RESEARCHING TOGETHER: A PARTICIPATORY APPROACH

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INTRODUCTION

Research is a vast and multifarious topic to dip into in a single chapter. It is of fundamental importance to physiotherapy students and practising therapists, for numerous reasons, from the requirements on physiotherapy students to conduct small scale projects to the general pursuit of research-based practice. In this chapter, we focus on a shift of thinking in research that is centrally concerned with the relations between those who conduct research and those who are research subjects. The crucial shift is from doing research on people to doing research with people. This is not to suggest that participatory research is the only approach that is of value within physiotherapy. It is rather a shift within social science research generally that challenges thinking within physiotherapy research and offers possible alternatives to more traditional approaches. We shall concentrate specifically on research in the field of disability as a significant context for the

development of a participatory approach, though recognising that the general principles have a wider application.

The chapter begins with an overview of the development of participatory research, what this shift in thinking is and why researchers have moved towards this approach. We then turn to disability research and discuss why disabled people are dissatisfied with research done 'on' them. In this context we look at what has come to be known as 'emancipatory research' and contrast this with participatory research to pinpoint key issues for researchers and disabled people. In the next section we highlight examples of research with disabled people that involves them and gives their perspective. Against this background we turn to the implications for physiotherapists. We provide an overview of published physiotherapy research in terms of the principles of a participatory approach and conclude by drawing out the implications for development.

RESEARCH WITH PEOPLE

Brechin states that, 'Research tends to be owned and controlled by researchers, or by those who, in turn, own and control the researchers.' (1993: 73) Researchers who adopt a participatory approach are attempting to change these power relations and to

ensure that research is owned and controlled by research participants as well as researchers. In characterising participatory research, Cornwell and Jewkes argue that 'the key difference between participatory and conventional methodologies lies in the location of power in the research process' (1995: 1667).

Participatory methodologies have arisen from qualitative research approaches which aim to reflect, explore and disseminate the views, concerns, feelings and experiences of research participants from their own perspectives. The realisation of participatory research goes beyond this, however, to engage participants in the design, conduct and evaluation of research, with the construction of non-hierarchical research relations (Zarb, 1992). Participatory research, then, attempts to change the social relations of research processes.

A crucial tenet of participatory research is that it is research with rather than on people (Reason and Heron, 1986). The research process is viewed as a potential source of change and empowerment for the research participants as well as a process for influencing professional policy and practice by reflecting the views and opinions of service users. Reason and Heron (1986) believe that participatory research invites people to participate in

the co-creation of knowledge about themselves. Using the term 'partnership research', Lloyd, Preston-Shoot, Temple and Wuu (1996) recognise similar principles: non-hierarchical research relationships in setting the research agenda, data analysis and dissemination.

Participatory research is an approach that has been evolving in recent years, particularly in the developing countries. Chambers refers to it as a new paradigm', 'a coherent and mutually supportive pattern of concepts, values, methods and action amenable to wide application' (1986:1). Furthermore there are a number of relevant approaches that claim to be essentially 'participatory', such as 'democratic research' and 'emancipatory action research'. The general change in terminology from 'research subjects' to 'research participants' is indicative of the influence of participatory approaches. Participatory research aims to involve, at every stage of the research process (choice of topics, methods, evaluation and dissemination), those towards whom research is normally directed, people who Chambers describes as 'the last', for example rural village dwellers in developing countries, patients and disabled people. Approaches have been developed

in finding common grounds between researchers and research participants (Mercer, 2002).

There is no place for 'subjects' or passive co-operation in this approach, instead everyone involved is an active participant. Ideally, the expertise and talents of everyone are utilized to the full and training is given if necessary; the approach does not, however, reject expert knowledge or help from outside, rather it aims to make traditional research more effective and more meaningful.

The development of participatory approaches in research can also be seen as part of wider developments in social and health care. Braye (2000) includes: the involvement of an individual service user, or prospective service user, in their own use of service; involvement in strategic planning for service provision and development; and the development of user-led services (such as Centres for Integrated Living established by disabled people). The trend towards the participation of disabled people in research can be linked with the development of user-involvement, citizenship and consumer participation (Zarb, 1995). The NHS and Community Care Act 1990, for instance, requires that local authorities should consult with service users in the review and

planning of services (Lloyd, Preston-shoot, Temple and Wuu, 1996).

The broad notion of 'participatory' in relation to research is associated with other principles in service planning and delivery, such as 'empowerment':

> Practice can be improved, too, by being imbued with clarity of thought, critical analysis and informed choice of approach. Both empowering practice and empowering research depend on being participatory, encouraging participants to 'own' the outcome by setting the goals and sharing in decisions about the most desirable process to be followed. (Everitt et al 1992: 50)

Partnership practice is also a model that appears consistently in professional literature. Key objectives include (Braye and Preston-Shoot 1993):

- Open dialogue with service users such that their views and concerns are represented in the definition of problems, prioritization of needs and in decision-making;
- Honesty about differences of opinion and how they are affected by the power held by the different parties in the partnership.

Other relevant and much used terms in the general literature would include consultation, choice and user involvement.

There is also, however, a widely held belief that terms such as empowerment and partnership have developed into fashionable buzz words and are often used loosely and uncritically (Gomm 1993). Baistow has argued, for instance, that while empowerment may have the potential to liberate, it can also open up regulatory possibilities. She states

> Far from user empowerment limiting the intervention of professionals into the lives of citizens, in current empowerment discourses we see space being created for new sorts of professional expertise to emerge and for new or transformed 'client groups' to be identified as the objects of this new type of professional attention. (1994: 41)

It appears, then, that empowerment can be central to the continued legitimacy of professionals and their interventions. Who is being empowered? Braye and Preston-Shoot (1995) discuss the whole notion of user involvement particularly in terms of users being in a negotiating position from which power can be exercised and where the exercise of that power has the potential to achieve its purposes. There are necessary key qualities and

characteristics if 'participatory' is to be more than a buzz word and empty rhetoric. In the following list (Braye and Preston-Shoot 1995: 118) we have used the term participation rather than involvement:

- Clarity about what participation is being offered, and what its limits are;

- Participation from the beginning in ways which are central to agency structures and processes but which are also flexible;

- Tangible goals for participation;

- Participation from black and minority perspectives;

- Individual and collective perspectives;

- Provision of time, information, resources and training;

- Openness to advocacy;

- Clear channels of representation and complaint;

- Involvement of key participants, not just some;

- Open agendas;

- Facilitation of attendance.

Recognising the need for critical reflection, Thompson (1998) argues that, as a practice principle, participation occurs not only at the micro-level of specific practice situations, but also at the wider

levels of service planning, policy development, evaluation, training

and so on. He states:

> Developing approaches based on partnership and
>
> participation is a challenging task, and one that demands
>
> considerable skill and commitment. (1998: 213 – 214)

Having begun by defining what is meant by 'participatory

approaches' in research, the next obvious question is why. Think

of a possible research project and suggest some reasons why you

as a researcher might adopt a participatory approach.

de Koning and Martin (1996) offer two reasons why participatory

approaches have grown in popularity. First, 'there is an increasing

recognition of the gap between the concepts and models

professionals use to understand and interpret reality and the

concepts and perspectives of different groups in the community' (p

1).   Second, 'many factors, cultural, historical, socio-economic and

political, which are difficult to measure have a crucial influence on

the outcomes of interventions and efforts to improve the health of

people' (p 1). Chambers (1997) identifies the following as some of

its key features: it breaks down the mystique surrounding

research; it ensures that the problems researched are perceived

as problems by the community to which the research is directed; it

helps to develop self-confidence, self-reliance and skills within people to whom the research is directed; and it encourages democratic interaction and transfer of power to the research participants. Participatory research is essentially about establishing equality in research relationships, that is giving more say in research to people who are more usually subjected to research.

In this way, too, issues of participation can be seen as closely related to ethical issues. Suto (2000), a therapist, conducted a qualitative exploration of how people with chronic schizophrenia use time and the environment to enact their daily occupations. She discusses some of the ethical difficulties that can arise studying a vulnerable population. These included: gaining access to the research site, through the home administrator rather than the research participants themselves; the unequal power relations between the researcher and the participants; and obtaining informed consent from the participants to undertake the research.

From an ethical standpoint, the justification of participatory research can be founded on the recognition that research is not necessarily a social good. Research is not justifiable simply on the traditional, modernist grounds of furthering knowledge, on the

basis that knowledge is intrinsically good. The research process can be detrimental to research participants and, on a broader basis, people who are not directly involved in the research. Domholdt (2000) lists types of risks for participants in therapy research. There can be physical risks such as the development of delayed muscle soreness from the use of isokinetic equipment. Psychological risks include adverse emotional reactions to data collection in investigations of sensitive topics. Social risks can emanate, for instance, from a breach of confidentiality. The fourth category of risks is economic, such as lost working hours (including for therapists involved in the research). Prentice and Purtilo (1993) also list legal risks (e.g. criminal prosecution).

Research has also been linked to wider issues of social inequality and social injustice including sexuality; sexual abuse; race and ethnicity; age; gender; and disability (Truman et al, 2000). The research process is bound up with social and political forces of which researchers should be aware. Research findings can affect political decisions, which may be detrimental to various people in society. Research on sensitive issues such as race may increase prejudice and discrimination, or create social unrest; research aimed at producing greater efficiency in a particular industry or

profession may reduce job satisfaction or give rise to widespread unemployment, and expenditure on medical research may limit expenditure on social research or social action. Furthermore, knowledge is often put to use in ways that are not beneficial to the people to whom the research is directed. Research into the treatment of a particular disease, for example, may serve to maintain the status quo by failing to address the social, economic and political factors involved in its aetiology.

As a therapist beginning to get involved in research, it is most likely that you will regard research as a good thing: to inform and develop practice; to contribute to knowledge and understanding and so on. A starting point for thinking about the ethics of research is, however, the possible harm to participants that might result from their involvement in the research. List what you feel might be the main risks of harm to participants either in research generally or in a specific project you have been involved in.

In the next section of this chapter, we take up the general issues we have raised in the specific context of disability research.

Disability Research: Towards Participatory and Emancipatory Approaches

In 1992 Oliver laid down the gauntlet to researchers in the field of disability studies. He stated:

> 'As disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than part of the solution . . . Disabled people have come to see research as a violation of their experiences, as irrelevant to their needs and as failing to improve their material circumstances and quality of life.' (Oliver, 1992: 106)

Since then, it seems, disability research has been in 'a state of transformation and transition' (Moore, Beazley and Maelzer, 1998: 11). Seemingly solid, traditional, modernist grounds have turned to shifting, sinking sands. Research is not justifiable simply on the traditional grounds of furthering knowledge with the presumption that knowledge is intrinsically good. All research is political, and research production and processes can further the oppression of those who are the subjects of research.

Critiques of disability research have analysed the processes through which research maintains and strengthens the status quo within a disablist society, such as Abberley's (1992) evaluation of the Office of Population Census and Surveys (OPCS). As French (1994) argues, research has traditionally reflected an individualistic stance to disability and served to oppress disabled people by depoliticizing the political. A project with which one of the authors was involved as a research subject serves as an example of research which clearly demonstrated an individualistic, tragedy model (see chapter ?). In a trial of a newly developed form of insulin, research subjects with diabetes were required to complete a questionnaire about '. . you and your diabetes . . . the way you feel and how diabetes affects your day to day life.' With each question was a choice of four answers ranging, basically, from 'very much' to 'not at all.' The first question set the scene: 'Do you look forward to the future?', with the implication that the supposed tragedy of diabetes may negate any hope for the future. The thirty-two questions were peppered with words of tragedy, such as 'fear', 'edgy', 'worry' and 'difficult'. Some questions addressed psychological responses to the tragedy, such as: 'Do you throw things around if you get upset or lose your temper?', 'Do you get touchy or moody about diabetes?' and 'Do you hurt yourself or feel

like hurting yourself when you get upset?' Two questions invoked

the essence of the tragedy model: 'Do you even for a moment wish

that you were dead?' and 'Do you wish that you had never been

born?' Thus, the ultimate version of the tragedy model, as

conveyed within this research, is that physical death is better than

the social death of disability. The agenda within the research is

that of the researchers, not the concerns of disabled people. For

instance, the causes of any anger are clearly conceived in terms of

the person's response to impairment, not the barriers faced within

a disabling society (or, indeed, completing a questionnaire of this

kind).

Many disabled people are of the opinion that medically orientated

research has not fundamentally altered their position (Abberley

1992, Oliver 1992). The way in which disability has been

researched has become a major issue for disabled people and

their organizations in recent times. In 1991 a series of seminars on

the subject of researching disability were organized by disabled

academics (Disability Research Seminars 1991), culminating in a

conference (Researching Disability: Setting the Agenda for

Change) in 1992.

Disability has generally been defined in an individualistic, medicalized way as an internal condition of the individual, and most research on disability, including the large Office of Population Censuses and Surveys (OPCS) government surveys reflect this orientation. Many disabled people, on the other hand, view disability in terms of social, physical and attitudinal barriers which could be removed if only the political will to do so were present.

If an individualistic stance is taken by researchers, then the questions posed will be based on impairment and not on discriminatory practices and lack of access. Oliver has reworded some of the questions used in an OPCS survey to illustrate this point. For example, in place of the question 'What complaint causes your difficulty in holding, gripping and turning things?', he substitutes the question 'What defects in the design of everyday equipment, like jars, bottles and tins, causes your difficulty in holding, gripping and turning them?' and in place of the question 'Did you move here because of your health problems/disability?', he writes 'What inadequacies in your housing caused you to move here?' (1990:7). Abberley believes that 'It is a political decision, conscious or otherwise, to employ questions of the first type rather than the second' (1991:158). The way in which disability is defined

is a serious issue, as findings may be translated into practice (French 1994).

The more recent developments in disability research have taken two quite distinct directions, though they are often related and, more often simply confused. They are associated with a number of terms but we shall use the most common: participatory research and emancipatory research. In a previous paper (French and Swain, 1997), we argued that these two methodological bases can be traced to distinct historical roots. Participatory approaches have developed from general qualitative methodology. They have been developed, generally, by non-disabled researchers who wish to break down the traditional hierarchical researcher - researched relationship.   It is important to understand that the roots of participatory research lie in the development of research methodology itself, rather than the development of a different understanding of disability.   Qualitative research is primarily concerned with meaning, interpretation and giving research participants 'a right of voice'. There is a commitment to seeing 'through the eyes' of research participants, and a belief that social behaviour cannot be grasped until the researcher has understood the symbolic world of the research participants. Researchers in

the qualitative tradition accept that the research in which they are engaged cannot be independent of their own values and perspectives.

This is not to imply that qualitative approaches are free of conflict, difficulties and ethical dilemmas when it comes to disability research. It can, for example, be difficult to find justifications for undertaking research into intimate, personal matters such as sexual behaviour or feelings of vulnerability following impairment or illness (Swain, Heyman and Gillman, 1998). It would seem that, participatory research reflects the concerns and views of disabled research participants and thus tends to reflect a social model of disability. However, participatory methodology is not inherently associated with a social model of disability. As Oliver (1997) states: 'participatory and action research is about improving the existing social and material relations of research production; not challenging and ultimately eradicating them' (p 26). It seems, then, that the participatory research paradigm has arisen from qualitative research approaches and philosophical arguments about social reality. Participatory research has been applied within disability research, but it does not have its roots in a different understanding of disability.

Emancipatory research, in the area of disability at least, has its roots in the growth of the Disabled People's Movement and the development of a social model of disability. The emancipatory paradigm takes the adoption of a social model of disability as the basis for research production (Priestley, 1999). It can be argued that emancipatory research, unlike participatory research, is not a research methodology as such, but rather part of the struggle of disabled people to control the decision making processes that shape their lives and to achieve full citizenship. As Barton states: 'The task of changing the social relations and conditions of research production is to be viewed as part of the wider struggle to remove all forms of oppression and discrimination in the pursuit of an inclusive society' (1998: 38).

Emancipatory research goes further than participatory research by aiming to change the social relations of research production, with disabled people taking complete control of the research process. In emancipatory research the social relations of production are conceived as part of the processes of changing society to ensure the full participation of disabled people. Barnes explains:

'Emancipatory research is about the systematic demystification of the structures and processes which

create disability and the establishment of a workable

'dialogue' between the research community and

disabled people in order to facilitate the latter's

empowerment. To do this researchers must learn how

to put their knowledge and skills at the disposal of

disabled people.' (1992: 122)

Barnes (2001) has pinpointed and discussed what he sees as the

core principles of an emancipatory research model. He argues

that:

1.   Accountability to the disabled community is a key component

      of this model.

2.   The emancipatory model is founded on the social model of

      disability.

3.   Researchers must make their position clear at the outset,

      'ensuring that our choice of research methodology and data

      collection strategies are logical, rigorous and open to

      scrutiny' Barnes (2001: 20)

4.   In terms of the choice of data collection methods, Barnes

      argues that from the point of view of the emancipatory

      model, all data collection strategies have their strengths and

      weaknesses.

5. In terms of 'the role of experience', Barnes states, 'what is important is that the discussions of disabled people's experiences, narratives and stories are couched firmly within an environmental and cultural context in order to highlight the disabling consequences of a society that is increasingly organised around the needs of a mythical, affluent non-disabled majority' (2001: 23).

6. In terms of practical outcomes, Barnes asks whether emancipatory disability research can offer anything different and argues that it can and has. He also suggests that doing emancipatory research cannot be conceived in terms of a single project or even a collection of projects, but is a continuous process and the organisation and content can only be determined by disabled people and their organisations. Furthermore, the evaluation of the effectiveness of the research can also, ultimately, only be determined by disabled people and their organisations.

In emancipatory research, the production of research is part of the liberation of disabled people, that is part of the process of changing society to ensure full participative citizenship. This is research conceived as political action in which the processes and

products are the tools of disabled people in the achievement of their liberation.

Although certain features of participatory and emancipatory research may overlap, one common confusion, it seems to us, is the equating of emancipatory research with the qualitative paradigm. There is no reason inherent within the nature of emancipatory research why it should adopt a qualitative methodology, as long as the research agenda is generated by disabled people themselves. Indeed, it could be argued that a quantitative approach is more likely. For instance, emancipatory research into the housing stock and, in particular, accessibility of housing for disabled people is likely to take the form of a quantitative survey to produce statistics to influence housing policies. Research currently which was undertaken at the Policy Studies Institute *Measuring Barriers within Society*, for instance, aimed to make a systematic analysis of physical, social, economic and political barriers using both qualitative and quantitative measures (Zarb, 1995). Oliver states:

> 'If the category disability is to be produced in ways
> different from the individualised, pathological way it is
> currently produced, then what should be researched is

not the disabled people of the positivist and interpretive

research paradigms but the disablement ingrained in the

individualistic consciousness and institutionalised

practices of what is, ultimately, a disablist society' (1996:

143)

Zarb sums up the fundamental difference between participatory

and emancipatory research as follows:

'Participatory research which involves disabled people in

a meaningful way is perhaps a prerequisite to

emancipatory research in the sense that researchers

can learn from disabled people and *vice versa*, and that

it paves the way for researchers to make themselves

"available" to disabled people - but it is no more than

that. Simply increasing participation and involvement

will never by itself constitute emancipatory research

unless and until it is disabled people themselves who

are controlling the research and deciding who should be

involved and how' (1992: 128).

Complicating the matter even further, Walmsley (2001) used the

term 'inclusive research'. Her discussion justifiably addresses the

issues of participatory and emancipatory approaches in research

with people with learning difficulties. She argues that inclusive

research raises questions that have been barely acknowledged in

the literature, such as: 'the consequences for non-disabled

researchers of acting as allies; which disabled people can and

should undertake research; how theory can be shared with or

generated by people with mental impairments; and the possible

dangers of research as political action' (2001: 203).

We conclude this section by saying that participatory research and

emancipatory research are two distinct, though by no means

incompatible, research paradigms. As Stalker (1998) suggests,

there are shared 'beliefs' within the two paradigms, but we believe

that the differences also need to be recognised. 'Ideal types' are

conceived here as a basis for critical reflection in terms of intention

and, in particular, the pursuit of social change.

Reflecting on Research

'Participation' can be seen as an ideal to which researchers can

aspire. In this light there are not two types of research,

participatory and non-participatory, but an imperative for

researchers to critically reflect on projects in terms of the

realisation of participatory principles. In developing processes of

critical reflection, we would suggest that two key questions need to

be addressed. The first question is: does the research address the concerns of disabled people themselves? Second, does the research promote disabled people's control over the decision making processes which shape their lives? The question can be directed at the decision making processes within the research, and the empowerment of the participants through their involvement in research. Clearly, such critical reflection should itself be participatory and these question can only be answered with disabled people themselves. In this section we shall look at some projects with disabled people that involves them and gives their perspectives. We have selected research that is of direct relevance to physiotherapists.

In relation to the first question, there are now numerous examples of studies that reflect the concerns of disabled people, adopting an open-ended agenda flexible to control by the disabled participants. The following projects have been selected to reflect a wide range of topics and participant groups relevant to physiotherapists. Closs (1998) explored the views of children and young people with life-threatening or life-shortening medical conditions. Six young people participated in the study by reflecting on their childhoods, 'responding to questions on key issues identified in the literature

and supplemented by them, and criticising drafts' (1998: 112).

From the data she collected a number of themes were considered

critical to the quality of children's and young people's lives,

including: the individual's understanding of their condition; feelings

of sameness/difference; educational experiences and attainments;

friendships; family; and experience of the medical/paramedical

services and hospital life. In relation to the last of these,

comments from young people illustrated some distressing

experiences, such as: 'If they didn't call it treatment you could call

it torture;' 'I could write a book about doctors, good, bad and

unspeakable;' and 'I realised I had nothing on under the sheet.

Maybe it was easier for them to put in tubes . . . but I felt really

embarrassed' (1998: 121). There were also some enjoyable

experiences: 'I don't think you can live for too long in the dumps.

I've had lots of laughs, lots of highs . . . (1998: 116).

Fifty people with aphasia were involved in a study of aphasia (Parr

et al 1997). In-depth interviews were adopted to allow important

topics and issues to be raised by the participants, in addition to

those on the researchers' agenda. One topic was people's

experiences of services. From participants' detailed accounts, for

instance, attributes of successful services included: availability and

accessibility; appropriateness and adequacy; flexibility and responsiveness; integration; reliability and consistency; respectfulness; ability to support communication; and ability to provide relevant and accessible information (1997: 66). The experiences of individual participants varied greatly. Madge felt that she had been supported and that the care she had received had been satisfactory. Rebecca's views were very different.

> Rebecca tried to convey the fact that her field of vision was impaired to one doctor: '*He said: "Explain what you mean" and of course I couldn't and he sat there sort of tapping his fingers. He said: "Well does that mean you can't see countryside?" I said . . . I just thought . . . I just didn't bother.'* Although she had intensive treatment from physiotherapists who were '*like Rottweilers'*, Rebecca had no contact with a speech and language therapist, despite her impaired communication . . . (1997: 74)

The volume by Ahmad (2000) reports two qualitative studies focusing on parents of pre-school deaf Asian children with thalassaemia major or sickle cell disorder and their interactions with professionals, from the points of view of both parents and professionals. Atkin et al (2000) report on parents' perspectives.

There were 62 parental interviews, 21 of which were in languages other than English. Semi-structured interviews were adopted as 'this approach is particularly recommended for the study of the ways that individuals express their understanding of themselves, in the context of their social, cultural and personal circumstances' (2000: 108). They found, for example, that parents face many problems in having their needs recognised, obtaining necessary information about the condition and sources of support, dealing with poorly co-ordinated services and dealing with often unsympathetic and poorly informed professionals. One parent explained:

> The medical side should be a bit more informed about the illness so they can inform us about it, but I mean we've come across doctors, nurses . . . and they've turned round and said, 'Well I don't know anything about sickle cell.' So straight away, I mean I doubt them straight away. I think, 'Well why are they caring for my child if they don't know anything about it?' (2000: 114)

The next example comes from research with people with learning difficulties. Atkinson (1997), along with others, has been developing an auto/biographical approach that,

Has the capacity to combine the political document with the historical – to reflect the lives which have been lived, but to see beyond the individuals to a wider view of learning disability. Auto/biography contains many voices and tells stories at different levels (1997: 22).

Individual live stories were recounted and shared in a group context. Nine participants, age-range 57-77 years, met on 30 occasions. One of the themes was 'tales of hospital life' and the following is a short extract in which Margaret tells her story of running away:

The sister would keep on at me, saying my work wasn't done properly. She was being horrible. I'd scrubbed the ward and she said I had to do it over again. I said, 'Well I aren't going to do it over again!' I told the doctor. He come round and he wanted to know what I was doing on the stairs again. I said, 'I've been told I've got to do it again, it wasn't done properly.' I planned it with the other girl, we planned it together. She was fed up. She was doing the dayroom and dining room, cleaning and polishing. Then I was put on it, as well as scrubbing. We planned to get into Bedford, walk across the fields. (1997: 91)

The following two examples are from therapy research. Martlew

(1996), a physiotherapist, evaluated on-site physiotherapy in a day

hospice providing care for patients with terminal illness, using

'client-centred action research'. She concluded that the learning

experience was 'greater because this study was conducted by a

practitioner-researcher doing her own action research' and that

'this study has confirmed the benefit of taking time to listen

sensitively - both for the professionals, to gain greater insight into

patient problems, hopefully leading to more appropriate and

therefore effective intervention; and for patients who feel supported

and understood' (p 564). Blanche (1996), an occupational

therapist, explored the effect of cultural differences on the delivery

of health care services through a life story approach with the

mother of a disabled child. She used a 'co-operative story making'

approach which rejects the ideology of 'observed versus observer'

and sees both the interviewer and the informer as building the

story together. She concludes that: 'clinicians need to

acknowledge the client's and their own culture as well as the

perceptions, expectations, values, and beliefs that are inherent in

each . . . Stereotyping persons and treating them as

homogeneous ethnic or racial groups saves time but is not

effective. Listening to a client's life story may give us the

information we need to place our services within the complexity of his or her life' (pp 174 - 275).

The final example is a more fully developed example of participatory research in that the participants were involved in the decision-making process throughout the research. The project was controlled, conducted and reported, with support, by the Bristol Self-Advocacy Research Group, a group of four people with learning difficulties (Palmer et al 1999). Their responses to the experience of conducting research were positive:

> We've all really enjoyed the research visits, meeting new people and making new friends:
>
> I was looking at my photographs yesterday when I was at home, and all the different places I've been. And I've got the photographs in my photograph album at home. I'm quite proud of what I did. And you feel very important. People say: 'You do do a lot.' They're quite impressed with what I do. I've achieved a lot – too much. (1999: 34)

The themes covered are: What is disability? Cutting out all the labels; Jobs and work; The staff who support us; Transport; and Self-advocacy – what does it mean? For example, under the theme of support, they write about being forced to be independent:

Staff people always think that we all want to be more and
more independent. This can be wrong, because they expect
us to do too many things ourselves. It should be our choice,
not theirs.

If you're married, you've got to give and take. One person
does one thing, and people help each other out. It's the
same in any house – I don't want staff to keep on forcing me
to be independent. How would they feel? (1999: 42)

Physiotherapy Research: Towards a Participatory Approach

Research of any kind may seem somewhat removed from the
everyday pressures of the practising physiotherapist although most
will have had considerable exposure to research ideas and
practice during their under-graduate education.   Physiotherapists
are, however, in an ideal position to involve disabled people in
research.   Unlike many health professionals, physiotherapists
frequently spend considerable time with their patients and clients
and are in a position to get to know them as people.   Sensitive,
empowering research can give invaluable insights into patients'
and clients' complex experiences of illness, disability and
impairment which may, in turn, have the potential to improve
physiotherapy practice as well as patient and client satisfaction.

Many patients and clients live with disability and impairment on a daily basis and the knowledge and experience they have gained should not be underestimated however young they may be.

Over the last twenty years physiotherapy education has moved into the university sector and has broadened its scope from a narrow biomedical perspective to one which includes a consideration of psychological, sociological and cultural aspects of health care.   It is now recognised that physiotherapy draws on a wide range of diverse disciplines to inform its practice. This is reflected in research textbooks for therapists where a large number of methodologies and approaches are explained (see for example Domholdt 2000, French et al 2001. Jenkins at al 1998, Seale and Barnard 1998).

This diversity is not, however, reflected in physiotherapy journals where a biomedical approach is still paramount leading to a concentration of articles based upon experimental research with little if any involvement by research 'subjects'.   We undertook a brief content analysis of the peer reviewed articles in the British Physiotherapy Journal from January 1999 to December 2001. This revealed that, with regard to research studies of patients and clients, the experimental method was three times more common

than the summed total of qualitative and survey methods.

Qualitative and survey methods which focused on health care

professionals (where for example their opinions and feelings were

sought) were over three times as common as those which focused

on the opinions and feelings of patients and clients.   Twelve case

studies and five studies using a documentary method were

published during this period.   All of these studies showed a strong

biomedical and quantitative orientation.   Psychological, social and

cultural perspectives were minor compared with the biomedical

perspective in this sample of journals, while the perspective of the

Disabled People's Movement was entirely absent.   This indicates

the dominance of biomedical knowledge within physiotherapy,

derived from experimental research, and the marginalisation of

other sources of knowledge including the direct voice of disabled

people themselves.

The Chartered Society of Physiotherapy regards knowledge of

research as an essential characteristic of newly qualified

physiotherapists (CSP 2002).   It argues further that graduating

physiotherapists should deliver services based upon the best

available evidence and that they need to be competent in:

     Initiating and enacting change
     Promoting equality

Seeking evidence and applying new knowledge
Responding to changing demands
Working in partnership with patients and clients
Making paramount patient/client experience.

Research which involves and empowers patients and clients in a

meaningful, rather than a tokenistic, way would be one means of

achieving these goals.   This is unlikely to happen, however,

unless Disability Studies and the voice of disabled people is given

space within the physiotherapy curriculum.   Disabled people have

spoken out about the ways their perceptions of disability frequently

clash with those of health professionals, and non-disabled people

in general, and how the neglect of their perspective has created

inappropriate policy and practice.   The following quotations

illustrate these point:

> "I just can't imagine becoming hearing, I'd need a
> psychiatrist, I'd need a speech therapist, I'd need some new
> friends, I'd lose all my old friends, I'd lose my job.   I wouldn't
> be here lecturing.   It really hits people that a deaf person
> doesn't want to become hearing.   I am what I am." (Phillipe
> in Shakespeare et al 1996)

> "….I cannot wish that I had never contracted ME, because it
> has made me a different person, a person I am glad to be,
> would not want to have missed being and could not
> relinquish even if I were 'cured'." (Wendell 1996:83)

With the implementation and the strengthening of the Disability

Discrimination Act (1995) and the growing philosophy of working

with patients and clients in partnership and collaboration, a move

towards participatory and emancipatory research in physiotherapy is becoming urgent.   Brothers et al (2002) believe that health professionals need to consult with disabled customers, disabled staff and disability organisations in order to prevent discrimination and to comply with the Act. .

Disabled people are being empowered by the Disabled People's Movement.   The question is can research by physiotherapists be part of that empowerment?

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