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Partnership research with older people – moving towards making the rhetoric a reality

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Partnership research with older people – moving towards making the rhetoric a reality

4 As nursing develops closer partnerships with older people in delivering care, it also needs to develop partnerships in order to create the knowledge base for practice in a way that challenges professional hegemony and empowers older people. However, the process of developing partnerships in research takes place against a background of academic research traditions and norms, which can present obstacles to collaboration. This paper is a reflection on the issues that have arisen in three projects where older people were involved in research at different levels, from sources of data to independent researchers. It points to some of the areas that need further exploration and development.

Key words: collaboration, empowerment, knowledge, partnership research

Introduction

In line with other helping professions, nursing, midwifery and health visiting have moved from traditional views of technical expertise as the prime shaper of health care, to a more equal relationship with service users and carers, which respects their expertise, knowledge, goals and choices. In nursing, this approach can be traced back to early debates about individualizing care through the development of the nursing process, named nurse systems and primary nursing, all of which were based on the recognition that patients should be at the centre of care. This development has not been without problems (Reed, 1992) and has raised questions about the processes and mechanisms for involvement. Nonetheless it is a move, which has included nursing for older people, despite, as McCormack (2003a) has pointed out, some attitudes and

expectations from nurses, older people and wider society are not always encouraging. These attitudes and assumptions are based on stereotypes of older people as passive and uncritical recipients of care, and work with them as low-status activity, which is not valued or prioritized in society. In health care, these negative attitudes may come from medical models of ageing, which view the older person as undergoing inevitable physical decline, which make effort spent on them less rewarding than time spent on younger people (Koch & Webb, 1996).

Alongside this increasing involvement of older people in shaping the nursing care that they receive, is a parallel move towards involving them in developing the knowledge base of nursing, through increased participation and partnership in research. One of the key foundations of this development is the changing view of older people as consumers of services

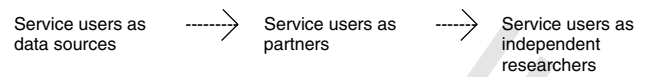
and research, who have rights and duties to express their views (Carter & Beresford, 2000). This changing view means that consumerism, in the form of the opportunity to have ownership of research, as opposed to passively accepting it, entails a more active participation in the creation of knowledge. This is grounded in the view that this involvement may not only have pragmatic or instrumental value in facilitating and focusing research, but will have an ethical value in reducing the disparity of power between the researcher and the researched, thus creating a more open environment for discussion and debate (Barnes & Walker, 1996; Goodacre & Lockwood, 1999)

However, moves to involve older people in research have had to contend with ageism, i.e. the assumption made by others that older people are not able to participate in research or indeed any other decision-making process, because growing older inevitably results in reduced capacity for involvement (McCormack, 2003b). This may be a common feature of all attempts to involve consumers in research, that many of them will be marginalized groups, whose activities are discredited and devalued, particularly if traditional scientific notions of objectivity and rigor are applied. While notions of objectivity in research are increasingly challenged within the research and academic community, and more space is cleared for discussion of the researcher's position and perspective (Rolfe, 1996), the extension of these critiques to embrace consumer-researchers may still be uncomfortable for those debating methodology.

Therefore, the debates about older people's involvement in research involve challenges to the norms of research structures, where knowledge development is increasingly seen, not just as the domain of academics, but a more inclusive activity (Rolfe, 2000). As Tetley and Hanson (2000, p. 70) have argued, traditional research approaches 'have been described as oppressive, disempowering, inadequate and inappropriate.... This has been particularly true for those whose needs are more complex, such as older people....' They point to the increasing popularity of participatory research as a way of countering this tradition, and outline some of the various forms it has taken, according to research contexts, resources and questions. Moving towards research, which is inclusive and based on partnerships, they argue, raises issues about power and control of knowledge, and the way it is evaluated, communicated and identified.

Levels of involvement

Involvement in research is not a simple process and there can be a number of degrees and levels, portrayed as a continuum in the following figure (Fig. 1).



6Figure 1 xxxx.

At one end of the continuum are 'service users as data sources' where, for example, service users may be interviewed or sent questionnaires to elicit their views or experiences. This has been the longest established tradition of involving patients and service users in nursing research – 'asking patients what they think.' This is important, and recent debates have been about how this can be done more effectively in ways, which accurately reflect users' views. However, the middle of the continuum is a more complex and more person-centred position, where service users may become involved at any of the stages of research, commissioning, writing proposals and designing studies, carrying out data collection and reporting findings. At the 'independent researcher' end of the continuum, the research is fully user-led, perhaps with funding, data collection and dissemination being directed by service users rather than academic researchers.

Each of these different positions on the continuum present different challenges and rewards, and requires different levels and types of support. Our knowledge of these implications is patchy and this paper is an attempt to present key issues in a way, which will allow further debate. As nursing research develops alongside the principles and values of practice, then this debate becomes essential if we are to make sure that the way we develop our knowledge for practice fits with our ways of practicing.

This paper reports on three projects where there has been an explicit attempt to identify and develop the roles of older people in research, at different points on the continuum, and to engage with some of these conceptual issues. They have been carried out over a number of years at the centre for Care of Older People at the University of Northumbria at Newcastle, and this paper is an attempt to review these experiences and identify issues raised and questions that need to be addressed.

Example 1: Quality improvement in care homes – promoting the voice of older residents

This study looked at the impact of a quality improvement package designed for use in care homes for older people, 'Qual A Sess' (Reed *et al.*, 1999). A key feature of the package was the setting up of panels to evaluate and improve identified aspects of care home life, panels that included residents, visitors and staff. As such, the intervention, which

was being evaluated was designed to empower residents, and so the methodology for evaluating the intervention had to assess the extent to which this had happened. In keeping with this spirit of empowerment, the methodology also had to enable residents to express their views and support them in doing this.

The evaluation involved carrying out focus groups and individual interviews with residents. The study could therefore be placed at the 'users as data sources' end of the continuum, as residents were not involved in planning or managing the study, and only became involved as interviewees. Making decisions about how and where interviews and focus groups were conducted, was based on the preferences of residents – some did not want to take part in focus groups, or preferred family members to be present. In focus groups, or interviews with others present, the researchers also had to be sensitive to group dynamics, encouraging less vocal residents to put forward their views, and managing very vocal residents when they threatened to dominate the proceedings. Similarly the involvement of staff members in interviews had to be carefully judged and ground rules agreed to avoid residents feeling pressured by their presence into suppressing complaints or caveats.

What we also found was that interviewing residents, either individually or in groups required skill and sensitivity to engage residents who had a range of different views, and some barriers to participating in interviews, because of mobility, sight, hearing or speech problems. In addition, care need to be taken to ensure that residents felt comfortable about talking to researchers, that they could be trusted, and that they would not be pushed into criticizing the staff or the home.

The study therefore drew on the researchers' interpersonal skills and sensitivity to the needs of older people. It also required the research team to take an explicit stance whereby the accounts of older people were privileged. This meant that what the resident said was not subjected to 'checking' with staff or visitors for accuracy or reliability, but was taken as a reflection of their experiences and their interpretation of these experiences. Notions of triangulation and other techniques used to confirm or disconfirm accuracy therefore became irrelevant, as they were felt to rest on assumptions about the greater reliability of staff and visitors and the relative unreliability of the residents' accounts. The inherent ageism of these assumptions was not in keeping with a development, which sought to give older people a voice in their care, but also not in keeping with a research approach, which was critical of notions of 'truth' as being an absolute and unequivocal goal of research (Reed & Payton, 1998).

Example 2: Looking at going home from hospital; a whole systems approach

In this study, older people were involved at all stages of the project. The project had arisen from development work carried out with the support of Newcastle Health Authority and the King's Fund, in which a 'Whole Systems Event' workshop involving 200 older people and service providers, was held focusing on 'Going Home From Hospital.' This followed a meeting at which an older woman told the story of her husband's discharge home from hospital, which had been extremely difficult and distressing, due to the lack of thought, planning and co-ordination between services. At the Whole Systems Event a suggestion was made that the group should carry out a research study, and the researchers present were asked to lead this.

The study aimed to discover what developments had taken place in discharge planning in the locality, and used Appreciative Enquiry as a methodological framework (Cooperrider & Srivastva, 1987). This is an approach to research and development in organizations, which directs attention to the aspects of activity that are successful, and which then explores how successful activity can be encouraged and facilitated. The process of Appreciative Enquiry had three stages, each involving a separate workshop:

- Interview training workshop to enable data collectors to elicit experiences of successful working from people involved in organizations.
- Analysing the data to develop models of why these activities worked and what factors helped them to work, through larger group exercises.
- In larger groups applying the models of successful activity to the development of action plans for the future.

The study has been reported elsewhere (Reed *et al.*, 2002) and involved a number of older people in a range of roles – as interviewers, data analysers, report writers and editors and as a co-author of a journal paper. The study therefore could be placed towards the middle of the continuum, with older people as partners in the research. However, there were some tensions between the researchers' and users' views of what constituted a good research study, which arose from differences between knowledge, experience and priorities. While the older people had extensive experience of services and had the improvement of these services as their priority, the experiences of the researchers were different, and their priorities, while also being to contribute to service development, placed this development in a context of academic criteria for rigorous research. This is similar to the point made by Cornwall and Jewkes (1995) who distinguish between the academic goals of 'knowledge for understanding'

and the participatory research goal of 'knowledge for action.' However, at the same time another set of criteria for research, which were less traditional and were about participation and relevance to practice, were supported by the research team, and this meant that adopting a 'purist' research stance, which did not take into account the views of older people was not an option. Involving non-researchers in the planning group did not resolve these tensions, but instead highlighted them.

For example, as interviewers, older people felt restricted by the structure of the interview agenda, and departed from this when they felt it was appropriate, leading to some inconsistencies in the data. Using traditional academic criteria about reliability, data collection processes could be challenged. However, using criteria of responsiveness and context relevance the data collection processes could be evaluated according to more pragmatic criteria. Data analysis and action planning were consensual, mainly because these activities took place in group meetings. Writing up the report was led by the research planning group, which included the older person who had told us about her husband's discharge, as was preparing a paper for publication. In the latter aspects of the study then, the public nature of the debates led to a clearer appreciation of the strengths and weaknesses of the approaches that had been taken, through the transparency of the discussions.

Example 3: Preretirement courses

This study represents the 'independent researcher' end of the continuum. An older person (co-author RW) approached the Centre for the Care of Older People with a request for help in some research he was contemplating. He had facilitated preretirement courses for more than 10 years and had found that almost invariably the primary concern of those attending was their postretirement financial status. Indeed in order to meet these anxieties about 50% of the course contents concern financial matters. However, he also had anecdotal evidence that after retirement, following a short settling down period, finance took a low priority.

He therefore wanted to examine the issues that older people felt most affected their quality of life in retirement so as to be able to offer suggestions for making the course more appropriate to the postretirement period. His request for help was based on the following:

- if he was to engage in research he wanted the study to have academic rigour;
- he felt he needed help with the research design;
- access to the facilities of the university library was essential;
- finally, he felt that commitment to a postgraduate degree would provide the necessary motivation to keep going.

Looking back he comments:

Interviewing other retired people was very enjoyable and I found we had many shared experiences, like parent and grandparenthood. My age was a positive advantage in this case as it made building up rapport so much easier.

From an institutional perspective student motivation differed from that of a younger person for whom the gaining of an academic qualification was likely to be a high priority. Here the outcome of the study was a prime motivator.

A number of problem areas were also identified. Firstly, the normal channels of finance are not open to older people so that the study had to be entirely self-financed. Had the student not had his own vehicle, transport to visit interviewees would also have been a problem. The scope of the study was restricted by the amount of time available and although the student was retired, he had other responsibilities that made demands on his time. This latter is, of course, counter to the widely held view that retired people's time is freely available. Finally while this particular student had the benefit of higher education during his earlier life, the opportunities to undertake higher education has not been as widespread as in more recent generations. Care has therefore to be taken to make any necessary training in research available to older people if a gap is found in that respect.

However, the question of research training raises some important questions. Training in research techniques may be important to increase confidence in independent researchers, but may also have the effect of reinforcing the traditional view of research being an expert activity that 'lay' people cannot take part in a meaningful way. As this study was part of an academic programme leading to a higher degree, one of the requirements was that the researcher should demonstrate understanding of research methods and methodologies, and therefore developing research skills was an integral part of the process. However, for independent researchers who wish to challenge these traditions the process of gaining an academic award may discourage overt questioning of the basis on which this award is made.

Levels of engagement and involvement

The examples of research studies given above suggest some ways towards mapping out different levels of engagement of older people in the research process, according to a continuum of involvement. Taking this further, Table 1 lays these points on the continuum in a more detailed way, using the notions of 'extended' and 'restricted' involvement. These levels of involvement are, of course starting points for thinking rather than a definitive typology. Nonetheless the

Table 1 xxxx

Research activity	Range of participation	
	Extended	Restricted
Developing research questions	Actively seeking users views on research priorities	Asking for comments after priorities set and questions identified
Developing methodology and research tools	Providing information about techniques to support decision-making	Using service users in pilots
Data collection	Collecting data	Used as sources of data
Analysis and interpretation of the findings	Engaging in the process of developing frameworks and carrying out the analysis	Allowing comment on the analysis
Project management	Involved in the day-to-day decisions about staff, budgets, schedules, etc.	Invited to comment on decision of research team, e.g. in a steering group
Writing up and reporting	Actively involved in report writing	Used to identify possible avenues for dissemination or to endorse reports

table does draw some important distinctions between designing a study, which has extensive user involvement and one, which has minimum involvement, and these distinctions are about the amount of power that users have over different research activities. They need not just to have their say, but to actively participate and influence research decisions. Furthermore, these decisions need to be important ones, not about minor issues but about key issues.

There are therefore a range of operational or process issues that need to be mapped out as well, and here there is clearly room for more methodological work. Issues of power sharing are key to the debates on user participation in nursing research, but the complexities of putting these ideas into practice are less certain. Researching in partnership with service users means turning upside down existing power relationships. While researchers and professionals have generally had control over what is researched and how, and indeed how it is presented, in a partnership some of this control must be shared out. In order to do this, researchers must think carefully about the ways in which they support users through their involvement.

Developing research questions

Identifying research questions from discussions with service users is difficult given the way in which research questions have to be formulated and expressed for funders and reviewers. They have to be expressed in precise terms, in ways that are researchable according to established research modes, and this language is different to the everyday language of most groups outside the research world. In example 1, the research questions had been determined entirely by the research team before they had even met any of the residents. However, when explaining the study to

residents it became apparent that the research questions we had developed made little sense and had low priority for the residents, who were not concerned about the specific use of Qual A Sess, but about general standards in the home. In example 2, research questions were developed through discussion, but this process was, at times, a difficult one. While service users wanted to know what could be done to make things better based on their experiences of using services, the researchers had more precise questions in mind, derived from reading the literature and using different methodologies. Practitioners had yet another set of questions, which had developed from their experiences and defined problems as they experienced them. In example 3, where the researcher developed the research questions himself, again this was based on experiences as an older and retired person, and were different to those developed by researchers in the past. If nursing research is to develop partnerships with older people, then it needs to start off by listening to older people, and reflecting their experiences in the research questions it asks.

Developing methodology and research tools

The choice of specific research methods and designs to meet research goals is dependent on specialized knowledge and expertise in research methodology. It is however, easy to move from acknowledging this to dismissing any less expert comments from service users. While the technicalities of research methods may not be familiar to service users, the overall goals of the study can be seen by them with great clarity, undistracted by the intricacies of techniques. This work, in establishing and maintaining research goals is essential, if other aspects of research planning are to follow a logical course.

Issues of validity and reliability may have great importance for researchers, but for service users they can seem like technical fussiness. In example 2, for instance, the search for a methodological framework for the study seemed to be unnecessary to the older people in the group, who took a much more pragmatic approach to investigation, simply wanting to go and ask people how things could be improved. As the study involved many different data collectors, the researchers in the group were concerned about reliability, but this was not a concern understood by others. The onus was therefore on the researchers to draw on their knowledge of research methods and their utility in eliciting users views when planning studies. This knowledge had to be communicated and offered to the service users and professionals for them to challenge. As a result the researchers became less rigid about methodology and began to see diversity as a strength of the study, while the service users became more aware of issues of reliability.

Data collection

The examples cited in this paper show a range of different positions that older people can have in the processes of data collection, from being sources of data (or 'subjects' as they are sometimes called) to being collectors of data. Each position requires support. In example 1 this required an understanding of the particular hearing and seeing problems that the residents had, along with an appreciation of any health problems they had which might affect participation. In examples 2 and 3 it required training and explanation of research methods. In both these examples, the older people researchers reported that they were able to easily establish rapport with older interviewees based on shared generational experiences. These experiences were not shared with younger researchers, and relationships with them would be correspondingly different. A note of caution must be introduced, in that rapport may not always be conducive to data collection, and may result in sidetracking from the research topic, or may not be reflected on critically. Training therefore should involve critical reflection, rather than become so tied up with technicalities that the value of involving older people as data collectors becomes lost in debates about their technical prowess.

Analysis and interpretation of the findings

In part, the frameworks for analysing data come from the research questions posed, and from the concerns and interests, which have informed these questions. If these have been developed in partnership, then the analysis, which follows

should also reflect joint thinking. In some studies, there is scope for identifying new ideas and concepts, and here service users may get left out of the debate. An iterative process, by which ideas are taken to service-users and debated, or in which service users can put forward their ideas for discussion is invaluable, and was established in example 2 through the series of workshops we had. In example 3, the researcher was guided by a series of pragmatic questions, but these were not always compatible with the requirements of a higher degree programme, which is examined through a thesis, which addresses theoretical issues.

Interpretation of findings is a different process to analysis, involving taking findings and drawing out their connections with debates and discussions elsewhere. Interpretation, then, is shaped by knowledge outside the study, of worlds of practice and policy, for example, where findings could inform change. Having older people as partners in research, therefore adds another set of experiences and knowledge to interpretation – instead of just looking at the impact of findings on nursing, a wider dimension can be added. In example 2 we were able to move towards extended participation, whereas in example 1 it remained restricted. Interestingly in example 3 analysis and interpretation was undertaken initially from the older person's perspective and was only later widened through discussion with the supervision team.

Project management

Project management, i.e. the organizing of activities and resources in order that the research can be completed effectively and efficiently, is a task that has often rested with one named individual, rather than a research team. For funders, identifying a lead researcher or principal investigator clarifies responsibilities and accountability, but such a hierarchical model does not facilitate user involvement in project management. If one person has to give an account of the study to funders, then it becomes difficult for this person to approve decisions, which they do not support and do not feel that they can defend.

Therefore, moving towards an extended role for older people in project management is difficult. In example 2 the strategy was to establish a project management group with clear roles and responsibilities for all members. For funders, there may still need to be a named project leader for purposes of financial management and accountability, and this precludes non-hierarchical project management. Another issue in project management is the question of resourcing. If costs are built into a project budget for materials and services, then this is likely to be via an established organization such as a

university. If older people are to be partners in managing projects, then they need to have access and rights to these resources – to be able to get letters typed and posted, for example, or to have access to IT equipment. Where universities are unable to set up systems to allow this, then the older person will remain outside the project management system. Similarly where researchers' time is costed and paid for by funders, this can cause problems for anyone receiving benefits, as it can cause eligibility problems. Therefore, older people may be the only people working on a project for free.

Writing up and reporting

A final stage of any project is pulling it together in the form of a report, papers or presentations, a process of dissemination, which is subject to a range of rules and conventions, particularly if the researchers want to gain academic recognition for the work by publishing in high status journals. There is a huge question about how researchers can give precedence to the views of older people when the report may have to follow these traditional conventions. For example the convention of prefacing the discussion with a summary of the literature can serve to diminish the user perspective as here the world of the service user has historically been given little priority. Similarly discussions of sampling or methods have little place for the older person's view.

There are therefore some questions about the final shape of reports and papers and how much say the participants will have in their writing and presentation. One strategy for incorporating the user view is to prepare a special report summary for users, and this was one strategy used in example 2. This goes some way towards giving appropriate feedback to participants, but does little to engage them with the research community, or it with them. The users report does not get seen by other researchers, and is not accorded the same status as, say, a paper published in an academic journal. Perhaps more importantly, the research community does not get to see what the users want or need in terms of feedback, and knowing about this is important in itself. In parallel, older people do not see the research report, and so opportunities for their learning are reduced.

A more radical approach would be to write and disseminate reports that integrate older people's views throughout. However, this would require some training and development for everyone to ensure that the processes of joint writing are managed well. Again, this is an area in which little has been attempted, and the complexities can only be guessed at. Some research traditions, such as ethnographic research, where the voices of the research subjects lead the discussion, or are at least placed in the text in ways that create this impression, have gone some way towards giving the user voice some prominence in the research report, but this is not the same as joint authorship of reports. Experimentation with report structures and writing activities to develop joint reporting with older people is still some way away.

Levels of support needed

From the examples cited in this paper, it is also possible to map out levels and types of support needed if partnership with older people is to move away from the restricted position. Table 2 indicates the range of support that might be needed to support users if extended participation in research projects is desired. It is essentially speculative, as we mentioned, much methodological work needs to be done to test out and explore different strategies.

Conclusion

The issues outlined in this paper are ones that we found important in our research work, some examples of which are outlined. Some of these issues have not been explored to any great extent, and indeed have only been recognized as issues at all recently. Ironically, the drive towards increasing partnerships in care and in research has rendered problematic areas, which researchers have, in the past, accepted without too much disquiet.

There is a need to develop a model of user participation in research that is shaped by philosophical, ethical and professional debates about partnership, but which also translates these into pragmatic issues. These pragmatic issues, about how partnership and participation is facilitated, need further

Table 2 Support and facilitation

Research activity	Type of support needed to achieve extended participation
General involvement in study	Safeguards of confidentiality and safety. Communication in accessible language
Research design	Valuing contribution to goal setting, clear processes for eliciting priorities and research questions
Data collection	Training, feedback and support
Data analysis	Developing analytical frameworks, which reflect user goals. Training/valuing
Dissemination and report production	Development of clear writing guidelines and processes, training

exploration and methodological development, and much of what we outline here is speculative and needs to be further tested and explored. Nevertheless this paper represents an attempt to map out what these methodological challenges are, and to go some way towards outlining a template against which studies and proposals may be matched. For those who claim that their studies do involve service users, the frameworks that we identified here may clarify the extent and type of this involvement.

However, there are some key questions that need to be debated if we are to move towards a true partnership research, where older people participate fully and equally. We need to ask whether, by inviting older people to take part in research we are empowering or exploiting them. In other words, is the experience useful and productive for the older people concerned, or is it simply time-consuming and frustrating for them, while the researchers can enjoy the advantages of their insights and experiences, while at the same time claiming a 'moral high ground' in research methodology?

If the experiences are frustrating or difficult for older people, we need to think about ways in which we can support them. Various strategies have been outlined in this paper, but one in particular has been suggested by the discussion of the higher degree student, the issue of research training. This was clearly required for the higher degree process, which is partly about demonstrating research competence within the conventions of the methodology of the subject examined, and there are arguments that it enables older people to participate more critically in research. Developing research skills, may also develop a way of approaching debates and topics that is driven by research models rather than the experiences, views and priorities of older people. In other words, if we want to involve older people because we feel that their voice will make a challenging contribution to a study, we may need to think how we can encourage this without drowning this voice out with researcher voices.

Finally, we need to think about issues of validity, reliability and rigor. This is not just about justifying our methods in the face of potentially hostile responses from conventional researchers, although we do have a responsibility to ensure that our messages are effectively communicated. We also have a responsibility to think about, and articulate what the differences might be between usual notions of validity and ones appropriate to partnership research. While developments in qualitative research have identified a place for subjective accounts of experiences to be given weight, there is still an expectation that the researcher maintains some degree of objectivity in the processes of analysis and reporting. This is usually demonstrated by what Koch and Harrington (1998)

have described as 'auditing' studies, and explicitly identifying processes of decision-making in the research. In partnership research with older people the transparency of this process may be even more crucial, and processes of challenging assumptions and interpretations may need to be even more rigorous. Postulating and exploring different interpretations of data, for example, may be one process, which needs to be engaged in more fully and reported more clearly in research dissemination. This would allow the study to make an important contribution to understanding and thinking, and to avoid its impact being reduced by readers' concerns about validity.

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