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USING NARRATIVES WITHIN A CONSTRUCTIVIST INQUIRY TO UNDERSTAND OLDER PEOPLE'S DECISION-MAKING PROCESSES ABOUT THE USE OF HEALTH AND SOCIAL CARE SERVICES.

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Despite the availability of health and social care services designed to support people in their own homes, older people often under-use or refuse these. It is now acknowledged that this phenomenon contributes to older people being admitted to hospital and long-term care in circumstances that could be avoided. In order to understand how the uptake of supportive and preventative services can be improved the first author (JT), supervised by GG and SD, developed a constructivist inquiry to explore what factors enhance or bar service use. This paper describes how narratives were used not only to help indentify decision- and choice-making influences, but also as a way of enhancing the hermeneutic processes associated with constructivism.

Keywords: constructivism; health care; decision-making; hermeneutics; narrative methods; older people; social services, utilization

Older people often underuse or refuse to use health and social care services designed to support them in their own homes (Joseph Rowntree Foundation, 2004). This has contributed to increased pressure on acute hospital services as older people are being admitted to hospital or long-term institutional care, which might otherwise have been avoided (Health and Social Care Change Agent Team, 2004). Consequently, current UK government policy continues to focus on developing services to support older people in the community and on reducing the numbers of older people in hospital and long-term care (Department of Health, 2006a; 2006b).

Despite this investment and commitment to improving care and services, previous studies of the uptake of health and social care services indicated that more research was required to understand how local authority budget constraints, pressure on hospital beds, mental capacity issues, individual financial resources and the cultural sensitivity of mainstream services might affect older people's decision- and choice-making processes (Atkin, 1998; Kane & Kane, 2001; Tanner, 2001; Wenger, 1999).

There has also been increased demand for user involvement in research and practice development (Nolan, Hanson, Grant, & Keady, 2007). However, some groups in society do not have the same opportunities to influence service development because meaningful participation is affected by a range of issues, including cultural divisions, language barriers, gender, ill health, time and resources (Boote, Telford, & Cooper, 2002; Fudge, Wolfe, & McKevitt, 2007). This paper describes how narratives were used with older people, often excluded from mainstream consultation processes, to engage them in research and to evaluate the hermeneutic processes associated with constructivism.

For researchers seeking to gain insights into people's experiences of a particular issue, a constructivist methodology is particularly useful as this approach acknowledges that peoples'

understandings of their lives and situations are multiple and complex (Guba & Lincoln, 1989). In order to appreciate how personal understandings and life experiences shape individual's actions constructivism requires investigators to find ways of working that enable them to work in partnership and negotiate meanings and interpretations with relevant stakeholders (Appleton & King, 1997; Geanellos, 1998; Koch, 1996; Rodwell, 1998; Schwandt, 2000). By working in this way it is argued that changes to health and social care practice arising from these insights will be more meaningful to service users (Mitchell & Koch, 1997; Rodwell, 1998).

Methodologically constructivism is underpinned by approaches that aim to collect data in a dialectic (reflective) and hermeneutic (jointly constructed) manner (Guba & Lincoln, 1989, Laughlin & Broadbent, 1996; King & Appleton, 1999; Wainwright, 1997). If researchers are to share information and undertake joint working within a constructivist inquiry the use of a hermeneutic circle is recommended, as this process enables the inquirer to introduce claims, concerns and issues from other respondents, their own experiences and the literature into a process for testing and verification (Engbretson & Littleton, 2001; Guba, & Lincoln, 1989; Lincoln & Guba, 1985; Rodwell, 1998). However, Rodwell (1998) argues that this does not have to be a physical circle, where the inquirer and respondents are in constant interaction. Instead, it is suggested that the hermeneutic circle should be a forum where perspectives can be presented, considered, evaluated, understood, rejected or incorporated into an emerging understanding of the phenomena under investigation (Rodwell, 1998). Although Rodwell considers the hermeneutic circle within a constructivist inquiry, her approach does not take account of Guba and Lincoln's argument that the constructions generated are always shaped by human experiences (Guba & Lincoln, 1989).

While looking for a way of accounting for human experiences within the hermeneutic processes of the study, the first author encountered the work of Engebretson & Littleton (2001). This work was of particular interest as it presented a constructivist-based model for nursing practice which recognized that a nurse should take account of the culture (beliefs and values), experience (both personal and professional), knowledge (formal and informal) and personal knowing (tacit knowledge) of both parties in order to understand a client's healthcare needs. Engebretson & Littleton's model was therefore modified and used to create a hermeneutic circle for this study. This model was of particular value, as it enabled the authors to illustrate how people's stories of decision-making could be informed not only by data gathered during the course of the study, but also by professional experiences and knowledge of the literature relevant to the study (*see Figure 1*).

The modified model provided a theoretical framework within which the data and personal experiences could be brought together. However, it was recognized that a practical vehicle was needed through which older people could be engaged in hermeneutic processes. Narratives were identified as a way in which this could be achieved.

"//INSERT FIGURE 1 ABOUT HERE//."

Method

The use of narratives to understand the individual experience of health and social care has a long history (see for example, Bytheway, 2003; Hogarth & Marks, 1998; Johnson, 2004). However, more recently there has been a renewed interest that has recognized the value of narratives to health and social care practitioners (Bornat, 1999; Brown, 2008; Bytheway, 2003; Greenhalgh & Hurwitz, 1998; Housley, 2000; Johnson, 2004; Nygren, Norberg & Lundman, 2007; Ridge & Ziebland, 2006). Although Ellis & Bochner (2000) argue that narratives can

enable people to see and understand their own story, Greenhalgh, & Hurwitz (1998, p. 381) claim that narratives can help practitioners and researchers understand people's experiences more holistically since they provide a " . . . meaning, context and perspective for the patient's predicament". Furthermore, Greenhalgh & Hurwitz (1998) suggest that narratives serve an important purpose in education and research because they are memorable, grounded in experience, encourage reflection, set a patient-centered agenda, challenge received wisdom and can generate new hypotheses. Since this study aimed to explore the factors that influenced people's decision and choice-making processes when using, or anticipating the use of, care services, it was also interesting to note Donald's (1998) work which suggests that narratives can provide insights into the effects of culture and history on individual's views of illness, care and treatment.

In the context of this study, narratives were initially seen as the gathering of people's stories based on their lived experience, and their use or nonuse of health and social care services. At the outset it was envisaged that narratives would be recorded in some way and fed back, so that key claims could be checked with each person. However, the structure and form of the narratives was not predetermined. Instead, reflecting the constructivist methodology that framed the study, it was seen more fitting to explore how narrative stories should be presented once some stories had been collected.

Participants

The study was undertaken in three study sites:

- A community support and out-reach service for Black African Caribbean elders.
- A day-care and community out-reach service for older people with memory or cognitive problems.

- Three luncheon clubs in an economically deprived area of a large city.

These study settings were chosen reflecting the factors identified earlier in this paper as barriers to consultation and service development.

Ethics approval for the study was granted by a local NHS research ethics committee. As part of the approval process, information sheets and consent forms were developed for the participant observation and interview phases of the study. At each study site the first author spent time talking to people, explaining the nature of the study and why she was engaging people in different service settings. After several visits, people were then asked if they would sign consent forms to give permission for notes to be made by the first author based on her observations and/or conversations. Some of the challenges associated with this process are documented in a separate paper (Tetley, et al. 2002).

The number of people attending each of the services varied. At the African Caribbean center approximately 40 people attended the luncheon club, 10 women attended the craft group, and home support workers visited six to eight people. At the day care centers for people with memory and cognitive problems, eight to 10 people attended on the two main days when the first author visited. Finally, between 40 and 50 people attended the luncheon club.

Following the initial visits to each center the following numbers of people gave their consent for the participant observation phase of the study in each setting: 25 people from the African-Caribbean service, 10 people (or their carers) from the services for people with memory/cognitive problems, and 31 people from the luncheon clubs. The varying numbers of participants providing consent reflected the overall size of each service. A list of who had given consent was kept by the first author every time she visited a center. No records were made of conversations where signed consent had not been obtained. Where general observations were made, care was taken to ensure that people who had not given consent were not identified. Even where written consent had been obtained this was re-checked with individuals each time the first author visited the study sites. When selecting

people to be interviewed each individual was asked to sign a consent form indicating they were happy for a tape recording to be made. A total of 24 people were interviewed (eight from each study site).

From Interview to Narrative

Following the interviews, the researchers wanted to give people the opportunity to reflect more critically on the information they had shared. The notion of taking back the full interview transcripts was rejected, as evidence suggests that people find these difficult to read, too information rich and as a consequence they can often focus more on grammar or syntax than content (Bornat, 2002; Clarke, 2000; Echevarria-Howe, 1995; Northway, 1998). In looking for alternative ways of taking data back to participants we noted the work of Ellis & Bochner (2000) who make a case for personal narratives being a way in which researchers can enable participants to "feel" the truth of their story and become co-participants, engaging with their story morally, emotionally, aesthetically and intellectually. Following this initial lead, the first author then reviewed the literature for additional guidance on the use and construction of narratives in a health and social care research project.

Constructing Narrative Summaries

Ellis & Bochner (2000) recommend that as a research text narratives should be a story of the individual's experience but written free from academic jargon or abstracted theory. To construct narratives and holistically analyze field texts such as transcripts, documents and observational field notes it is therefore suggested that researchers must read, reread and sequence the raw data until it goes beyond description and thematic development, until the researcher can understand the lived experience of the person telling their story (Ollerenshaw, & Cresswell, 2002). The first author, supervised by GG and SD, therefore started the narrative constructions

by reading the transcripts of interviews in conjunction with the notes made in the field notes during the participant observation phase of the study. For example,

One of the men from the luncheon club network (Mr Smith) told the first author (JT) that he had been receiving home care support for around eight years. When JT spoke to him about his decision to use homecare, he explained that the hospital had suggested this service after he had been in hospital for five or six weeks, following a slight stroke. JT then noted in her field diary that when she interviewed Mr Smith she wanted to ask if he minded having home care. In the interview Mr Smith said:

> No. No I didn't mind, no. Well I preferred it rather than going into a nursing home and that. It's far better than going in a nursing home. I prefer it.
>
> Although Mr Smith's response in the interview illustrated why he had agreed to accept homecare JT noted in the narrative that:
>
> Mr Smith told me that he has regular home carers most mornings, lunchtimes and evenings. When the regular home carers come to see him Mr Smith finds the service is good. Unfortunately, however, he has told me that sometimes the home carers don't turn up.
>
> When JT asked Mr Smith about this in the interview, he said:
>
> Sometimes they don't turn up, and sometimes they're late and sometimes they're early. You have some [that] are better than others, you know, but sometimes they come early and that sort of thing and I mean for teatime, sometimes they come at 3:00. Well I mean I've only just had my lunch, you know, and I have to refuse them. So by and large its some are better than others.

When JT returned to share the narrative with Mr Smith he confirmed that in the main he was happy with the homecare service he received, but he accepted and continued to use the service, primarily because it enabled him to stay in his own home, even though it was not always fitting his personal and domestic schedules.

Results

The final narratives were therefore a summary of our conversations recorded in field notes or interviews. Whilst some direct quotes were used these were carefully chosen to highlight a particular point. Participants were asked to read and comment on the narrative summaries. Notes were made of any comments and corrections required. Everyone was then offered a copy of the final version of their narrative. Using the narratives as part of a hermeneutic process proved to be a useful process in relation to:

1. Enabling commentaries by participants, on a structured summary of the information that they had shared.
2. Identifying the factors that people identified as affecting their decision and choice-making process, when using or contemplating using care services.
3. Identifying the influence of life experiences in relation to decision and choice-making processes that might not have been immediately obvious.
4. Enabling a more holistic perspective which drew on the formal interview material and the notes that I had made during the time I had undertaken participant observation work in each setting.
5. Enabling me to feed back to participants the value of the information that they had shared with me.
6. Raising empowerment and ethical issues.

The narratives fulfilled these six points in the following ways

Enabling Commentaries by Participants

When the narrative summaries were returned to individuals, this often generated further discussion. For example, some people gave an update about their current situation. When Mrs Rodgers (from the the African-Caribbean support service) was interviewed she described how she had applied for aids and adaptations to her bathroom when she was struggling at home during her illness with breast cancer. A note of this had been made in her narrative which prompted her to explain that someone from the Aids and Adaptations Service had recently fitted a support rail around her toilet and given her a board to help her get into the bath. She said that she didn't really need these any more but she had them fitted anyway in case she needed them in future.

During the construction of the narrative for Harry from the luncheon club, it had been noted that his decision to buy an electric scooter to help him get around was of particular interest because this had in turn led him to apply for a ramp to be fitted to the step outside his house. On the day that JT took Harry's narrative back to him she was surprised to see that the new path and ramp were being fitted by local contractors. Harry said that when he got the letter about the work, so soon after she had last visited him, he wondered if she had managed to get things speeded up. JT said that she had not, and explained that an occupational therapy colleague had warned her that anyone trying to speed up the process of fitting a ramp on the grounds of deteriorating health could actually make matters worse. Harry himself said that he could see that if they thought he might die sooner rather than later, then they would not see the need to do the work; he laughed at this.

Because the narrative had described the problems that Harry had experienced applying for an adaptation to the pavement, it prompted him to recount his recent difficulties applying for pension credit. Harry described how he had had to fill in the application form four times. He explained that he had bought a black pen especially to complete the form, but each time it was returned. On the fourth occasion he explained that he had rung the pension office who told him that the pen he was using was not dark enough! Harry went on to say that despite this difficulty it had been worth the effort as he was now £100 a week better off. He was so pleased with this outcome that he showed JT his pension book and was happy to talk about his finances, which many of the other older participants were reluctant to do. After reading and commenting on the narrative, Harry said that he had not realized that he had told JT so much, but he was pleased that someone had taken an interest in him.

In addition to generating comments on the fidelity of the narratives some participants also said that they had enjoyed reading their stories. Indeed after reading her narrative Mrs James from the African-Caribbean day center hugged JT and said she could not have wished for anything better. She took a copy of her narrative home and said she was going to frame it. For people like Mrs James the experience had evidently contributed to a sense of pride and an affirmation of her personal identity.

Identifying Decision and Choice-Making Influences

Whilst a more detailed analysis of the interviews was conducted to explore decision and choice-making in relation to the use of care services, the narrative summaries also highlighted tentative issues for discussion when JT returned to participants in the study. In one example, Mrs James (from the African-Caribbean community) explained that she was cared for by her daughter. It was noted in the narrative that:

> Her daughter, Nadine, does most of the housework and laundry. Mrs James and her daughter do the food shopping together and get a taxi back home. Because Nadine lives with Mrs James they don’t get any help with care, they also don’t claim any benefits. Mrs James told me that they had been advised that Nadine could claim the attendance allowance but when they saw the application and the detailed information that they would have had to provide they didn’t apply.

This example enabled JT to check with Mrs James about whether filling out paperwork had acted as a barrier to applying for benefits. She indicated that this had indeed been the case.

The narratives also worked well with people from the centers for dementia care. For example, during her initial meetings JT had become aware that one of the women (Doreen) had refused to go back to a social services day care center to which she had initially been referred. In the narrative JT noted that she wanted to interview Doreen because she had tried another day care service for people with memory problems and had not enjoyed it. When she had stopped using this particular service she moved to the Alzheimer’s society day center. More specifically, JT wanted to find out why she did not enjoy the other day center and why she particularly enjoyed the day center she was now attending. In the narrative JT wrote:

> Doreen was referred to a social service day care center from the NHS assessment center to which she had originally been referred. She attended for a while but didn’t enjoy it as she said that the staff didn’t interact much with the people who attended the center. Jane said:
>
> It wasn’t a patch on [the NHS day center], you see. But we said, well stick it out and try it, and she did do, and then she got used to it after a while. And occasionally she said, oh we don’t do anything, they just all sit at one end gossiping, the staff,

and leave us to gossip between us. She wasn't very happy. And we said, well there's no other alternative really.

Doreen then became ill and said she didn't want to go back to the social services day center and so Jane had to start looking for an alternative. Jane told me that finding an alternative day care service for people with dementia was difficult. She also said that when she had been looking for alternative day centers and luncheon clubs near to where Doreen lives she was put off some of them because she felt the people there were much older than her mum. This prompted Jane to contact the dementia charity again to see if they could help them.

Through the narrative JT was therefore able to combine material from the observations and informal conversations with Doreen and her daughter, Jane, at the day center with quotations from the interview to cross-validate the issues that appeared to have affected their decision-making in relation to day care.

Other narratives enabled JT to establish how people had been involved in decisions about the services they received. Whilst undertaking participant observation in the African-Caribbean day center and outreach service JT accompanied a worker when she visited an older woman who was in the process of moving into long-term care. JT noted in her field diary that her move to a nursing home could be regarded as a fait accompli (Nolan et al. 1996). In the narrative JT wrote:

I asked Mrs Taylor about her health problems and she said that she didn't really know what had happened with her legs. She knew she had had problems with the veins in her feet, she couldn't stand up for long and was getting cramps. At first she had her toes amputated and then her foot. When she first went home from hospital she was able to walk in her flat with a frame. She had support from home care to

clean and look after her and had a commode but she was still able to cook for herself. She also had the District Nurse visit twice a day to give her insulin. After her amputations the wounds took a long time to heal because of her diabetes. Since her last admission to hospital she was unable to look after herself which is how she came to be moved into the nursing home where I met her. When I interviewed Mrs Taylor she told me:

The doctors in the [hospital] say they would send me in this home. I didn't even know about it. He sent me and I think they pay, they pay the fee for the, I think in December, January and February, two months. They say erm the time of how I have to start paying for myself now, is March. But that's why I, that's why he came in here he was fixing up the social people, to get the money.

At the end of the narrative JT noted that Mrs Taylor was able to confirm that she had not been given any choice about the move to a nursing home. She claimed she was moved to the home from hospital and had stayed there. The use of narratives therefore provided a mechanism for verifying the factors shaping older people's decision-making in this context.

The Influence of Life Experiences

When JT was writing up the narrative summaries the main purpose had been to provide people with an easy-to-read synopsis of the information they had shared with her. However, reflecting the work of Studs Terkel on the Great Depression (Terkel, 1970), JT became aware that when people told their stories key historical events had often affected their decision- and choice-making processes. One example of this can be seen in the interview with Mr Smith, a 96-year-old man from the luncheon club. JT made what was intended to be a light-hearted comment about his long life and good health being related to the fact that he had never married. Whilst

partly wishing that she had not made this comment, his response to the question made her think about the influence of people's lived experiences through difficult times on their decision-making. In the interview JT had said:

> JT I was surprised when you said you were 96.
>
> Mr S Well as I say, I'm fortunate in that respect I think.
>
> JT Do you think you've survived [so] well because you didn't marry?
>
> Mr S I don't know, I think I made a mistake in not marrying, actually. I went through the early 30s and late 20s through the depression. Well I went through that lot and that was it, that period. And then I used to read a lot, go to the library, that's where I learnt my photography. I used to take books out from the library. I read every book in the library in photography. Some I had four or five times I used to take them out. And that's where I learnt it.

At the time, this comment did not appear to be of particular importance. However, as JT prepared the narrative summary she suddenly saw this statement in another light and added the following comment:

> The issue of the economic depression of the 1920s and 30s affecting people's decision-making was of interest as my father-in-law, who is slightly younger than Mr Smith, was profoundly affected by his father's unemployment during this time. Having lived through the depression has affected his decision-making with regard to marriage, money, work and taking risks in life. This highlighted to me the importance of understanding someone's biography in the context of the historical time that they lived.

After her return visit JT added to the narrative:

I checked this out on my return visit to Mr Smith by asking him if I was right to think that the economic depression had had a profound effect on him. He said it had because he was unemployed and couldn't get work for a long time. During this time he was sent on a training course and got a few weeks' work but this finished after a few weeks. He said they coped as a family because his brother worked as a miner and his mother got a war widows pension. Mr Smith reiterated that it was during this time that he visited the library and learnt about photography. Whilst he was unemployed he earned some money by winning prizes for his photographs and taking wedding photographs. Mr Smith told me that his experiences at this time also affected his political views. He embraced left wing political activities and became a Union Shop Steward.

Enabling a More Holistic Perspective

Greenhalgh & Hurwitz (1999) have argued that narratives enable practitioners and researchers to understand people more holistically because they provide a meaning and context to the person's story. As JT looked across the narratives she found many examples of this. In one instance a woman from the luncheon club network told her about her painting and embroideries. In her narrative JT wrote:

> Violet has enjoyed painting and embroidery over the years and there were some wonderful examples of her work on the walls of her flat. Violet told me how she started painting on recommendation from a regular customer who brought his disabled daughter for clothes to the department store where she worked. Violet had been off work with what she called nervous exhaustion. I used a quote from the

interview in the narrative to illustrate how she explained how other people influenced her decisions to try new things:

> He said, now I want you to start painting. I said you must be joking. He said, no I'm not. I said, I can't paint for toffee, I said, I can't even draw for toffee in any case, so I said it's no use me wasting money on that. He said, you are going to learn how to paint. So I said, oh. And his wife stood there and she was grinning like a Cheshire cat, you know. When it came to with talking to him, he used to teach people like his daughter, that was his job, teaching them to paint and everything. So he said, I think you could do it. So he said, I will tell you what, get a piece of brown paper, and some newspaper, put them on the floor and get some paint, distemper or anything you want, put your brush in and just literally throw it on the paper. I said, you're having me on aren't you? He says, I am not. He says, that's what you want and he said you will find out it will help you so much. He said will you do it for me? So I said, alright. I didn't know whether to or not.

JT also wrote in her narrative:

> During the time that I met with Violet at the luncheon club she shared some of her health problems with me. She also told me how her GP had influenced her and her husband's decision to move to a flat when they were both very ill. By interviewing Violet and constructing her narrative I was able to check out how the role of others influenced people's decision-making processes.

The influence of professional and social networks in her life was interesting as research studies have found that social networks and social support can help older people maintain good health (Glass, et al. 2000). Moreover, a review of the literature (Hurdle, 2001) indicated that a

combined use of professional support and social relations were particularly important to women and they positively influenced women's health behaviors.

Establishing a more holistic understanding of the individual was important for the next stage of the study because the first author planned to undertake a more detailed analysis of the individual transcripts. It was evident that the second stage of the analysis would require JT to break down the content of the interviews into a range of codes and categories. When starting to think about this JT compared the value of the narratives in relation to the literature presented earlier in this chapter. As Donald (1998) suggested, the narratives had indeed provided insights into the effects of culture, history and people on individuals' views of illness and care. Supporting the views of Greenhalgh & Hurwitz (1998), the narratives also helped to provide a more integrated understanding of people's experiences that took account of important biographical contexts and their meaningfulness.

Enabling Feedback of the Value of Shared Information

By using narratives JT was able to explain to people the value of the information they had shared with her. In relation to one of the black male participants, Mr Morris, JT wrote:

> I have enjoyed meeting Mr Morris; he has always made me welcome and we seem to have enjoyed each other's company. Mr Morris has a strong character and knows what he likes and wants. I like the fact that he won't accept poor quality care services and challenges people when he isn't happy and stands up for himself. I wish more older people had the courage that he has. Since he has been in the nursing home, Mr Morris has made it clear to the staff when he hasn't been happy with things such as not having enough warm bedding on his bed and being served food that he doesn't like. I have interviewed a lady (Mrs Taylor) who is also from the African Caribbean community in

the same home as Mr Morris. Mrs Taylor told me that when she saw Mr Morris refuse his dinner she also pushed her plate away. I feel that he gives others the confidence to say no.

Indeed, Jerrome's (1992) study of older people and their social networks found that elderly peers can act as positive role models for their contemporaries:

> " . . . providing opportunities for self expression, a sense of security, a supportive network, a chance to confront some of the ambiguities and losses of ageing (p. 53)".

In another instance, a woman who JT had met at the luncheon club network shared some difficult and painful memories. In the narrative JT wrote:

> I would really like to thank Laura for sharing her experiences with me. My time with her gave me some powerful and unexpected insights into people's experiences of applying for care and services in later life.

Laura had shared an experience from her life that could not be discussed in a public forum because of the associated stigma. Whilst JT could not re-tell this particular experience, without Laura's openness and honesty, it would not have been possible to understand how hidden and difficult stories can influence decision- and choice-making processes. This finding is also reflected in the work of East (1999) who found that women are often negatively affected in their abilities to seek welfare and help by hidden barriers related to domestic violence, childhood experiences of victimization, mental health issues (addiction and depression), and low self-esteem.

Whilst the narratives proved to be a useful tool for sharing the interview material with participants, and for starting the formal analysis process, there were issues about their use that need further consideration.

Empowerment and Ethics

After reading her narrative one participant said that she felt that she had said things that she should not have done. She asked for the narrative and all the accompanying interview data to be destroyed. This was done. A similar experience was encountered by Clarke, Hanson & Ross (2003) who found that when introducing a biographical approach to care, one woman had been prepared to talk about her past but after a while she had become upset as she did not want to recall painful past experiences and refused to participate any further in the project. The request to destroy all the interview data about this woman raises the important issue of ethics. In this particular instance, the adopted approach (constructivism) coupled with a strong moral imperative about the importance of participants owning their narratives, propelled JT down a route where consent by and respect for participants was pivotal. Put another way, this was about the maintenance of high ethical standards and a commitment to research with people rather than research on people (Heron & Reason, 2001; Reason, 1994).

The request to destroy material was of additional interest, as JT had struggled to include painful or very personal information in the narrative in as sensitive a manner as possible. Indeed, Heath (1998) advises that where people have experienced pain, humiliation, violence and chronic illness, narratives can help people rediscover a sense of self worth and dignity.

The examples from the narratives given earlier illustrate how JT also tried to reflect back to participants the value of their individual contributions to the research. JT consulted each individual carefully about the content and construction of each narrative. For example, one woman had shared a very difficult issue about her past experiences of health care. Whilst these experiences still influenced her view of care and services, we talked together and agreed that it would be best to omit any details relating to this issue from the narrative. Despite all these efforts, it must be acknowledged that if the aim of narrative working in research and practice is

to work in partnership with participants, the right to censor information provided or request its destruction must lie with the person whose story is central to the narrative (Brody, 1994; Hudson-Jones, 1999).

Discussion and Conclusion

The use of narratives in this study enabled the researchers to gain a preliminary understanding of the factors that had influenced people's decision- and choice-making processes when using or contemplating the use of care services. These included:

- experiences of struggling to manage their everyday care needs
- the role of personal factors (including resilience, alternative forms of support and social networks)
- individual values and norms
- the influence of biographical journeys, life history, faith, loneliness and bereavement
- individual responses, when faced with bureaucratic processes
- the availability of acceptable service alternatives
- system pressures constraining choice and control in decision-making.

These preliminary insights provided a useful starting point for the third stage of the study which was to be an inductive analysis of the data. Moreover, it was hoped that this final stage would lead to the development of an explanatory framework of the factors that older people themselves has identified as affecting their decision-making processes around health and social care services. These preliminary findings generated from the narratives were therefore particularly valuable as Lincoln & Guba (1985) argue that the first phase of theory development, prior to the use of qualitative data reduction and analysis procedures, should be underpinned by a process where there is a development of working hypotheses, concepts and hunches. They

suggest that these can then be used to develop themes and categories and can help explain relationships between the final concepts that emerge (Lincoln & Guba, 1985).

As the authors reflected more broadly on the use of narratives within a constructivist methodology they were also able to see other important contributions that they had made to the study. As noted earlier in this paper, hermeneutics is important within the constructivist methodology because constructivism is fundamentally based on interpretive principles. Geanellos (1998), on the other hand, argues that a danger of hermeneutic philosophy is that it does not require the interpreter to check what the person who told the original story meant. Indeed, Gadamer (1990) argued that hermeneutics simply requires the interpreter to grasp the meaning and significance that is transmitted from the original story or text. As JT was personally committed to participatory working in research, she was not prepared to accept that her interpretation of any data gathered during the course of the study would be adequate. The narratives therefore became a data-handling process that enabled JT to share her interpretations of people's stories and experiences with individuals and seek their feedback.

It has also been argued that the concept of philosophical hermeneutics was developed to advance an ontological argument that people's understandings of their lives and existence are not just based on the here and now, but also by history and culture (Linge, 1977; Guba & Lincoln, 1989; Parsons-Suhl, Johnson, McCann, & Solberg, 2008). The use of narratives within the hermeneutic circle was therefore of additional value, as illustrated in this paper. Narratives enabled participants to make sense of their own experiences in the context of the study that was being undertaken. They also enabled JT to relate one aspect of a person's life to their whole existence and visa versa.

Despite the advantages that the use of narratives brought to the study, the challenges associated with this process need to be acknowledged. As this paper has demonstrated, the use of narratives is not a simple process. The development of the narratives was time consuming, as data from field notes and interviews were revisited and used to create 24 individual narrative summaries that varied between four and 15 pages. JT also then revisited 22 of the 24 people (two people were not available due to changes in their circumstances) to provide an opportunity for them to read and comment on their narrative summaries. The construction of the narratives was also challenging because the summaries included personal information that could remind people of difficult life events. Efforts were made to ensure that the content of the narratives was a balance of personal, pleasurable and, where necessary, more sensitive information. This process could be criticized as the initial interpretations of the data were made by the researchers. The fact that the narratives were well received by all but one older person suggests that the decisions and processes used had created narrative summaries that were accurate and, in most cases, acceptable and authentic.

To conclude, although the construction and use of narratives within the inquiry process was time-consuming, their use within the hermeneutic circle provided a practical tool for feeding back qualitative data gathered during the course of the study. More specifically, as the authors worked through the process they started to recognize that it was the combined use of narratives and constructivism that enabled them to understand more fully how people's ontological constructions influenced their decision- and choice-making processes when using, or contemplating the use of, health and social care services.

References

Appleton, J.V., & King, L. (1997) Constructivism: A Naturalistic Methodology for Nursing Inquiry. *Advances in Nursing Science,* 20(2) 13-22.

Atkin, K. (1998) Ageing in a multiracial Britain: demographic, policy and practice. In M. Bernard & J. Phillips. (Eds.), *The social policy of old age*. (pp. 163-182). London. Centre for Policy on Ageing.

Boote, J., Telford, R., & Cooper, C. (2002) Consumer involvement in health research: a review and research agenda, *Health Policy,* 61(2), 213–236.

Bornat, J. (1999) *Biographical interviews: The link between research and practice.* London. Centre for Policy on Ageing.

Bornat, J. (2002) “Doing life history research”. In A. Jamieson & C. Victor (Eds.), *Researching Ageing and Later Life: The practice of social gerontology.* (pp. 117-134). Buckingham, Open University Press.

Brody, H. (1994) “My story is broken; can you help me fix it?” Medical ethics and the joint construction of narrative. *Literature and Medicine,* 13(1), 79–92.

Brown, L. D. (2008) Making it Sane: Using Narrative to Explore Theory in a Mental Health Consumer-Run Organisation. *Qualitative Health Research,* 18(12), 1673-1686.

Bytheway, B. (2003) *Everyday living in later life.* London. Centre for Policy on Ageing.

Clarke, A. (2000) Using biography to enhance the nursing care of older people. *British Journal of Nursing,* 9(7), 429-433.

Clarke A., Hanson, E. J., & Ross, H. (2003) Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing,* 12(5), 697–706

Department of Health. (2006a) *Our health, our care our say: A new direction for community services*, London: Department of Health.

Department of Health. (2006b) *A new ambition for old age: Next steps in implementing the National Service Framework for Older People. A resource document,* London: Department of Health.

Donald, A. (1998) The Words We Live In. In T. Greenhalgh & B. Hurwitz (Eds.), *Narrative Based Medicine: Dialogue and discourse in clinical practice.* (pp. 17-28). London. BMJ Books.

East, J. F. (1999) Hidden Barriers to Success for Women in Welfare Reform. *Families in Society,* 80(3), 295-304.

Echevarria-Howe, L. (1995) "Reflections From The Participants: The Process and Product of Life History Work". *Oral History,* 23(2), 40-46.

Engebretson, J., & Littleton, L. Y. (2001) Cultural Negotiations: A Constructivist-Based Model for Nursing Practice. *Nursing Outlook,* 49(5), 223-230.

Ellis, C., & Bochner, A. P. (2000) Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research.* 2nd ed., 733-768. Thousand Oaks: Sage.

Fudge, N., Wolfe, C .D. A., & McKevitt, C. (2007) Involving older people in health research, *Age and Ageing*, 36(5), 492–500.

Gadamer, H-G. (1990) The universality of the hermeneutical problem (translated D. Linge) In G. Ormiston & A. Shrift (Eds.), *The Hermeneutic Tradition from Ast to Ricoeur.* (pp. 147-158. Albany: State University of New York Press.

Geanellos, R. (1998) Hermeneutic philosophy. Part 1: implications of its use as methodology in interpretive nursing research. *Nursing Inquiry,* 5(3), 154-163.

Ginn, J., & Arber, S. (1998) Gender and old age. In M. Bernard., J. Phillips. (Eds.), *The social policy of old age.* (pp. 142-162). London: Centre for Policy on Ageing.

Glass, T. A., Dym, B., Greenberg, S., Rintell, D., Roesch, C., & Berkman, L. F. (2000) Psychosocial intervention in stroke. Families in recovery from stroke trial (FIRST). *American Journal of Orthopsychiatry,* 70(2), 169-181.

Greenhalgh, T., & Hurwitz, B. (1999) Narrative Based Medicine: Why study narrative? *British Medical Journal.* 318, 48050.

Greenhalgh, T., & Hurwitz, B. (1998) *Narrative Based Medicine: Dialogue and discourse in clinical practice.* London. BMJ Books.

Guba, E. G., & Lincoln, Y. S. (1989) *Fourth Generation Evaluation.* Newbury Park. Sage.

Health and Social Care Change Agent Team (2004) *Avoiding and diverting admissions to hospital: A good practice guide*, London. Department of Health.

Heath I (1998) Following the story: continuity of care in general practice. In T. Greenhalgh., & B. Hurwitz. (Eds.), *Narrative Based Medicine: Dialogue and discourse in clinical practice.* (pp. 83-93). London: BMJ Books.

Heron, J., & Reason, P (2001) The practice of cooperative Inquiry: Research "with" rather than "on" people. In P. Reason & H. Bradbury (Eds.), *Handbook of Action Research*. (pp. 144- 154) London: Sage.

Hogarth, S., & Marks, L. (1998) The golden narrative in British Medicine. In T. Greenhalgh & B. Hurwitz (Eds.), *Narrative Based Medicine: Dialogue and discourse in clinical practice.* (pp. 140-148). London: BMJ Books.

Housley, W. (2000) *Story, narrative and team work.* The Sociological Review. 48(3), 425-443

Hudson-Jones, A. (1999) Narrative in medical ethics. *British Medical Journal,* 318, 253-256.

Huebner, A., & Betts, S. C. (1999) Examining Fourth Generation Evaluation: Application to Positive Youth Development. *Evaluation,* 5(3), 340-358.

Hurdle, D. E. (2001) Social Support: A Critical Factor in Women's Health and Health Promotion. *Health and Social Work,* 26(2), 72-79

Jerome, D. (1992) *Good Company: an anthropological study of old people in groups.* Edinburgh. Edinburgh University Press.

Johnson, J. (2004) *Writing Old Age.* London. Centre for Policy on Ageing.

Joseph Rowntree Foundation (2004) *From* welfare *to well-being: Planning for an ageing society*, York: Joseph Rowntree Foundation.

Kane, R. L., & Kane, R. A. (2001) What older people want from long-term care, and how they can get it. *Health Affairs,* 20(6), 114-127.

King, L., & Appleton, J. V. (1999) Pearls, Pith and Provocation: Fourth Generation Evaluation of Health Services: Exploring a Methodology That Offers Equal Voice to Consumer and Professional Stakeholder. *Qualitative Health Researcher,* 9(5), 698-710.

Koch, T. (1996) Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing,* 24(1), 174-184

Laughlin, R., & Broadbent, J. (1996) Redesigning Fourth Generation Evaluation: An Evaluation Model for the Public-sector Reforms in the UK. *Evaluation,* 2 (4) 431-451.

Lincoln, Y. S., & Guba, E. G. (1985) *Naturalistic Inquiry.* Beverly Hills: Sage.

Linge, D. E. (1997) *Hans-Georg Gadamer Philosophical Hermeneutics.* California: University of California Press.

Mitchell, P., & Koch, T. (1997) An attempt to give nursing home residents a voice in the quality improvement process: the challenge of frailty. *Journal of Clinical Nursing,* 6(6), 453-461.

Nolan, M., Hanson, E., Grant, G., & Keady, J. (2007) *User participation in health and social care research: Voices, values and evaluation*, Maidenhead: McGraw Hill/Open University Press.

Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., & Kent, B. C. (1996) Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing,* 24(2), 265-274.

Northway, R. (1998) Engaging in participatory research: some personal reflections. *Journal of Learning Disabilities for Nursing and Social Care,* 2(3), 144-149.

Nygren, B., Norberg, A., & Lundman, B., (2007) Inner Strength as Disclosed in Narratives of the Oldest Old. *Qualitative Health Research,* 17(8), 1060-1073.

Ollerenshaw, J-A., & Cresswell, J. W. (2002) Narrative Research: A Comparison of Two Restorying Data Analysis Approaches. *Qualitative Inquiry,* 8(3), 329-347.

Parsons-Suhl, K., Johnson, M. E., McCann, J. J., & Solberg, S. (2008) Losing One's Memory in Early Alzheimer's Disease. *Qualitative Health Research,* 18 (1), 31-42.

Reason, P. (1994) *Participation in Human Inquiry.* London: Sage.

Ridge, D., Ziebalnd, S., (2006) "The Old Me Could Have Never Done That" How People Give Meaning to Recovery Following Depression. *Qualitative Health Research,* 16 (8), 1038-1053.

Rodwell, M. (1998) *Social Work Constructivist Research*. London. Garland.

Schwandt, T. A. (2000) Three epistemological stances for qualitative inquiry: Interpretivism, Hermeneutics and Social Constructionism. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Inquiry*. (2nd ed., pp. 189-213). Thousand Oaks: Sage.

Tanner, D. (2001) Sustaining the self in later life: supporting older people in the community, *Ageing and Society*, 21 (3), 255–278.

Terkel, S. (1970) *Hard Times.* London: Allan Lane/The Penguin Press.

Tetley, J., Haynes, L., Hawthorne, M., Odeyemi, J., Skinner, J., Smith, D., & Wilson, V. (2003) Older people and research partnerships. *Quality in Ageing,* 4(4), 18-23

Wainwright, S. P. (1997) A new paradigm for nursing: the potential of realism. *Journal of Advanced Nursing,* 26(6), 1262-1271.

Wenger, G. C. (1999) Choosing to pay for care. *Health and Social Care in the Community,* 7(3) 187-197.

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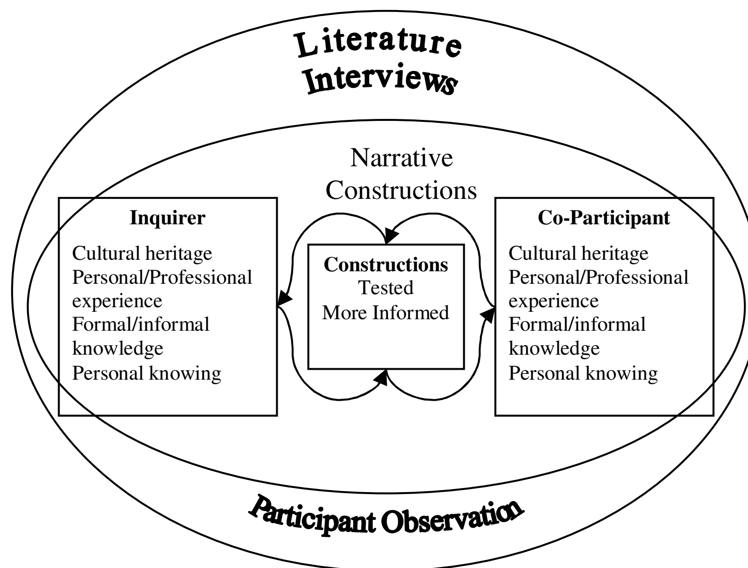
Figure caption

Figure 1. **Hermeneutic circle (Based on Engebretson and Littleton, 2001)**


Literature
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More Informed
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Participant Observation