Innovative methodologies – can we learn from including people with dementia from South Asian communities?

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Abstract

South Asian people with dementia are a considerably marginalized group who remain excluded from literature commenting on service use or on the experience of living with dementia. This paper uses an examination of methods employed in a study that aimed to find ways of making contact with and gaining access to people from South Asian communities with a diagnosis of dementia to explore some of the constraints in undertaking this kind of work. The paper opens with a discussion of the opportunities for methodological learning from the inclusion of people with dementia from South Asian communities. The central argument is that work in the area of dementia and minority ethnic groups does not require any fundamentally different method and is only considered innovative through its inclusion of previously excluded individuals. The routes to inclusion are then outlined before dealing more specifically with some of the concerns and issues encountered during the study. The paper concludes that inclusion in research can be seen as a series of issues about power, relevant to practice and research, where individuals previously considered too difficult to reach or impaired to include can offer important insights into their personal experiences of service use.

Introduction

In recent years, research, policy and practice have witnessed growing interest in including the views of marginalised groups in planning, delivering and monitoring health and social services (Department of Health, 2000, 2001; Hanley et al, 2002; Scottish Executive, 2001, 2002). A key response to this increased interest is the corresponding focus on finding methods that can be used to gather the views of people previously excluded from research. The purpose of this paper is to examine the methods used in a feasibility study that aimed to find ways of making contact with and gaining access to people from South Asian communities with a diagnosis of dementia and to explore their experiences of service provision (Bowes and Wilkinson, 2002a).

Firstly, we discuss opportunities for methodological learning from the inclusion of people with dementia from South Asian communities. We introduce the focus on method and argue that work in the area of dementia and minority ethnic groups does not require any fundamentally different method and is only considered innovative through its inclusion of previously excluded individuals. Underpinning this argument is a challenge to the view that some groups are 'hard to reach,' highlighting the disjuncture between the policy rhetoric, methodological progress and the subjective experiences of individuals (Cook, 2002). Secondly, we outline the feasibility study and describe the rationale for the project, as an attempt to explore effective and safe ways of making contact with and including marginalised individuals in a research study. The third and fourth sections deal more specifically with some of the concerns and issues encountered during the study. In undertaking this study we were able to overcome perceived access difficulties and make contact with families who were willing to take part in the study. However, the time constraints and other barriers meant that getting the views of people with dementia proved more problematic. We discuss these problems in sections three and four. These sections are based on two key questions. The first addresses effective and ethical ways of making contact with research participants and focuses on the five key issues of ethics committees, inclusion criteria, diagnosis, gatekeepers and consent. The issue of power in research relationships is central to this section and its complexities and negotiated nature are highlighted. The second question addresses eliciting information from participants and in particular discusses the importance of language in the effectiveness of the feasibility study. The paper concludes that inclusion in research can be seen as a series of issues about power, relevant to practice and research, where individuals previously considered too difficult to reach or impaired to include can offer important insights into their personal experiences of service use.

Including People with Dementia from South Asian Communities?

Despite a growing interest in the needs of older

people with dementia from minority ethnic populations (Patel et al, 1998) very few studies exist that focus on South Asian people and dementia (Brownlie, 1991; Anderson and Brownlie, 1998). A review in 2001 by the Mental Health Foundation identified the need for research in a number of areas relating to minority ethnic populations and dementia (Milne, 2002). A small study exploring the awareness and understanding of dementia in minority ethnic populations found that knowledge about dementia among carers of older people was limited (Adamson, 2001). Nevertheless, as the minority ethnic populations in Scotland begin to age (Bowes and Dar, 2000a, 2000b) it is important to understand the perspectives and experiences of this minority group.

The lack of work to date may be a reflection of a more general negativity directed towards the needs of minority groups and a belief that minority communities 'look after their own' (Blakemore, 2000). However, it is also possible that the lack of voice given to people from minority ethnic groups who have dementia is due to an assumption that their inclusion requires special methods or is generally too difficult. We argue that that being a person from a minority ethnic community and/or having dementia does not require new or unusual methods to facilitate inclusion in research. The innovative nature of such work is its focus on the inclusion of previously missing voices through the use of standard research methods whilst still taking account of the central issues of power and control in the research relationship (Bond and Corner, 2001). This study makes no claims to being participatory or emancipatory: employing qualitative methods to facilitate the gathering of previously excluded voices does not necessarily promote significantly empowering or participatory research (Bhavnani, 1988; Bowes, 1996). Nevertheless, we highlight the necessity of developing new ways of extending thinking around an issue and gathering data to support this. In this context 'innovative' includes the practical ways of making contact with individuals, asking appropriate questions and eliciting information on their distinct individual experiences.

The Imperative for Inclusion

Demographic changes with the aging of the minority ethnic populations increases pressure to know more about their views and service use (Blakemore, 2000; OPCS, 1991). However, demographic factors are not the only reason for greater interest in marginalised groups – arguments around rights and consumer perspectives have also influenced the move to include the views of people from minority groups in research (Bowes and Dar, 2000a).

Recent attempts to focus more on the views and experiences of marginalised groups are evident in the area of ethnicity (Ahmad and Atkin, 1996; Bowes and Dar, 1996). Bowes and MacDonald (2000) compare findings on majority and minority ethnic older people, concluding that there were both similarities between and variations within each group, and suggesting that the development of person-centred (rather than culturally targeted) services is appropriate for both.

Similarly, there is growing interest in psychosocial and biographical aspects of life for people with dementia, and the perspectives and the subjective experiences of people with dementia are now being sought (Sabat, 2001; Downs, 1997; Keady, 1996; Wilkinson, 2002a). Despite this growing focus on the self, personality, thoughts and feelings of the person with dementia (Cotrell and Schulz, 1993; Kitwood, 1997a, 1997b), there is limited work where this focus has been extended to include individuals from minority ethnic groups (Brownlie, 1991; Anderson and Brownlie, 1998). It is now important for the provision of services to also have evidence from people who fall into both categories.

There are interesting similarities and differences between research including people with dementia and people from minority ethnic groups. Both experience marginalisation and exclusion, in this case in research, on the basis that they are too difficult to communicate with or too hard to reach to be included (Patel et al, 1998). Now however, these assumptions are increasingly challenged and researchers are starting to accept that the key challenges relate to adequate skill and preparation at research, policy and practice levels.

44

The Feasibility Study

The research aimed to ascertain the views of a number of participants, beginning in stage one with interviews with 11 local professionals working with South Asian people with a diagnosis of dementia. They covered a range of disciplines, including social work, psychiatry and general health, and both statutory and voluntary sectors. The main stage of data collection reported in this article involved building a series of case studies around four people with dementia from South Asian communities (i.e. Indian and Pakistani[1]) and their families and carers. Each case study explored techniques for ascertaining the views of the individual with dementia and their families and carers, and collected data about their experiences of dementia, and issues for them in relation to service use. The fieldworker on the project was a South Asian woman who was able to speak several relevant languages and had a cultural understanding of the communities with which she was working. This assisted access to people for this study.

Making contact and engaging with individuals with dementia and their families who were able to take part in this study proved to be the most difficult aspect of the study in the time allowed. As the fieldwork period came to a close, we had identified 12 potential case studies and had completed four. Issues of access were compounded by small numbers and the sensitivity of the topic, especially as the disclosure of diagnosis was rare.

It is important to separate the culturally specific aspects of the *findings* relating to service provision and practice reported elsewhere (Bowes and Wilkinson, 2002b, 2003) from those of *method*. Our concern in this paper is with method, relating to issues of power, inclusion and consent and we examine these now by focusing on the two key research questions:

- What are the most effective and ethical ways in which South Asian people with dementia can be identified and included in research?
- How can the views of South Asian people with dementia and their families and carers be most effectively ascertained?

What are the Most Effective and Ethical Ways in which South Asian People with Dementia can be Identified and Included in Research?

In ensuring that the identification and inclusion of research participants are both effective and ethical, the inclusion criteria are crucial. Inclusion criteria and procedures for making contact with research participants have to pay attention to ethical issues and underlying power relations between the researcher and the respondent (Bowes, 1996; D'Cruz, 2000). In defining who can take part, the inclusion criteria reflect issues of safety for the participants and also the power of the researcher in making such decisions. Researchers' power is reflected in decisions about inclusion criteria, however great the efforts made to ensure safety for participants. Participants for the feasibility study had to be from a South Asian background, have a diagnosis of dementia and be in touch with a service through which we would make contact with them. These seemingly basic criteria for making contact with study participants soon became contested and negotiated issues modified by the ethics committee, the problematic nature of diagnosis disclosure, the influence of gatekeepers, and the operationalisation of consent by carers and the individual themselves.

Ethics committees

The proposed procedures for defining and including research participants were reviewed by the multi-centre and local ethics committees in Scotland. The application for ethical approval was useful in checking that the inclusion criteria and the pathways for making contact with families were clear and offered maximum safety to both researcher and respondent. However, the process also raised issues for undertaking this type of social research around resources, attitudes and relevant procedures. Although standard practice, the process was resource intensive and time consuming, involving a huge amount of paperwork and applications to a number of different committees to make contact with a small number of participants. The questions raised by some committees around the ability to include people with dementia in the research illustrated some problematic attitudes towards more inclusive social research. Concern about ethics committee understandings and knowledge of social science

methodology has been raised elsewhere (Coomber, 2002; Williamson et al, 2002) and the current review format that prioritises invasive (physical or mental) research adds to the difficulties in approving procedures for the inclusion of people in social science work. Although people with dementia are clearly a group requiring protection, it is also imperative that their views are included in research. An example of a potential barrier to inclusion is the emphasis placed on written consent through the signing of a consent form. In reality this is a problematic requirement for a population where literacy may be low and where written consent can be inadequate for a fully informed consent process (Coomber, 2002). While the surveillance of the ethics committee is essential for the safety of both researcher and research participants, it is also essential that the committee understands and gives support to the inclusion of individuals previously considered too vulnerable or difficult to include in research.

Inclusion criteria

The ability to make contact with a significant number of participants was a key concern of the study. Initial work with members of the project research advisory group on local issues, key gatekeepers and services provided an essential introduction into the complexities of including vulnerable individuals. These early discussions around who to include ensured that we were especially conscious of the issues of power and control particularly against the necessity to employ inclusive criteria for participation. The focus on South Asian people with a diagnosis of dementia was central to the study. Until recently, inclusion criteria have tended to be based on common and narrow definitions of capacity. Often there is an assumption made that the cognitive impairment relating to dementia results in the individual being unable to communicate effectively or having insufficient insight to comment on their own experiences (Cohen and Eisendorfer, 1986). In line with a medical model approach to people with dementia, a commonly used measure of inclusion and capacity to participate was the mini mental state examination (MMSE) (Folstein et al, 1975). This psychological scale is commonly used by clinicians to give a 'score' of crude cognitive ability and can be used in research studies to provide a cut-off score that is then used to identify

who to include or exclude from the research (Anthony et al, 1982; Cockrell and Folstein, 1988; Crum et al, 1993).

Despite the MMSE measure being initially included in the feasibility study design, it was not undertaken for several reasons. Crucial for this population was the lack of a fully validated version for use with minority groups (Rait et al, 2000). In addition, there were ethical difficulties for a non-clinical researcher administering a psychological test with significant implications attached to its results. More importantly for extending inclusion, a recent questioning of this method in a research context (Mozley et al, 1999) found that participants with scores well below the commonly used cut-off point were still capable of taking part in research and expressing their views and feelings.

Rather than trying to 'measure' ability or use more structured methods, the feasibility study emphasised ways of including each person through more qualitative and sensitive methods throughout initial contact, consent and data collection. Individual experiences and views could then be gathered in ways that took account of context, more recent experiences and information on significant life events and significant others for the person with dementia. Where necessary, several conversations were undertaken with people to build trust and allow for variation in individual conditions and readiness to participate. Being responsive and flexible to individual circumstances allowed some of the power and control in the research relationship to be redistributed, with families deciding the time, location and length of interviews and the issues and concerns to be covered that were relevant to their own experiences of using services. Even so it proved difficult to make contact and spend time with individuals with dementia themselves. Often families were very protective of the person they were caring for, and this was respected in undertaking the interviews. The majority of the case study data drew more on conversations and observations with family carers than with the individuals with dementia. In addition to the difficulties of negotiating access, imbalance was due to the problematic aspect of diagnosis and the limited number of individuals who knew they had dementia and we discuss this further in the next section.

The problematic nature of diagnosis disclosure

A primary criterion for inclusion in most recent research gathering the views of people with dementia is that the individual has received a diagnosis and is able to talk about what this means for them.

This basic criterion presents one of the key difficulties for inclusion in recent research where the focus has been on the person with dementia (Wilkinson, 2002b). The importance of an early diagnosis to enable people and their families to respond to the prognosis of dementia is clearly emphasised in recent policy (see for example, Department of Health, 2001; Philp et al, 2000). However, diagnostic practice remains variable within primary care (Eefsting et al, 1996; O'Connor et al, 1988; Wind et al, 1995; Cooper et al, 1992). In England and Wales a survey of over 1000 GPs found approximately half reported that they did not practice early diagnosis (Audit Commission, 2002) and there is similar evidence in Scotland (Downs et al, 2002).

Whilst this deficit has considerable implications for the management of dementia for the individual, it also creates fundamental difficulties in research (Wilkinson and Milne, 2003; Pratt and Wilkinson, 2003). Throughout the feasibility study, the identification of participants with a diagnosis of dementia did prove to be difficult and time consuming, because the disclosure of the diagnosis was rare. This situation meant that individuals were excluded from being given the opportunity to consider taking part in the research. In the case studies of families who did agree to take part, it was often difficult within the time constraints of the study to engage sufficiently with the person with dementia themselves. Often, the individual had been diagnosed very late into the progression of the illness and had significant cognitive impairment. Although it is increasingly evident that meaningful communication is possible for individuals with significant cognitive impairment (Crisp, 1995; Killick and Allan, 2001), the time was not available in this study to explore these possibilities further. To ensure that a diagnosis was not inadvertently disclosed to anyone in this study it was essential that the status of the individual's knowledge was checked before any approach was made. In this study a mechanism to ensure that the potential participant had received a diagnosis was to check with gatekeepers during the initial process of approaching the individual.

The influence of gate keepers

To ensure that potential participants were identified and approached in ways that secured their confidentiality and supported the process of informed consent, we relied on local service providers to act as gatekeepers, identifying individuals who met the inclusion criteria, making initial introductions and setting up meetings. The researcher made contact with gatekeepers through a variety of sources including social and community events, local community organisations and more formal organisations such as the local hospital, the Hindu temple and the Sikh temple. It was important to use a combination of the formal with informal contacts to ensure information on the project was widespread, especially through word of mouth, within a short time.

A project advisory group supported the study and their connections with and knowledge of local communities were crucial in supporting leads and contacts from a very early stage. Each contact with a case study family was made usually through at least two, three or even four contacts and gatekeepers. At each stage it was important to check that the individual (and usually their family) had received a diagnosis of dementia and to ensure that as much information about the research project was made available in accessible formats to aid the decision making process.

There is no way of knowing if gatekeepers excluded people before the researcher could make an approach. The essential element is to be open and work with the gatekeepers to be clear on the reasons for the inclusion criterion. It was possible that gatekeepers exercised their power in making a decision to exclude an individual for reasons other than not meeting the inclusion criteria. People with dementia and especially people from minority ethnic groups are often considered vulnerable by the service providers and carers who were acting as our gatekeepers and perhaps correctly, are very protected. We were working with limited numbers of families through a network of local professional and family gatekeepers. This often meant we faced issues of 'ownership' of the person with dementia.

47

In a context of complex caring and family structures this can often lead to conflict between gatekeepers and therefore to the exclusion of the person with dementia before an approach can be made. This is difficult ethical territory where the aim is to be inclusive, yet respectful and safe, and there is no easy solution. Each individual approach in our study was different and required individual consideration and negotiation before a position of agreement was reached where it was possible to proceed further with the consent process.

The operationalisation of consent

The operationalisation of consent procedures is a crucial aspect of ensuring that inclusion is effective and ethical. Consent in dementia research is now a much-debated issue (American Geriatrics Society, 1998; Dewing, 2002; Hubbard et al, 2002). Traditional methods of competency-based consent and informed consent are being challenged and replaced with ideas of more person centred 'inclusionary' consent where it is attempted to give the interests of all parties involved equal consideration (Dewing, 2002). However, for the purpose of the feasibility study, it was felt that traditional competency-based informed consent was necessary for such a highly sensitive area of research and this required careful negotiation to ensure that particularly vulnerable people were included safely. We aimed to get consent from the people with dementia themselves, although we had already gone through a protracted process to reach individuals with dementia, as described above.

Simple information booklets and consent forms, as developed in earlier studies (Wilkinson, 2002b), were useful in discussions with the carers to aid decisions on whether to participate or not. These were all translated into the individual's first language. Face-to-face discussion was also considered important, as a problem of illiteracy had been encountered in a previous study (Bowes and Dar, 2000b) when the information and consent questions had been recorded onto tape. However, for the feasibility study, the printed information supplemented by face-to-face conversation was sufficient for participants to give initial consent to proceed.

Following initial informed consent at each meeting, consent was renegotiated and viewed as an ongoing process (Dewing, 2002; Hubbard et al, 2002). Where time was spent with a person with dementia, the consent process involved taking account of non-verbal indicators as well as verbal cues and recognised the need for extra time to be structured into the research design to allow for additional visits to spend time with the person with dementia and their family. This was of particular concern in this study where finding time when the carers and people with dementia were available for interview was difficult. In particular, carers often had family and work responsibilities on top of being full time carers with the associated stress of this role.

In summary, the process of just reaching people with dementia from South Asian communities was protracted. It involved several stages including receiving formal ethical approval, negotiating with a number of gatekeepers, negotiating a sensitive yet broad inclusion criterion that ensured the individual to be approached was aware of their diagnosis; and finally undertaking a detailed, informed consent process that continued throughout the data collection period. Once a family had agreed to take part in a case study, a new range of methodological concerns were apparent when faced with the data collection process and we now address some of these.

How can the Views of South Asian People with Dementia and their Families and Carers be Most Effectively Ascertained?

Once the initial informed consent had been granted by the family carer(s) to undertake a case study, then the primary purpose of the research relationship was to elicit the experiences and understanding of the person with dementia and their carers. In total, for the feasibility study, four case studies were completed in the time available but within these it was primarily interview data from the carers and some observational data that formed the basis of each case study.

The main barrier to eliciting the perspectives of the individuals with dementia within each case study related to having the time and communication skills required to engage with the individual. The traditional question and answer format of interviewing as part of building a case study is less pertinent when interviewing people with any form

of cognitive impairment (Stalker et al, 1999). People with dementia have been perceived as being unable to verbally communicate their thoughts and feelings and this has lead to the assumption that individual communication would be meaningless due to the cognitive impairment and its impact on sense of self (Cohen and Eisdorfer, 1986).

For this study we drew heavily from the lessons learned in other social research on dementia (Gubrium, 1993; Goldsmith, 1996; Killick and Allen, 2001; Wilkinson, 2002a) and learning disability research (Stalker et al, 1999). The most important aspect for the effectiveness of the data gathering process was the amount of time spent with each family. This time allowed relationships of trust to be created and for the researcher to gently explore issues as they arose, thereby responding to the agenda of the participants rather than the research schedule. Such an approach was essential in families where there was often distrust or limited understanding of the research process (Bowes and Dar, 2000a) and where dementia was a difficult and sensitive subject. The preparatory work in gaining access, although time consuming, was useful in building this relationship with the family and also in gaining early insight into the complexities of family relationships, all of which had an impact on how the case study data were then gathered. Even so, there was insufficient time in the study to build the degree of intimacy and trust with the individuals with dementia themselves to feel that their views had been elicited to the same degree as the carers.

Although processes of establishing an ethical and sensitive relationship with families are pertinent to both the general field of dementia research and to research specific to minority ethnic groups, one issue remains culturally specific – that of language. Although this has been well rehearsed elsewhere (Bowes and Dar, 2000a; Shah, 1999) it is worth reiterating that language was an important consideration for the effectiveness of the study.

Initially, we had to overcome translation problems especially associated with how to talk about dementia in South Asian languages (Adamson, 2001). Whilst it was not essential that the researcher was someone from a South Asian background to 'match' with the participant, it was

essential that they were fluent in vernacular languages (Bowes and Wilkinson, 2002a and b; Bowes and Dar, 2000a; Shah, 1999). When the data collection is based on an open-ended approach with time spent with the individual and their carers, it is important that the researcher is fluent in the first language being used. It is also important to recognize that language and cultural literacy are closely related and, especially where the participant has dementia, communication becomes more than verbal conversation, and is more reliant on interpreting behaviours and non-verbal cues. Indeed, there is a need for further work on communication with people with dementia in different cultural contexts.

It is important to recognize that the difficulties encountered in eliciting the perspective of individuals with dementia are not insurmountable. To gather the views and feelings of someone with dementia, especially as their cognitive impairment increases, requires a greater input of resources to ensure that the time and skills are available.

Conclusion

Despite the increased interest around including the views of marginalised groups in recent years in the fields of research, policy and practice (Department of Health, 2000, 2001; Hanley et al, 2002; Scottish Executive, 2001, 2002), the methodological response to this is still at an early stage. We began this paper with a discussion of the learning opportunities encountered from trying to include people with dementia from South Asian communities in research. We conclude by highlighting the similarities in the assumptions and issues around including people with dementia and people from South Asian communities. Being a person from a minority ethnic community and/or having dementia does not require different methods *per se* – just to be more inclusive and skilful in using existing methods with greater flexibility. Inclusion in research can be extended when taking account of the central issues of power and control in the research relationship. Such an approach requires a greater sensitivity to ethical issues, making contact with the individual in a supportive and safe way, and having time to spend with the person to find ways to communicate.

49

Additional time and resources are often required in the early preparatory, but crucial stages of the work, and then throughout the data collection stages. It is important to draw on a variety of sources including a combination of formal and informal contacts and word of mouth when making contact with participants. Once contact is made, and throughout the whole research process, continuing negotiation of informed consent is essential. This process of ensuring understanding of the research can be aided through the use of information and consent sheets, but conversation about the research remains crucial in building trust. Importantly, in the context of research involving people from minority groups, whilst it is not essential to 'match' the interviewer to the participant, it is important for the researcher to be fluent in the participants' vernacular language.

Despite the increased level of resources required, it is important to elicit the views and experiences of groups traditionally viewed as 'difficult to reach' and exclusion on the basis of cognitive ability is no longer valid. Equally, funders have to be aware of these additional requirements for inclusive research and be willing to make funding as well as ethical commitment to this kind of work. The benefit of this will be to break down barriers created by the assumption that different skills and methods are required to include people with dementia from South Asian communities and to open up the most fundamental source of information and understanding – the person themselves.

Note:

1) Bangladeshis were excluded, due to extremely small numbers.

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51

52

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54