

How Research Relates to Practice

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Introduction

Before offering a comment on the papers in this special edition I would like to explain that my experience of working with older people has been very much on a practical basis. Much of my work with older people has been through the Fife User Panels Project (see Cormie and Warren, 2001). This brings together older people to enable them to articulate their thoughts on their care so that they can influence service planning and delivery. There are six panels in Fife each of which consists of up to eight people who meet monthly for about two hours. The majority of Panel members are well over 80 years with a good number in their nineties. The Panels have exerted some influence on planning and practice in Fife, and beyond, and are seen as a valuable resource for those designing services as well as for practitioners. Although none of the Panel members had dementia, a great deal of what has been described in the papers in this special edition echoes the experience of the Fife work.

One thing all the papers have in common is the value the researchers place on the individual's personal experiences. There has been much discounting, particularly in research, of the use of anecdotal material in obtaining the views of particular groups. Here it is clearly demonstrated that there are positive outcomes in pursuing this way of working. Much of the work of the Fife User Panels started off in the same manner with very fruitful consequences. As Steven Sabat states in his paper, when recognising the limitations of the cognitive approach:

'What we don't come to know about at all are the people with AD what they don't like, what provides them with purpose, meaning pride, peace enjoymentThis is precisely what we need to know in having a more developed understanding of the effects of AD being able to enhance the quality of life of such people.' (p. 5)

In Marie Mills' contribution she also spells out the value of hearing and understanding the value of the individual's life stories. As she says, 'It is possible to 'tell' one's story through words and behaviour and inform health and social needs, including

spiritual needs' (p. 35). Mills also makes the key point that different approaches will be required for different people: 'older people do not fit neatly into the category of 'old age'' (p. 35). She goes on to say that a '... younger therapist can only hazard a guess about how it feels to be old.' (p. 35). In the Fife work the Panel members were quite adamant that, if the NHS wished to hear the voice of very old service users, then it should be specifically theirs and not the voice of any 'younger' third party of older people.

The *Lifegrid Method* as demonstrated by Lee Berney and David Blane shows the benefits, both for the researcher and the individuals, in constructing a much fuller picture of an individual's life using chronological 'aide memoirs'. Additionally, Berney and Blane highlight the fact that, as well as aiding in the research work there can be therapeutic benefits for the individual in this 'life review'. Using a laptop computer with the older people as part of the lifegrid approach was an interesting way of allowing them to feel more involved. This was reflected in the Fife work when the idea of social workers using laptops when doing an assessment of 'clients' was being discussed with Panel members. One member made the point, in approving the system, 'This way we can see what you are writing in as well as our replies!' In other words, more inclusive for them.

Building up relationships is seen as important by all the researchers and specifically mentioned by Marie Mills and Ailsa Cook. In Cook's work on using video, she makes the point that time was spent getting to know the residents and chatting to them about the research. Similar advice about getting to know the participants was given by the Fife Project to Edinburgh Social Work which was involving older people in a 'one off' event. The project write-up noted, 'Looking back, it was clear that this preparation made all the difference to the quality of the consultation'. One of the key points made in *Working with older people* (Cormie and Warren, 2001), is that time is needed to build up relationships both between the researchers and the older people and between the older people themselves. Cook does express concern, however, that the participants have very little understanding as to the purpose of her filming. Initially, with the

Fife Panels Project the members were very unclear what to expect but the 'enjoyable and fun' aspect of meetings had much to do with their continuing participation.

In any group work, verbal and non-verbal aspects of discussions are very important and have to be noted. As Cook explains, her use of the video gave the opportunity for more closer examination of the interaction taking place. Not only is it useful to be aware of body movement and other non-verbal aspects when delving more deeply into what is happening, but it can be helpful in ensuring participation in its fullest sense, as was found in the work in Fife.

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Heather Wilkinson and Alison Bowes demonstrate that there is little difference in the methodology used when working with people with dementia from an minority ethnic group as compared with that employed with any person with dementia. They discuss the problems there can be with gatekeepers and in the Fife Users panel, despite having clear criteria as to who will be involved, there are some encounters with gatekeepers who will resist or even attempt to block potential participants. In the Fife work it was found that some service providers suggested that older people would be incapable of articulating any views or responded by saying 'you don't need to ask them that is what we are trained to do'.

What comes through in all the papers is that taking a more person-centred approach results in individuals feeling more respected and valued and has beneficial outcomes for the researcher but, more importantly, for those older people taking part. It is very necessary to recognise that people with dementia, as with all older people, are not a homogenous group and there is a need to have as broad a view as possible in determining the issues for all participants in such research.

The imaginative ways of working with those with dementia as described in these papers are very encouraging, but what must not be lost is the need to carry the work forward so that there are positive outcomes for the quality of life of such people. Listening well and noting what is being said is the first and very important step, but, as stated by Barnes and Walker (1996) 'It is the responsibility of those gathering information to analyse the views and experiences provided by users, and identify what the implications are in service terms.'

References

Barnes, M. and Walker, A. (1996) 'Consumerism versus empowerment: a principled approach to the involvement of older service users', *Policy and Politics*, 24(4): 375-94.

Cornie, J. and Warren, L. (2001) *Working with older people. Guidelines for running discussion groups and influencing practice*, Bristol: Policy Press.

