

A Meeting of Minds: allowing older people with dementia to share their thoughts and experiences about health and social care, using counselling skills

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Abstract

There are significant numbers of older people who have and who will have some type of dementia and the extent of the limitations of present knowledge is painfully apparent. However, psychotherapeutic interventions, especially with older people with dementia, indicate some interesting lines of inquiry with the literature suggesting that reminiscence is a useful tool in researching the experiential world of dementia and can be combined with counselling skills. Moreover, entrenched positions and attitudes towards dementia are changing. Dementia is no longer perceived as an entirely negative state of being. It is now argued that older people with dementia can retain/maintain personhood and well being. They can 'tell' their story through their words and behaviour. Their story underpins and informs health and social needs. This article explores the use of counselling skills in researching the views and experiences of people with dementia.

Introduction

This paper incorporates a number of perspectives. It is concerned with the biological, psychological and social aspects of dementia, and the difficulties inherent in researching this topic. It also considers the relatively new approach of using counselling skills to gather such information, and suggests that it is likely that good qualitative researchers probably possess many of these skills. The importance of the relationship between the researcher and participant is also discussed, together with the recommendation that the investigator requires support and supervision when researching sensitive topics with vulnerable people over time. Finally, it is suggested that the growing practice of group work with people, who have a mild to moderate dementia, may provide a more suitable venue to ask about their health and social care needs. This would appear to meet the demands of the research, and encourage well-being in participants.

Background

We are part of an ageing world. By 2025, older people will account for 9.7 per cent of the total world population (World Population Prospects, 1986). An ageing population, supported by a smaller working population, may lead to an inability/reluctance to sustain expenditure on their health and welfare. In the UK there is also a significant increase in the number of older adults. In 1981, Britain had a total elderly population of 9.7 million (Falkingham, 1989). The numbers of young elderly, that is those aged 60-70 years, are

decreasing, but the numbers of those aged 75+ years are increasing. This will have major implications in terms of health and social care resources. Among the health and social care needs associated with later life is dementia. Cheston and Bender (1999: 61) estimate that 670,000 people in the UK have some form of a dementing illness, with perhaps 13,000 of these under the age of 65. About 500 new cases are diagnosed each day. Ineichen (1987) suggests that 7 per cent of the total population of elderly in industrialised societies will develop a dementia and, among those aged 80+ years, this figure may be as high as 20 per cent. Thus, the greatest risk associated with dementia is ageing.

Dementia is perhaps the most feared illness of all. It is an illness that strikes at our very existence and can devalue our humanity. It is loss writ large. With the overemphasis on rationality rather than relationship within Western society, people with marked cognitive impairment can be regarded as different, and a frightening reminder that this, too, may be our own future (Kitwood, 1997a; Mills and Coleman, 1994).

Cheston and Bender (1999: 51) argue that 'dementia is a diagnosis by exclusion' but every type of dementia has one thing in common: a loss of intellectual power (Woods, 1989: 18). Odenheimer (1989) defines dementia as a clinical syndrome of acquired decline of cognitive functions that is characterised by impaired memory, plus deficits in higher cortical functions, such as language or visuospatial function.

The Dementias

Among the irreversible dementias are three main subtypes: dementia of the Alzheimer's type (DAT), Lewy-body dementia (LBD) and vascular or multi-infarct dementia (MID). DAT is thought to account for two thirds of all dementias, LBD 7-30 per cent and MID 10-20 per cent (Cheston and Bender, 1999; Woods, 1989). People with DAT commonly tend towards problems with language, and recognition of people and places. MID decline tends to be patchy, with some abilities more affected than others. LBD is associated with delusions and hallucinations. As with all of the dementias, DAT, MID and LBD lead to a decline in the ability to communicate. Even relatively early on, there are difficulties in word finding and/or recall. If the dementia is accompanied by hallucinations, then the person in the early stages may not be sure if the people they see actually exist. Thus, relating and communicating to others may be a potentially anxious exercise, further damaging low self-esteem (Kitwood, 1997a).

Damasio, Van Hoesen and Hyman (1990: 97-98) argue that the symptoms associated with DAT emerge gradually and insidiously, after many years of silent damage. In some parts of the system, this damage may affect more than half of the available neurons before symptoms become manifest. Importantly, they point out that affected cortical regions will function defectively, rather than not at all. Research into the dementias has led to greater understanding of the problem and to the development of pharmaceutical interventions that alleviate symptoms. But, to date, there remains no proven cause or effective cure. It is the understanding of the psychological processes in dementia and reframing of the condition which encourage well-being in those with this illness. Entering the experiential world of people with dementia allows us to understand how they think and feel, and how to improve their quality of life. It also highlights the importance of relationship in this disease.

The Importance of Psychological Processes in Dementia

Kitwood (1989) has suggested two 'vicious circle' theories of the dementing process that are based on [one] the neurological impairment and [two], some

assumed psychogenic causation of neurological impairment. He argues that the labelling or medical diagnosis of neurological impairment produces a type of malignant social psychology imposed on the neurologically impaired individual, that can damage the fragile self-esteem and personhood of the older person. He further suggests that there is considerable overlap between the observed condition of the brains of mentally well-presented and those of demented elderly people (Kitwood, 1989). Indeed, this is one of the questions for future research, proposed by others in the field. Damasio et al (1990: 98) state that the issue of when enough impairment is enough, is important and unresolved.

Kitwood has been largely instrumental in bringing this issue into the forefront of academic and practitioner discussion, through the exploration of the relationship between the experiential self and the adaptive self that we present to the world. Dementia removes the cognitive supports that surround the adapted self and leaves the experiential self exposed and vulnerable. If the experiential self is weak and damaged prior to exposure it is even more susceptible to attack. It is this self that is sought and supported by all age groups within most forms of psychotherapy, where painful stories are told to another in the hope of achieving some understanding and resolution.

The importance of story cannot be underestimated. Life and story are intertwined, with both supporting and informing the other (Widdershoven, 1993). Moreover, Knight (1986) perceives the life story and its evaluation as central to the psychotherapeutic process, arguing that, in a sense, all psychotherapeutic interviews are life reviews. Butler (1963) suggests that most older people need to examine their life in order to justify their existence. Further, McAdams (1993: 11) reminds us that 'If you want to know me, then you must know my story, for my story defines who I am. And if I want to know myself then I, too, must understand my story'. Viney (1995: 248) finds that reminiscence comes naturally to people nearing the end of their life span, arguing that 'story retelling' is a highly appropriate form of therapy for this age group in which both the older story teller and the therapist construct a new, less hurtful, interpretation.

Mills and Coleman (in press) found that older depressed adults appear to benefit from brief psychodynamic interventions, based on life review and reminiscence principles. Moreover, Garland (1994), Mills (1998) and Sutton (1997), among others, suggests that older people with dementia can be encouraged to reminisce and review their lives. Recounting life stories, with the help of interviewer counselling skills, proved therapeutic for participants, and generated much rich data. In addition, participants were also able to touch on present day concerns (Mills, 1993; Mills and Coleman, 1994; Mills and Walker, 1994). In recent years, our understanding of the use of life story/ reminiscence work with demented elderly people has grown considerably (Bartlett and Cheston, 2003; Bornat, 1994; Coleman, 1994; Cheston, 1996; Gibson, 1998; Haight and Webster, 1995). Thus, the literature supports the view that older people with dementia can retain/maintain personhood and well being through relationships with others.

It is possible to 'tell' one's story through words and behaviour, and these stories can underpin and inform health and social needs, including spiritual needs, as the following vignette indicates: An elderly Eastern European Jewish lady, a refugee who did not speak English, was admitted to a busy London hospital ward. She clutched her handbag to her tightly. It contained very little except a small lump of old lard wrapped up in some paper. This was perceived as rubbish by the staff who wanted to dispose of it for hygienic reasons. The patient became very agitated and distressed when they tried to gently take it from her. She became so distressed that an interpreter was called to the ward. It transpired that the woman had been passed from country to country and the only thing she had to represent continuity in her life was this small piece of kosher rendered fat. This had been with her through all of her experiences. It was a symbol of her faith and linked her to her lost family and community. Acting as a transitional object, it continued to provide her with a sense of identity in the face of overwhelming loss. This explanation led to the understanding of the many meanings attributed to this object, including the important relationships in her life. Staff were also able to understand the older person herself, including her spiritual needs. Comparing this story with the

experience of someone with dementia is not difficult, and does indicate the need to be open to other explanations and approaches. Meeting spiritual and other needs in dementia may also require 'translators and educators'.

Nonetheless, the trend towards early diagnosis of dementia, together with possible pharmacological interventions, suggests that there will be an increasing number of people with mild dementia more able to verbalise their differing and diverse needs. Moreover, the steady growth in personal accounts of the experience of dementia indicates that society is more willing to accept these narratives and to accord empowerment to those who suffer from this illness (Davis, 1989; McGowin, 1994; Rose, 1995). Coleman (1986) suggests that not all older people will want to engage in the life review process, or even in that of reminiscence. This was found to be true with older people with dementia (Mills, 1998). However, even when older people are willing to work psychotherapeutically, or to take part in research, other important issues must be considered. There is a need to have knowledge of the ageing process itself, and to recognize that older people do not fit neatly into the category of 'old age'. Older people have had different life chances, experiences and concerns. The problems they bring to the work may require the therapist/investigator to adopt a more flexible approach, to be prepared to work at a slower pace, including the need to speak clearly. If younger, the therapist/investigator can only hazard a guess about how it feels to be 'old' and the effort involved to remain independent in late life. It is particularly important that the person with dementia does not feel overwhelmed.

Zarit and Knight (1996) draw attention to the complexity inherent in working with older adults, citing work by Woodruff (1985) who finds that older adults arouse more slowly than younger adults, but take longer to return to a state of acquiescence, and Malatesta and Izard (1984) who report that older people's facial expressions can simultaneously express characteristics of several emotions. Of some importance for younger workers is their finding that younger people are less accurate in identifying emotion in pictures of older faces. But, in order to fully engage with people with dementia, it is necessary to understand

their emotional world. This is not an easy task.

Kaplan (1990) argues that:

Working with clients who have dementia can raise deep emotions because dementia compromises much of what makes us unique as human beings ... As researchers, practitioners, and as human beings, we bring with us feelings about ourselves and our parents, grandparents and significant others. Whether or not we are aware of these feelings - or experience them directly - they influence our work

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Thus, the researcher needs to be prepared to enter the world of people with dementia, but to recognise the personal cost to themselves. Counsellors and psychotherapists are taught how to protect themselves and their emotional health, and are required to have regular supervision. This is necessary because counselling and psychotherapy endeavour to provide the client with a safe and facilitating environment to use the mind of another to explore personal pain and concerns. Within dementia, those who have this illness also use the mind of another, whoever that other may be, to make sense of their world. Resolution is possible in dementia, often at a deeply unconscious level (Cheston, 1996; Mills, 1997, 1998; Sinason, 1992). It is suggested that researchers who engage in sensitive work with this client group also require this knowledge and support. Sutton and Cheston (1997) stress that when we 'hear' the pain in the person with dementia, we do so at some cost to ourselves.

Cheston (1996) argues that good dementia care is essentially psychotherapeutic. It is concerned with each person's unique subjective experience. It validates personal experience and focuses on establishing meaning/understanding. It is also concerned with issues of life history and identity enhancement. Implicit in this, is that dementia work is concerned with relationships.

The Importance of Relationships in Dementia

Mikhail Bakhtin, the Russian philosopher states that:

I cannot manage without another, I cannot become myself without another; I must find myself in another by finding another in myself (in mutual reflection and acceptance) (Bakhtin, 1984: 287)

Heard and Lake (1997) argue that our ability to form relationships with others is given to us through evolutionary and social influences. Building on the need of the other for survival purposes, humans have developed non-verbal and symbolic patterns of relating (Stern, 1985; Trevarthen, 1979). This is most clearly demonstrated in the attachment between mother and child, where Bowlby (1969) argues that care-giving and care-seeking attachment behaviours in the care-giver/child dyad are adaptive and instinctive. Moreover, attachment behaviours are thought to often operate outside of conscious awareness (Bretherton, 1985). Attachment theory contends that the need for safety and reduction of anxiety triggers infant attachment behaviours which are activated in times of stress. Further, psychodynamic arguments suggest that these experiences will be represented in a variety of ways throughout vulnerable periods in the lifespan. Miesen (1992, 1993) hypothesises that the vulnerability associated with feelings of permanent loss and fearfulness in dementia will also reawaken such attachment experiences (Munnichs and Miesen, 1986). These feelings may generate behaviours, such as parental seeking or, as is so frequently and distressingly observed in the later stages, the calling out, crying and need to be close to another. Thus, it is within the uncertainty of dementia that the need for the certainty of the other is made most manifest. It is only the positive nature of the relationships in dementia that can make the condition bearable (Coleman and Mills, 2001; Kitwood, 1997a; Mills, 1997, 1998). Kitwood (1997b: 11) argues that the maintenance of personhood in dementia requires a living relationship with at least one other, where there is a felt bond or tie. Using Buber's (1937) 'I-Thou' as opposed to 'I-It' concept, he suggests that the person with dementia is held and carried by the

Thou of the other. It is paradoxical, perhaps, that this type of relationship is less problematic in dementia which effectively destroys psychological defences, but can permit the person with dementia to relate more authentically to another (Kitwood and Bredin, 1992). This notion of relationship applies equally between the researcher and the vulnerable other in qualitative studies. Further, recruiting older participants for research purposes can be problematic, especially if the area under investigation is sensitive and likely participants are viewed as vulnerable by 'gate keepers' who control access to such groups. The role of the researcher is increasingly scrutinised. Researchers are becoming more aware of the difficulties of accessing older participants for qualitative studies. Recruitment can be time consuming, costly and increasingly dependent on researcher interpersonal skills. Further, the emphasis on patients' rights by medical ethical committees can lead some to be less enthusiastic about this type of research. In addition, the quality of the relationship between researcher and participant appears to be of importance, especially in research into sensitive issues, which may involve several meetings over time (Mills et al, 2002).

The Importance of the Relationship Between Interviewer and Participant in Qualitative Research

There is an extensive literature on the characteristics of qualitatively orientated social research, together with descriptions of the interpersonal skills required of the social researcher (Lofland and Lofland, 1984, among others). However, the importance of the relationship between the investigator and the investigated requires further examination. Jones (1991) speaks of the complex relationship between researcher and participant and the need for researcher reflexivity about the nature of this relationship. Bannister et al (1994) draw attention to the need for 'critical personal reflexivity' on a number of levels where the personal experiences of the researcher inform, yet do not invalidate the findings. But Marshall (1984) also argues that the researcher's personal qualities form a tripartite relationship with the process and outcomes of the research. Further, Hollway (1989:9) finds that it is impossible: to separate 'me' from 'theoretical ideas', from 'field

notes'. Thus if the 'me' of the researcher is so much part of the investigation, so too is the 'me' of the participant. Qualitative studies are accounts of multi-layered relationships:

All areas [of this relationship] stand in a close relationship to each other, they determine each other and are dependent on each other, through action and reaction, activity and effect, generation and processing of information
(Kleining, 1982: 231)

The importance of this relationship becomes evident when the topic under investigation is highly sensitive in nature. Denzin (1989) suggests that it is this sharing of emotional experiences that leads to a greater understanding. This interactional experience requires the researcher to enter into the experience of another. But this is when we, as investigators, can become overwhelmed by the pain expressed by participants, and may feel inadequate to deal with it. Case study evidence indicates that the relationship between researcher and participant requires careful nurturing, monitoring and support (Mills, 1998). The need for an easily accessible and strong support system has been argued earlier in this paper and elsewhere (Coleman, 1986). It has been argued earlier in this paper and elsewhere for an easily accessible and strong support system (Coleman and Mills, 1997), a comment that has been made by other researchers such as Marshall (1986). She, together with Reason and Rowan (1981), suggests co-counselling as a method of coping.

It is however, the personal aspect of this 'relational methodology' that is perhaps under-defined and undervalued in descriptive studies. Certainly Merriam (1988) suggests that researchers who have little tolerance for ambiguity and who prefer working in structured situations are probably not suited to carry out qualitative research. The degree of researcher personal skills has great bearing on qualitative studies that involve relational research. Chernitz (1986), Hawker (1982), and Lofland and Lofland (1984) suggest that these skills are notoriously difficult to describe. Nelson-Jones (1993) however indicates a number of helper attributes applicable to the counselling relationship that might be perceived as being a valued part of the qualitative researcher's skills. These are

altruism; humanism; intellectual curiosity; worked-through emotional pain; commitment to competence and people orientation. This latter attribute is concerned with Holland's (1973) taxonomy of personality or profiles of personality types. It is this social personality type that predominates in the profiles of counsellors. The characteristics of this profile suggest that they might well predominate in the personality profiles of researchers engaged in naturalistic inquiries. Certainly, qualitative researchers investigating sensitive topics, and who retain participant cooperation over time, are likely to possess counselling attributes.

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Moreover, the nature of qualitative longitudinal research can be likened to the therapeutic process. Jones (1991:211) points to the fact that she, together with other researchers, has noted the therapeutic and counselling role of some interviews. However, the entire research process in qualitative longitudinal research can be seen in this light and it is here that counselling principles can inform this work. Counselling contracts are similar to research agreements with participants, and are also subject to stringent ethical requirements. As far as possible the counsellor makes clear what is expected of the client and through client expectations of the counsellor, defines the counselling role. Researcher expectations are also made clear to participants and, as in therapy, the participant is free to withdraw from investigation at any time. Further, similar to psychotherapeutic interventions, the researcher/participant relationship has a beginning, middle and an end. Researchers should be sensitive to the possibility that participants can be anxious at the beginning, and may 'tire' by the middle of the investigation. They may also need to express sadness over the ending of this relationship during the final interview. However, in any qualitative dementia research over time this is more complex. The participant with dementia may not be able to recall a proposed ending, but certainly may miss the researcher.

The Use of Group Work to Investigate the Health and Social Care Needs of Older People with Mild or Moderate Dementia

Practical applications in using reminiscence and

counselling skills to investigate health and social care needs in older people with dementia, suggest that emotionally focused group work might be an effective method, especially with those who are in the mild to moderate stages of the illness. The literature on groupwork with this client group in the UK is in its infancy (Cheston et al, 2002, 2003), but their work clearly shows the value of story telling as a way of linking and making sense of the present and the past. A number of recent groups, facilitated by a skilled counsellor from the Alzheimer's Society, and myself, found that story telling was an effective tool. Individual recall also seemed to improve in the group. Collaborative memory research supports this argument (Thompson, 2002).

Further, people who attended the groups felt able to voice present worries and concerns about their health and social relationships. Frequent reference was made to the fact that they felt it safe to express their views in the group, as was the importance of relationships with other group members. Although it is recognised that this approach is grounded in counselling principles and facilitators should be appropriately qualified and skilled, the groups warmly welcomed occasional visitors, having previously given their permission for them to attend. Moreover, they were interested in what the visitors wanted to discuss. It felt a warm and supportive way to enter the experiential world of people with dementia and to gather sensitive and valuable information.

Conclusion

This paper has sought to cover a variety of complex topics which come together to enable greater understanding of older people with dementia, and how best to seek their views. This complexity reflects the nature of dementia and the need to employ innovative methods to understand how we might seek to improve quality of life in those who have this illness. It is hoped that it is clear that the many concepts discussed in this paper have a common theme, which is that of relationship, and the argument that understanding of what it is like to have a dementia is only made possible through relationship. Much responsibility is placed on us as researchers to work both ethically and therapeutically with this client group.

It is not an easy task. However, when we listen to the voice of people with dementia the rewards are many.

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