing, as a “genius of suffering”, (15). Yet even in these opening pages there is the beginning of a psychological investigation (15), with the narrator early on diagnosing Harry as a product of a life-denying repressive code of late nineteenth century “German Rectory Syndrome” (“the linking of quite exceptional intelligence and moral sensitivity to deep feelings of guilt and inferiority”), an education which had made him this self-repressed, narcissistic loner who cannot bear normal bourgeois society – the Steppenwolf.

A wolf of the Steppes that had lost its way and strayed into the towns and the life of the herd, a more striking image could not be found for this shy loneliness, his savagery, his restlessness, his homesickness, his homelessness. (22)

This man has a skewed relation to the traditional archetype of the Wolf. The Wolf here is not the barbaric, monstrous, carnivorous beast, wild and free, but a different kind of wolf – moody, introspective, discontented, lonely, suicidal. And yet, for the narrator, there is something alluring and even heroic about this strange Wolfman: he stands apart from the narrator’s life and values, “a narrow, middle-class life, but solid one, filled with duties”. The Steppenwolf stands out against the herd, the jingoistic militarism and the popular taste of his times. The ‘Preface’ ends with the question of where he has gone, and what he represents. All he has left behind is the strange ‘Journal’ which takes up the remainder of the novel, and it is left to the reader to decide.
So far so interesting – the beginnings of an intriguing case study. Who is this misfit, what does he represent? And there is already the beginning of a psychological interpretation, of Harry as the victim of upbringing and circumstances, a case study of induced self-repression and those who cannot dance with the Wolf. It is a classic case study of ego dissociation, what Alice Miller describes as the “Drama of the Gifted Child”. But there are further questions too. Whose dream is this narrative? Could it just be a third-person case study, or could one, from the start, see it as the unwitting self-disclosure of the solid sensible duty-bound nephew? The text is, however, playing games with us, our thinking and perceptions.

This is but 10% of the text. From this point the narrative shifts to Harry’s own journal, in which he amplifies the initial portrayal of this discontented, suicidal loner and misfit, the “homeless Steppenwolf, the solitary, the hater of life’s petty conventions”. But this initial portrayal of the ironic intellectual and cultured observer of middle class custom presents also an ego-orientation to life which clearly signals a deeper underlying narcissistic identification of unassimilated libidinal energy, a half-recognised wolf:

There is much to be said for contentment and painlessness, for these unbearable and submissive days, on which neither pain nor pleasure cry out, on which everything only whispers and tiptoes around. But the worst of it is just this contentment that I cannot endure. After a short time it fills me with irrepressible loathing and nausea. Then, in desperation, I have to escape into other regions, if possible on the road to pleasure, or if that cannot be, on the road to pain. When I have neither pleasure nor pain and have been breathing for a while the lukewarm insipid air of these so-called good and tolerable days. I feel so bad in my childhood soul that I smash my rusty lyre of thanksgiving in the face of the slumbering god of contentment and would rather feel the most devilish pain burn in me than this warmth of a well-heated room. A wild longing for strong emotions and sensations seethes in me, a rage against this toneless, flat, normal sterile life. I have a mad impulse to smash something, a warehouse perhaps, or a cathedral, or myself, to commit outrages, to pull off the wigs of a few revered idols, to provide a few rebellious schoolboys with the longed-for ticket to Hamburg, to seduce a little girl, or stand one or two of the representatives of the established order on their heads. For what I always hated and detested and cursed above all things was this contentment, this healthiness and comfort, this carefully preserved optimism of the middle classes, this fat and prosperous brood of mediocrity. (35)

Here, clearly is the expression of a neurotic disposition towards the world which rests on a curious kind of ego-based logic of dissatisfaction. Certainly, as the self-diagnosis that follows confirms, this has social and cultural resonance, putting Harry’s plight as a typically anti-bourgeois and anti-materialist revolt, but it is also presenting itself as an essentially psychological and emotional
condition of schizoid intellectual detachment, as he prowls the city’s streets and pleasure haunts at
night, despising of his fellow humans and despairing of finding solace, acceptance or understanding:

And, in fact, if the world is right, if this music of the cafés, these mass enjoyments and these
Americanized men who are so pleased with so little are right, then I am wrong, I am crazy. I
am in truth the Steppenwolf that I often call myself; that beast astray who finds neither home
nor joy nor nourishment in a world that is strange and incomprehensible to him (39)

Is this psychological disposition an expression of normality or a radical call for healing and therapy?
Were there time we might dwell on further enumeration of Harry’s condition, the basis upon which
it has developed, and the basis also upon which it might be healed. It is at this point, however, that
this work is done for us, through the remarkable device of the ‘Treatise’ which is passed to Harry as
he prowls the midnight streets, a “A Treatise on the Steppenwolf” which lays out for Harry the base
of his false but necessary emotional logic, a simplistic bifurcation of ego-relation with the inner
Wolf, a straight binary opposition between being Human and being a Wolf:

...Harry does shocking violence to his poor soul when he endeavours to apprehend it by so
primitive an image. Although he is a most cultivated person, he proceeds like a savage that
cannot count further than two. He calls himself part wolf, part man, and with that he thinks
he has come to an end and exhausted the matter. With the ‘man’ he packs in everything
spiritual and sublimated or cultivated to be found in himself, and with the wolf all that is
instinctive, savage and chaotic. But things are not so simple in life as in our thoughts. Nor so
rough and ready as in our poor idiotic language; and Harry lies about himself twice over when
he implies this niggardly wolf-theory. He assigns, we fear, whole provinces of hi soul to the
‘man’ which are a long way away from being human, and parts of his being to the wolf that
long ago have left the wolf behind. (74)

Rather, the Treatise argues (in a curious form of self-objectification, for in what dream is this being
argued, and what part of Harry’s psyche is outlining the case?), Harry needs to appreciate that a
complex man such as himself cannot be understood through this simplistic, childish and artless
division into wolf and man, and that ego-based psychology cannot fully accommodate the psyche:

Harry consists of a hundred or a thousand selves, not of two. His life oscillates, as everyone’s
does, not merely between two poles, such as the body and the spirit, the saint and the sinner,
but between thousands, between innumerable poles....every ego, so far from being a unity is
in the highest degree a manifold world, a constellated heaven, a chaos of forms, of states and
stages, of inheritances and potentialities.. (70/71)

There is, however, a game-like quality to the narrative from this point onwards – and we are still
only a third of the way through. The remainder of the narrative is a kind of reading happening, a
process of discovery and awakening, a game played with the reader’s own expectations of
propositional understanding, the thesis to be proved and Harry to be explained – the narrative of
the psychological detective who can unravel the case and explain both whodunit and whydunnit. From this point onwards the narrative becomes a dreamlike evocation of “Life Coaching” on acid (quite literally), as Harry is drawn into a psychedelic encounter with the playful, the erotic, the Dionysiac, a dismantling of his ego and expectations as he meets a woman (Hermine) who takes him hand, teaches him to dance and jettison Mozart for the foxtrot, procures him a girlfriend (Maria), introduces him to a mercurial bisexual Mexican jazz musician (Pablo), culminating in an orgiastic encounter in a “Magical Theatre”, part cinema and part Hall of Mirrors, which serves also as a clear image of the multiple images and possibilities of the inner psyche and latent archetypal content. It culminates with Harry stabbing Hermine, and then being cajoled by Pablo (who appears as Mozart, representative of the Immortals), that he must learn to keep playing the game of life, renew and destroy himself many times over, and above to learn to laugh.

At face value this is strange and bewildering, for what can it mean and what is it trying to say? These are the questions which haunt the undergraduate essay. But that is to assume that the text is an explication rather than an exploration, an outcome rather than a process, a destination rather a journey, defying the conventional (and defusing) expectations of the psychological case study, thwarting the desire for “Harry” to be solved and thereby cured. It is possible to read Steppenwolf as a clear-cut narrative of therapy and transformation, healing and the reintegration of previously unintegrated states and possibilities of life. From this perspective the narrative is defused into a kind of psychedelic version of A Christmas Carol, the humanisation of a Scrooge-like middle-aged misanthrope who learns to re-engage with his former younger self, an emotionally undeveloped Tiny Tim version of Harry as the adolescent, one who undergoes restorative therapeutic processes to get healed.

This is the narrative approached in terms of straight ego-based terms, focusing on the rehabilitation of a more rounded and adjusted ego-relation to the world. But the text is more plural, inconsistent and richer than this. Approach in archetypal terms the text reveals itself to be more ironic and psychologically dense, as a narrative and dream of the whole Self, in which the ego is compelled to encounter its dependence and dynamic relation with archetypal elements, not simply the ego/shadow dialectic of Harry as civilised man and Harry the Wolf. From this perspective the narrative closer to record of a dream and therapy session, in which characters are but elements of his own whole Self, and also draw from archetypal relations. Given that the novel was itself drawn
from Hesse’s own firsthand encounter with Jungian practice, and his fascination with archetypal psychology, it is not surprising that the text should open itself so readily to these perspectives from depth psychology.

Central to the approach from depth psychology is the conviction that the ego rests upon and draws from underlying depth processes, patterns, the archetypal dynamics and inner relations which Jung and post-Jungians identify as the inner figures, gods, patterns and motifs which belong to the Collective (biological and/or cultural) Unconscious. Harry, for example, draws upon an enabling (but probably disabling) imagining himself as lone Wolf, and through this identification – “I am the Steppenwolf” – shores up a negotiated and consoling sense of who and what he is. The image of the Steppenwolf, prowling around the outskirts of the village and shunning bourgeois normality, provides a partial and provisional solution to his sense of himself. But, as the text appears to suggest through the fascination with mirrors, images and hallucinations, this is but a kind of narcissistic projection, a form of ego-identification which appears to work, but only partially, as a kind of provisional accommodation. That he longs for death and oblivion, the release which comes from suicide, indicates that it’s not the most effective of long-term rehabilitative strategies for psychic wholeness.

The pedagogic drive which runs through the narrative is directed towards a process of encounter and engagement with other elements of the Psyche, other parts of the Self, a fuller repertoire of archetypal figures and contents. To appreciate we might turn towards an earlier narrative of bourgeois psychic self-division, Robert Louis Stevenson’s *Dr Jekyll and Mr Hyde* (1886). In the conclusion to the ‘Case’ Jekyll expounds upon his growing realization of the realities of psychic bifurcation and the dynamics of internal psychic economy as experienced by the bourgeois professional. Speaking of his process of realisation of the “confederacy” of selves within the apparently unitary self Jekyll (“Je-kill”) recounts how he comes to see that there are reasons why his morality-bound respectable life is not fully adequate:

Though so profound a double-dealer, I was in no sense a hypocrite; both sides of me were in dead earnest; I was no more myself when I laid aside restraint and plunged in shame, than when I laboured, in the eye of day, at the furtherance of knowledge or the relief of sorrow and suffering. And it chanced that the direction of my scientific studies, which led wholly towards the mystic and the transcendental, reacted and shed a strong light on this consciousness of the perennial war among my members. With every day, and from both sides of my intelligence, the moral and the intellectual, I thus drew steadily nearer to that truth by
whose partial discovery I have been doomed to such a dreadful shipwreck: that man is not truly one, but truly two. I say two, because the state of my own knowledge does not pass beyond that point. Others will follow, others will outstrip me on the same lines; and I hazard the guess that man will be ultimately known for a mere polity of multifarious, incongruous and independent denizens. (p. 81)

In this conclusion to Jekyll’s narrative there is testament of a wider cultural process of which Steppenwolf provides later expression, the process of “discovery” of the limits of the ego-bound Cartesian bourgeois self, and the acceptance of the depths, multifariousness and polytheistic basis of the dynamics between the “I” and the “Not I”, ego and Psyche, character and depth, self and Self.

Within Steppenwolf the process involves the encounter with the characters and images within the Self: Harry’s confederacy of inner characters who appear distinctive and separate, but who are clearly part of the whole “Harry” package whilst also being expressions and versions of wider archetypal patterns. Within classical Post-Jungian criticism the readiest strategy at this point might well be to match these against the Archetypes identified by Jung and his follows – the ‘Anima’, the ‘Great Mother’, the ‘Trickster’ etc. This sort of Vulgar Jungianism, with its reliance on a mechanical and reductivist allegorical re-writing of a ‘text’ mapped against the master code of the archetypes, is not without its dangers, serving to diminish the text in the service of taxonomical orderliness. But it can bring insight also, particularly in a text such as Steppenwolf. This is clearest in the case of the mysterious woman Hermine who befriends Harry and awakens him to the joys of dancing, flirtation, relationship, emotional investment. Her part within the text is that of the classical ‘Anima’ figure. It is she who performs what the text appears to present as female service to Harry’s masculine-oriented ego, setting out to save and redeem him, taking him on a journey so that he can relate, fall in love, find value and feeling. This figure (whose name is clear reference also to what Jung terms the Anima, the Soul and Breath of life and being) acts as a kind of ambisexual “inner handmaiden” within the narrative, pulling Harry out of his suicidal phallo-logocentric thinking into the world of Feeling, from Logos to Eros. That “She” (and the reference to the title of Rider Haggard’s novel is significant given Jung’s use of the novel to explain elements of the ‘Anima’), is only partly an exterior figure for Harry. Her name is a playful reference to Hesse’s own forename and also, in the text, to Harry’s male friend, Herman. The fact that she resembles Herman at times is clearly far more than accidental, and she refers to Harry as her “brother” whilst also being his lover. Her role as teacher and counsellor is clear in passages such as the following:
That is why we are drawn to one another and why we are brother and sister. I am going to teach you to dance and play and smile, and still not be happy. And you are going to teach me to think and to know and yet not be happy. Do you know that we are both children of the devil? (148)

And subsequently, when Harry acknowledges that he believes (intellectually) that “human beings consist of ten, or a hundred, or a thousand souls”, Hermine clarifies the terms of her mission for Harry:

‘I like that very much,’ cried Hermine.’ In your case, for example, the spiritual part is very highly developed, and so you are very backward in all the little arts of living. Harry, the thinker, is a hundred years old, but Harry, the dancer, is scarcely half a day old. It’s he we want to bring on, and all his little brothers who are just as little and stupid and stunted as he is. (149)

Hermine’s reference to “we” confirms that Hermine is not alone within the Hall of Mirrors of Harry’s Psyche, and here we acknowledge the importance of two other figures, Pablo and Mozart. Pablo, the Creole jazz saxophonist, is a charmer, someone who is easy in the company of both men and women, a kind of trickster figure who is both expansive and generous in attitude represents a radical polar opposite to the over-thinking Harry who lives so much and perhaps only within his own head. Pablo assumes a shape-shifting mercurial quality throughout the narrative, leading Harry on towards a vision of the highest of the Immortals, represented in the figure of Mozart. It is Pablo who directs Harry to attend the “Magic Theatre” within himself:

And if you were to enter the theatre as you are, you would see everything through the eyes of Harry and the old Steppenwolf. You are therefore requested to lay these spectacles aside and to be so kind as to leave your highly esteemed personality here in the cloakroom where you will find it again when you wish. (206)

Pablo’s task, he declares, is to welcome Harry to a school of humour:

You are to learn to laugh. Now, true humour begins when a man ceases to take himself seriously. (207)

The lesson itself appears to be a painful one for Harry. In true psychedelic fashion he experiences the highs and lows of this ‘trip’ through the Magic Theatre, meeting Mozart and having Brahms and Wagner pointed out to him, before the final Dance of Death. He comes across the two naked figures asleep on a rug, “the beautiful Hermine and the beautiful Pablo side by side in a sleep of deep exhaustion after love’s play” and, filled with jealous rage, stabs Hermine in the breast. As she has prophesised from the start, it is his destiny and her wish that he should kill her. It is left to Mozart to draw out the message to Harry:
You have made a frightful history of disease out of your life, and a misfortune of your gifts. And you have, as I see, found no better use for so pretty, so enchanting a young lady than to stick a knife into her body and destroy her. (248)

At this point, the closing pages of the narrative, Harry appears to realise the errors of his ways, being condemned to learn to laugh

I knew that all the hundred thousand pieces of life’s game were in my pocket. A glimpse of its meaning had stirred my reason and I was determined to begin the game afresh...

One day I would be a better hand at the game. One day I would learn how to laugh. Pablo was waiting for me, and Mozart too. (252-3)

This ending appears to be a moment of closure, of pulling threads together and defusing the raw power of the narrative’s interrogative intent. It would be inappropriate, however, to leave the narrative here with a suggestion of successful rehabilitation, all issues and symptoms addressed, signed, healed and delivered. Rather better, I would suggest, to review the narrative as a process and an intervention as an account of ego-Other dynamics. From this perspective Harry’s ego-orientation with the Wolf is a partial strategy for the over-thinking intellectual man of culture struggling to evade the dread of bourgeois conformity, and he under goes a kind of sentimental education, part trip and part vision. But what does he learn? Does he get healed? We would like to believe him healed, but perhaps this is an unhelpful wish, based on an inappropriate desire for a defusing explanation – one must learn to laugh and endure. It is an ego-question, and produces a different narrative than the multiple and interrogative process of encounter and discovery recorded through Harry’s Dream. Rather the narrative is a departure, a call for a reading and engagement with aspects and elements of the whole self which rests not simply on ego alone, but one the relations between ego-consciousness and all that is not-I within the whole psyche. This may make for a more disturbing therapeutic narrative, but it is a kind of therapy all the same.
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Potential of narrative inquiry approach in developing a psychosocial understanding of Inflammatory Bowel Disease (IBD) in children; an essential addition to health related quality of life (QoL) instruments?

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Abstract

Inflammatory Bowel Disease (IBD) is a chronic disease of the digestive system affecting children of any age. Symptoms include diarrhoea, failure to thrive, stomach cramps, fatigue and depression. Historically, biological and psychological studies have contributed exclusively to an understanding of IBD. This study explores the potential of adopting a narrative approach to help develop a sociological understanding of IBD which could complement previous understandings and approaches in the clinical setting.

A quantitative approach to understanding psychosocial aspects of IBD was adopted by culturally adapting and validating a disease specific health related quality of life (QoL) instrument (IMPACT-III (UK)). One hundred children with IBD completed the instrument and statistical validation was confirmed. IMPACT-III (UK) can be used by health care professionals (HCPs) to measure the psychosocial well being of their patients with IBD alongside their physical needs.

Narrative interviews were conducted with a boy with IBD aged 11 and his mother and a girl with IBD aged 13. Through a process of follow up interviews and using principles of the constant comparative approach, stories were constructed collaboratively with the respondents. The stories highlighted how IBD affected the QoL and happiness of the children and their families.

Narratives emphasise how a person lives with IBD in a disabling society and contributes to a sociological understanding, although qualitative research is rarely used in the clinical setting to inform professionals. This paper suggests that HCPs could use narratives alongside QoL instruments to develop a psychosocial understanding of their patients. Such practice would complement a patient centred agenda and help encourage effective use of psychosocial indicators in clinical practice.

Keywords: Inflammatory Bowel Disease, narrative inquiry, Psychosocial, quality of life, sociology.
Introduction

Inflammatory Bowel Disease (IBD) is a term used to refer to two main chronic diseases; ulcerative colitis (UC) and Crohn’s Disease (CD) which can affect children and adults of any age. Patients with IBD have inflammation at different points along their gastrointestinal tract and encounter periods of remission and relapse of disease activity at unknown stages in their lives. Symptoms include diarrhoea, failure to thrive, abdominal cramps, fatigue, and loss of appetite which can be alleviated through a range of treatments including nutritional therapy, drug therapy (including steroids) and surgery.

Nutritional therapy requires a child with CD to consume an exclusive fluid diet for six weeks (usual practice in Booth Hall Children’s Hospital, Manchester). Dietary treatment is socially difficult as children have to persevere with this strict regime whilst watching friends and families eat their usual food. If the child is unable to drink enough of the liquid diet a nasogastric or gastrostomy tube may be used and this further sets the child with IBD apart from their peers.

When corticosteroids are used to treat IBD, their side effects caused by long term use, can be serious and include Cushing’s syndrome, nausea, impaired healing, bruising, increased risk of osteoporosis and stunted growth (British Medical Association and Royal Pharmaceutical Society, 2001). Drossman et al., (1991) found effects of medication were second in the list of top concerns for adult IBD patients and could also concern the paediatric population.

Surgery can be used to correct bowel problems for patients with UC and involves the removal of the affected section (colectomy). This may result in the bowel opening onto the abdominal wall via a stoma and a bag being used to collect the diverted stools. The psychological effect of having a stoma fitted can be traumatic, with adolescents reported to worry about peer acceptance, sexual dysfunction and ability to participate in sports (O’Brien and Bridget, 1999).

Due to the socially embarrassing symptoms of IBD, children can encounter both psychological and social problems alongside dealing with physical changes and interventions. Some children with IBD
are dissatisfied with their body image due to poor growth or due to the side effects of treatment such as steroids, which makes them feel different to their peers (Decker, 2000; O’Brien and Bridget, 1999). Others experience social impairment as it is difficult to leave the house or play with friends (Akobeng et al., 1999; Moody et al., 1999). Performance, attendance at school and participation in sports may be affected (Akobeng et al., 1999; Moody et al., 1999; O’Brien and Bridget, 1999) whilst other children worry that having IBD may affect their chances of getting a job in the future (Moody et al., 1999). Psychological problems include depression, low social competence, maladjustment and low self esteem (Engstrom and Lindquist, 1991; Engstrom, 1992; Levine and Levine, 1999) and a recent study has shown how perceived stigma can have a negative effect on the psychosocial well-being of patients with IBD (Taft, et al., 2009).

Historically, biological and psychological studies have contributed exclusively to an understanding of IBD. Such understandings are individualistic and can result in children blaming themselves for having IBD (Ogden, 2006). A truly interdisciplinary approach to healthcare is needed to achieve the best possible psychosocial care for their patients. German researchers have examined how NI can be utilised to explore CD (Perleberg et al., 2006) but do not explain how it may be useful in the clinical setting. This study evaluates the extent to which NI helps develop a sociological understanding of IBD and how it can complement a more traditional quantitative approach in the clinical setting. A quality of life instrument was developed to measure the psychosocial well-being of children with IBD and the NI technique utilised to establish stories of children with IBD and their families. The study was approved by the Salford Trafford Research and Ethics Committee.

**Quality of Life Instrument**

**Background**

Health related quality of life (QoL) is a term used to describe how illness and its treatment affect people in their everyday lives. To have a fuller understanding of a persons QoL one needs to explore the effect the illness has on all aspects of their lives. The first phase of this study was concerned with developing a disease specific QoL instrument for children with IBD.
Method

A disease specific QoL instrument was culturally adapted and validated for British children with IBD (IMPACT-III (UK)) (Davies, et al., 2005; Ogden, et al., 2008, in press). The original IMPACT questionnaire was developed in Canada by Griffiths, et al., (1999) and further amended by Dutch researchers (Loonen, et al., 2002, IMPACT-II Netherlands) to contain 35 items.

A computerised touch screen version of IMPACT-II has also been developed by British researchers (Sage, et al., 2001). The computer version allows QoL scores to be calculated instantly which facilitates the use of the instrument by HCPs as an outcome measure in the clinical setting. A British study showed children preferred the computer version of IMPACT because it was more fun, easier to understand and because they liked computers (Maity & Thomas, 2001).

A pilot study was conducted in the UK with twenty children aged 8-16 years who completed two versions of IMPACT-II with different response scales (Likert and visual analogue scale), to evaluate the preferred response option. Children also commented on the language, layout and phrasing of questions. A main validation study was further performed which asked 100 children with IBD to complete either a paper or computer version of IMPACT-III (UK) to help confirm statistical Validation (Davies, et al., 2005; Ogden, et al., in press).

Results

Children preferred the Likert scale and minor amendments were made following children’s comments on the clarity of the questionnaire (Ogden et al., 2008). The amended British version of IMPACT is further referred to as IMPACT-III (UK).

Psychometric evaluation of IMPACT-III (UK) suggested good internal structure and internal reliability of each domain. A five factor structure was most suitable for the British sample consisting of the following domains; IBD symptoms, Energy, Concerns/worries about living with IBD, Embarrassment and Body image. QoL scores range from 0 (the worst possible QoL) to 100 (the best QoL). The computer version of IMPACT-III (UK) collected comparable results to the paper questionnaire and reduces the time taken to calculate QoL scores (see Ogden et al. in press for further details).
Discussion
Incorporating IMPACT-III (UK) in clinical practice should ultimately allow HCPs to quickly and effectively measure the psychosocial well-being of children with IBD alongside their physical needs. QoL instruments are used in the adult IBD population and are proven to be important and useful additions to clinical practice. QoL instruments enable a measure of outcome that is meaningful and significant to health professionals, patients and their families (Abbott, et al., 1997; Abbott and Gee, 1998; Abbott and Gee, 2003). They can complement information gained from clinical measures of the disease (i.e. the Crohn’s Disease Activity Index, (Yoshida, 1999) whose focus is exclusively on a patient’s disease activity. Assessing change and progress through laboratory or clinical tests is useful, however, it is also important to examine a person’s psychosocial satisfaction (Higginson and Carr, 2001). Variations in QoL may exist amongst patients with similar disease activity due to a variety of reasons (i.e. coping strategies, social circumstances) and could be examined further. Finally, QoL instruments can help evaluate how different treatments affect patients’ lives and whether or not they have a beneficial effect on well-being (Abbott et al., 1997). If treatment is suited to a patient’s lifestyle it may be that they are more likely to comply with the chosen treatment regimen.

Ultimately, outcomes of consultations using IMPACT-III (UK) could benefit the patient as treatment decisions will not be derived from physical outcomes alone. HCPs must continue to make clinical decisions based on physical presentation however, it is crucial to also consider the psychosocial elements of paediatric IBD as its symptoms and common treatments severely impacts upon a child’s social life.

The validation of the computer version of the IMPACT-III (UK) is particularly appealing as patients’ QoL can be calculated immediately. Consideration of the domain scores could help arrive at clinical decisions that are more suited to patients’ lives. The culture of medicine should encourage the merits of understanding the psychosocial impact of IBD if medical decisions are to be satisfactory for clinician and patient. The development of purely quantitative means to measure the experiences of children with IBD may not be adequate enough to challenge the health care service culture. Another approach is needed that has further potential to add more qualitatively to the knowledge base of HCPs.
The Narrative Inquiry (NI) Technique

Background
NI is a medium through which to present and reflect upon life experiences (Goodley, et al., 2004) and presents more than a snap shot of peoples’ experiences, by describing in detail individuals’ thoughts and actions. NI has recently gained credence (Goodley, 1996) and the frequency of narrative based research exploring issues such as disability and illness are high (Bogdan & Taylor, 1994; Davies, 1993; Gerschick & Miller, 1995; Groce, 1992; Keith, 1994; Morris, 1991; Shakespeare, et al., 1996). NI is respondent led and helps understand the experiences of individuals in a format accessible to patients, parents, academics and health professionals. Illness narratives appear useful in developing a sociological understanding of IBD by depicting individuals as complex human beings and showing how society has a large part in shaping the reactions towards different types of illness.

Method
Interested participants from the QoL study gave their contact details for recruitment in this phase of the project. Type, duration of disease and sex of the individual were considered when choosing suitable participants although only a very small number of children were recruited due to the time consuming nature of NI. A boy with UC aged 11 and his mother and a girl with CD aged 13 were selected and sent an information sheet about the study. Once informed consent was obtained, interviews were conducted, recorded and transcribed verbatim, interview scripts were utilised along with mind maps and using principles of the constant comparative approach (Glaser and Strauss, 1968), the first drafts of the stories were constructed. Drafts were sent to the respondents before the next interview for comments and amendments. This collaborative approach continued for as long as necessary with follow-up interviews and stories were regarded as ‘complete’ once respondents and the researcher were content that they reflected an accurate description of respondents’ experiences of IBD.

Results
The stories are best consumed in their original format but for the purpose of this paper excerpts from the stories will highlight some key themes to demonstrate the potential of NI as a method for understanding social aspects of IBD.
Each of the respondents had their own ways of living with IBD and these were successfully conveyed in their narratives.

‘I understand that other people can get very sad about having the disease but I’m not that sort of a person. I have UC and that is that, it isn’t very nice and sometimes it hurts, but I think by accepting that I have it and by taking the medicine like I’m asked to, I can get on with having a normal life.’

**Nathan (male with UC, aged 11).**

‘... being a parent, you read up on what UC and IBD is all about. I found out that there was a possibility that one day he would need surgery. I just couldn’t visualise this... I just thought... that once Nathan starts eating solid foods like curry and hot pots, when he starts growing up and bulking out, everything will be alright again. His bowel will start to settle down and he will be normal again and not need surgery.

I suppose that’s how I coped with it really, denial I suppose you could call it. Although... I was coping and being realistic about things on an everyday basis. I realised that we had to get Nathan through the symptoms he was experiencing, and I managed to do that by being aware of the closest toilets and all that. ‘**Claire (mother of Nathan)**

‘Mum and Dad were worried that I would take the news of having CD badly. I have to admit I am more in shock than anything! When the doctor gave me the booklet I felt like I was in a dream again and it was someone else who had the disease. It is nice to know what I have wrong with me and that the doctors and nurses can try and help me now.’ **Katey (female with CD, aged 13)**

Nathan’s story was different to Katey’s as it focussed more on his everyday life. His UC was mild compared to Katey’s CD. Katey’s story discussed her IBD a lot and how HCPs influenced her attitudes towards treatments;

‘The nurse told me that they would have to put like a flexible camera up my bottom... I thought it sounded disgusting but she said that it was just like going to the toilet or something, so I trusted her and let them go ahead with it... I started crying because it really, really hurt... I heard Dad getting
angry and saying to Mum that it was a children’s ward and they should know how to talk to children and they should know what would hurt us or not.’ **Katey**

‘I went to hospital to find the nurses had ordered me some strawberry milkshakes ready for the long month ahead. In the morning I had a nice nurse helping me to drink the carton. It got really sickly and because I am still ill, I felt like I couldn't drink all of it. The nurse really helped me, she told me not to worry and put it back in the fridge until I felt I could take some more. I think she must know what it tastes like, because it gets worse and more sickly the warmer it gets, so it was nice of her to put it back in the fridge for a while. She kept giving me little aims by saying in fifteen minutes we would try another few mouthfuls which really helped me along.

... Today another nurse was working. She was not as nice as the one I had yesterday though... Today the nurse was not helping me drink the shakes but just telling me that it was for my own good. I already know that but it doesn't make it any easier to drink. I was in a bit of a mood after that and it made me not want to drink them even more.’ **Katey.**

Many narratives highlighted the paradox of the desire to tell others about their IBD (to gain support) but not tell everyone (in case of bullying);

‘Break time was difficult but not as difficult as lunch time. Having to sit there while other people ate was absolute torture... Jessie had a pizza and it looked really nice. Stacey offered me a crisp and I couldn't take one. She didn't do it on purpose to be mean, she just forgot. I felt really stupid sitting there with a carton but Stacey said it made no difference to anyone and nobody really noticed. That made me feel a little bit better.

... Stacey said that [Phillip] had asked why I drank the drinks and if I had something wrong with me. I have lost weight because of my CD... Phillip said ... I was a bit thin and [people] were talking about me behind my back. This really made me feel sad and I started crying. When I got home I told Mum what they had been saying and she told me it was only because they didn't understand and perhaps I should tell them. When I told Mum that they would probably make more fun of me, she understood and told me to remember that it was none of their business. It was them that were being stupid and immature.’ **Katey**
‘I don’t try to hide my IBD (this is why I have told some of my closest friends). At the same time I don’t go around bragging about it like I am someone special! I think by telling everyone that I had IBD would make it harder in the long run and might mean that certain nasty people would bully me.’ Nathan.

This small selection of excerpts should help appreciate the potential of the NI approach whilst highlighting some key concerns for children with IBD and their families.

Discussion
People (including HCPs from Booth Hall Hospital, children with IBD and their families) felt the stories provided insight into the lives of the children. Stories help place the individual in the context of the social environment and allow people to realise the implications of both the disease and treatment on lives. HCPs should be encouraged to read the full narratives as reading the stories allows empathy to be gained which may aid future interaction and consultations with patients.

The NI technique appears to be more conducive to helping develop a sociological understanding of the topic of IBD than the QoL instrument. The results of IMPACT-III (UK) could serve to pathologise the patient population especially if HCPs use them to detect further ‘problems’ within the individual and further label them as certain patient ‘types’. Nevertheless, both approaches together can potentially encourage HCPs to appreciate the implications their practice has on others’ lives. Reading narratives could aid HCPs empathy of children with IBD and may encourage a true appreciation of the significance of ‘the social’. The importance of QoL data would then be apparent and IMPACT-III (UK) could be implemented effectively in practice.

Towards a sociology of IBD and a socially aware health service.
HCPs are significant people in the lives of those with chronic illness and potentially can help alleviate some of the negative psychosocial effects of having IBD as well as the physical. Therefore HCPs should be given as much information about the psychosocial nature of IBD to enable them to fully appreciate the impact of their decisions on patients’ lives. Some of the central themes in sociological theory integral to contextualising the data collected by both methods can help consolidate the importance of the social understanding.
Disability theory from academic and activists perspectives challenge the notion of ‘disabled bodies’ as ‘deficient’. The social model of disability they propose describes impairment as a physical or mental difference and disability as the disadvantage or restriction of activity caused by a society that does not take account of people with impairments (Oliver, 1992). Such a definition provides potential for people with impairments/chronic illnesses such as IBD, as focus shifts from pathologising their experiences to understanding their concerns in terms of socially oppressing attitudes and environments that contribute to their realities. Such disablism appears to act as a significant causal factor for the adverse social problems faced by some children with IBD;

‘It is still a bit horrible using the toilets in school though because sometimes I take a while and I think that others are wondering what I am doing.’ Katey

Some children with IBD feel they cannot go out because they do not have appropriate facilities for their needs. The above quote supports the finding by Taft et al. (2009) that even the perceived social stigma attached to flatulence and issues of the bowel causes children to feel bad about using toilets outside their homes. It is the environment and attitudes that impact on Katey’s well being in this example, as supported by the social model of disability.

Despite the potential of the social model of disability, Shakespeare (2006) and others (Thomas, 2007) fear that it serves to dichotomise impairment and disability and does not allow ‘impairment’ to be socially interpreted as disability is. HCPs could argue that their work is concerned with ‘impairment’ and not with issues of ‘disability’. Shakespeare demands an exploration of the social dimensions of impairment and believes that if equality for people with impairments is to be realised, the dichotomy between impairment and disability should not be over-stated. The impaired individual cannot be removed from their social environment, therefore social arrangements regarding children with IBD should be considered by HCPs when understanding their impairment, to ensure their inclusion into mainstream activities is attained. By understanding the social plight of children with IBD, a socially sensitive decorum and decision may transpire amongst HCPs which could ultimately enhance patients overall well being.
Sociological theories of the body also seek to understand the links between biology and culture and to work towards an embodied understanding of reality. Sociologists understand that grand narratives (such as biomedical explanations) are limited and need to be critically evaluated to uncover the realities of lives. There are cultural as well as biological considerations in all aspects of health and illness (Morgan and Scott, 1992) therefore the study of IBD needs to become more critical of an exclusive biomedical and pathological approach. Having IBD for some children is difficult because of the impact on their lives and an understanding of this from their perspective (aided by NI) is essential.

Clough states ‘the final analysis lies in the reader’s own ‘reading’ of the story’ (Goodley, et al., 2004, p.161). This could prove useful for both interpretation of QoL and narrative data. It is crucial that HCPs in the care of children with IBD are granted access to different kinds of information highlighting psychosocial aspects of IBD. It is not possible in the scope of this study to assess the impact of the development of IMPACT-III (UK) and/or stories upon the HCPs but it appears that both methods can be used together to demonstrate the complexity of living with IBD. If HCPs develop a psychosocial awareness of their patients, they may be less likely to think of their clients as medical ‘cases’ that need to be dealt with individually. By engaging with the data gained from the above methods, the social implications of HCPs clinical practice and the contextualisation of the social could ultimately encourage inclusion and improvement of the lives of children with IBD.
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