
GUEST EDITORIAL

USING QUALITATIVE RESEARCH METHODS FOR DISABILITY RESEARCH IN MAJORITY WORLD COUNTRIES

Sally Hartley*, Mohammad Muhit**

ABSTRACT

This article undertakes to explore the use of qualitative methods in relation to disability research and disability classifications, drawing on medical, social and educational perspectives. It reviews what qualitative research entails, what skills are required to carry it out and why and when it should be used. It gives examples of on-going research in majority world settings and describes what quantitative researchers can learn by engaging in the qualitative paradigm. It concludes by summarising suggestions for a way forward.

INTRODUCTION

Services for people with disabilities throughout the world have evolved as an extension of medical and educational practice. These practices are based on information gathered from a predominantly positivist quantitative approach (1). Positivist approach is one that believes the world operates by the laws of cause and effect. Observation and measurement are the core scientific endeavours, knowledge of anything beyond that which we cannot measure, is impossible. This is an approach where 'proper' scientific research is seen to be based on quantitative methodology, with 'random control trials' as the ultimate 'gold standard' (2) and where Measurement itself gives scientific credibility, which is not awarded to the unmeasured or the immeasurable (1). However in the medical arena Holeman (3), points out that 'the almost sole recognition given to quantitative methods has trained students inadequately, established flawed standards of practice and research, and delayed the development of essential medical knowledge.'

WHAT IS QUALITATIVE RESEARCH?

Qualitative research embraces the view that as far as peoples' perceptions are concerned, there is no one single truth. In other words, different people in different places at different times, interpret things differently. This philosophical viewpoint serves to challenge the validity of socially oriented data that is collected using quantitative methods. It demands an alternative set of methods for exploring peoples' perceptions, one that is contextually and culturally

related. It therefore, seeks to find the answer to questions about the meaning and individual interpretation of life. It is used to answer open questions relating to peoples' attitudes and beliefs, in a given contextual setting. A series of articles in the BMJ provide helpful initial guidance on this topic (4, 5).

Qualitative research also offers the opportunity of closing the gap between the science of discovery and the implementation of such discoveries. It does this by studying things in their natural settings and by providing a vehicle for collecting and analysing information based on the participants' views and the way in which they make sense of the world. This serves to reinstate 'people' at the centre of the research agenda (6). Stone and Priestly (7) argue that this is particularly important in both disability and in majority world research, where research has been based in an oppressive theoretical paradigm, and 'decades of 'scientific' research have perpetrated the marginalisation of disabled people' so that 'research has become part of the problem' (7). Majority world is 'where the vast majority of the world's people live, yet they have access to a fraction of the world's wealth and power' (8). A more emancipatory approach is required to move forward in a positive way and qualitative methods offer potential in this arena.

SUPERIOR OR INFERIOR?

The perception that quantitative research is superior regardless of the research questions asked, is not supported by the literature (9, 10). They argue that qualitative approaches are better for investigating subjective meanings within a culture, understanding attitudes and beliefs and unravelling the dynamic constructs of culture and social traditions. Quantitative methods on the other hand, have their strengths in identifying universalities and making statistical or probabilistic generalisations, or in determining the correlation between two measurable phenomena.

Superiority is therefore dependent on an appropriate relationship between the research questions and the methodology (1, 9). There is also a need for research to be valued for its capacity to alleviate the problems felt by the community and not knowledge for knowledge's sake.

Unfortunately, the misguided perception that quantitative research is a superior method, has impacted on the capacity of researchers to secure funding and this in turn has influenced the frequency or infrequency of its use (11).

EASY OR DIFFICULT?

There is a general misunderstanding that one research method is easier or more difficult than the other (9). But good qualitative research is no easy option. Whilst it may not demand

complex numerical skills, it does require a high level of linguistic competence, good interpersonal communication skills, long-term commitment and in the present research climate, determination. The term 'qualitative research' should therefore, not be confused with the word 'quality research'. It is just as easy to do poor qualitative research, as it is to do poor quantitative research.

COMPLEMENTARY OR COMPETITIVE?

Qualitative research methodologies support the idea that there is a range of different ways of making sense of a given situation. They move away from knowledge for the sake of knowledge, to valuing it for how it can alleviate problems that are felt by communities (6). However, it is only when used together with quantitative research, that it provides the capacity for researchers to uncover a complete picture of the relevant issues, and give a holistic picture. Black (1) and Cresswell (9), therefore, quite rightly argue that the methods are complementary and not competitive.

THE FIVE TRADITIONS

Qualitative research methodology can follow five traditions of research strategies—ethnography, grounded theory, case study, phenomenological research and narrative research. In ethnography, the researcher studies an intact cultural group in a natural setting over a prolonged period of time by collecting, primarily observational data (12). In grounded theory, the researcher attempts to develop a general and abstract theory grounded in the views of the participants. The research process involves collecting interview data and analysing the data, using several methods of coding to develop the theoretical model of the process, action or interaction under investigation. Case studies aim to develop an in-depth analysis of a programme, event, process or individual. Multiple sources of data are used including documents, archival records, interviews and observations, to illustrate the case in depth. Understanding the essence of human experiences about a phenomenon, as described by the participants, is the objective of phenomenological research. It usually involves long interviews of a limited number of participants to develop patterns and relationships of meanings, as experienced and described by the participants of the study. Narrative research, is a form of inquiry in which the researcher studies the lives of individuals, through the collection of life stories usually by interviews. It provides a detailed picture of an individual's life. The choice of particular research strategy depends on the objective of the study and the phenomenon under investigation. For example, researchers might study an individual's experience (phenomenology), or an individual's life (narrative research), explore the process, activity, events and outcome (case study and grounded theory), or explore the behaviours and rituals of a culturally defined group (ethnography).

QUALITATIVE DATA COLLECTION METHODS

Data collection methods for qualitative research largely originate from the field of anthropology, sociology and psychology. Qualitative data can be collected by systematic observations, conducting interviews and focus group discussions, collecting public and private documents and emails and through audiovisual materials like photographs and video-tapes. Each type of data collection method has its own advantages and limitations. The most commonly used data collection methods for qualitative studies, include different types of interviews and focus group discussions to explore the participant's perspective on the research topic. Rifkin and Pridmore (13) provide a useful text for the beginner in these data collection techniques.

QUALITATIVE RESEARCH AND ACTION RESEARCH

Qualitative research can be considered 'Action Research', but this is not inherent within the definition. However, qualitative approaches have many of the key components of action research, such as participation of the stakeholder groups, educative aims, and an iterative rather than linear processes (14). This puts it into a strong position for developing a participatory or emancipatory approach as recommended by disabled researchers and the disability rights movement (15). This does not mean that quantitative studies cannot aspire to Action Research criteria also, but that by the nature of the process, might be more complex and difficult to achieve within the framework of a totally quantitative study.

WHAT QUALITATIVE RESEARCH IS NOT

Ironically it is often easier to say what qualitative research is not. It is not about numbers (its currency is words), it is not a haven for innumerate scientists, but an opportunity for researchers with mature emotional intelligence and advanced linguistic and conceptual skills, to make their contribution to scientific debate and subsequent policy and planning. Qualitative studies do not attempt to predict an outcome, as in many quantitative studies, rather they seek to explore questions to which the answer is not known and predictions cannot be made. Additionally, as qualitative research does not seek to make statistical generalisations, it does not use random sampling. This does not weaken such studies, but allows rich data to be collected on the fullest range of possible views, by purposively selecting people with different backgrounds and experiences. Qualitative research does not follow a linear process. It provides the opportunity to be flexible and iterative, to adjust aims and purposes and collect data in several stages, with the eventual possibility of producing a theoretical frame work which has been grounded in the data. The aim is to represent the widest possible view of the situation, by exploring the different perceptions and meanings, given by the different stakeholders. Additionally, when selection of the participants uses clear inclusion/ exclusion criteria and rigorous interview procedures, sampling to redundancy shows that there is rarely a need for large samples.

WHY USE QUALITATIVE METHODS IN DISABILITY RESEARCH?

Published research in the area of disability in majority world countries is generally scarce (16, 8) and is traditionally and historically dominated by the quantitative approach (17, 3). The research that is documented, focuses on either the prevalence of impairments, biomedical issues or the efficacy of interventions in numerical terms (11). This is problematic for doing disability research on a number of counts.

Firstly, the predominantly quantitative approach to disability research has resulted in a dominance of impairment-related studies and the social aspects of disability have been ignored and under investigated. Over the past decade or so, the introduction of the social and rights model have provided a long overdue challenge to the individual/medical model of disability and has served to reflect the social construct of disability, which had been previously ignored. The International Classification of Functioning and Disability (ICF) (18) gives clarification to the difference between impairment (described as the deviation from normal functional or structural integrity of the tissue, organ or part of the body) and disability. Disability is an umbrella term for impairments, activity limitations and participation restrictions. Disability is characterised as the outcome or result of a complex relationship between an individual's health condition, personal factors and of the external factors that represents the circumstances in which the individual lives. Because of this complex relationship, different environments may have a very different impact on the same individual with a given health condition. ICF has also described the role of participation as involvement in a life situation. This provides a framework where medical, social and rights models can be combined to give a comprehensive/holistic picture of disability. To achieve improvement in disability services and research, there is a need to embrace this 'universal model' (19) and cease the rhetoric of allegiance to one model in particular. Interestingly, a similar parallel exists between the quantitative and qualitative approaches to research. Traditionally the medical model associates with the quantitative approach and as such, struggles to be meaningful when used in situations relating to peoples' perceptions that are complex and dynamic. These are more effectively described qualitatively, but both research methods are required for a complete picture, just as all models are required for a complete understanding of disability.

Secondly, there is a need to utilise qualitative methods to collect information which is culture specific and for researchers to act on the knowledge that the complexities of human behaviour, and the dynamic and cultural nature of such behaviour, may be beyond the scope of quantitative methods (11). Being culturally informed, safeguards the ethical issues relating to validity and allows the people in the community to direct the research so that it reflects their perceptions and needs, and not just those of the researcher. The researcher may have a different agenda such as promotion, or a narrow interest in a specialised and possibly irrelevant topic.

There are also a number of practical problems in using quantitative methods for disability research. For example, the low prevalence rates of different impairment groups, make it extremely difficult to draw any statistical conclusions from a quantitative study and the heterogeneity of these groups further confounds quantitative research designs and makes controlling for variance a logistical nightmare (20, 21).

The capacity of qualitative research to investigate the attitudes and beliefs of the people in the community contributes towards improving the validity (and therefore the value and ethics) of the research. However there is also a need to recognise the limitations of both the quantitative and qualitative approaches and for researchers to be trained to conduct both types of studies with rigour and confidence. Nowhere could this be more appropriate than in the field of disability research in majority world countries.

WHEN TO USE QUALITATIVE RESEARCH METHODS

1. EXCLUSIVELY

When little is known

Disability research in majority world countries is still in its infancy. Many individual countries simply do not have ANY research on particular topics in the disability field (8). Qualitative research methods are known to be appropriate and effective when little or nothing is known about the situation, as they do not require a predictive statement and therefore seek the answers to open questions. (8, 22, 23, 24). In such a situation, predictive, or closed quantitative questions are inevitably based on culturally different norms, imported from other settings. This creates a situation, where, however rigorously the research is conducted, the outcome is likely to be inappropriate in that particular setting, and irrelevant to the problems the local people are facing. In such situations, there is a need to base service development on cultural realities and develop new innovative services, training and policy based on the complex and dynamic actualities. Muecke (6) argues that qualitative research has the capacity to do this and that it has a vital role to play, in putting people and culture back into development by documenting ignored social realities. This makes qualitative research methods a strong initial research option in majority world countries (6).

When target populations are vulnerable

Qualitative methods are also an effective tool when the target group are vulnerable, as is inevitably so, when focusing on people with disabilities. Other common vulnerable groups are women, illiterate groups and people with HIV. An on-going qualitative study in Uganda by the author and colleagues, is looking at the coping strategies of families with disabled

children. Little is known about how families cope with disabled children even though WHO/ILO and UNESCO (25) in their joint position statement recommend that such services should be based on local perceptions of need. The information this study has generated (in press) is providing a valuable basis on which to develop community-based rehabilitation (CBR) initiatives in Uganda and is also improving the validity and relevance of CBR training in the country. Similar procedures are being used by the Bernard van Leer Foundations to investigate practices in Early Childhood care and development (23, 24). Another ongoing study by the authors is looking at the perception and attitudes towards the children with vision related disability in Bangladesh. This study is also exploring the need for service provisions for the children with vision related disability in Bangladesh, as perceived by the children themselves and their families. Use of qualitative research methods provided the opportunity to listen and include the voices of the vulnerable population, in programme planning.

When policy information is required

Quantitative studies have given decades of comparative data that have been used to inform policy and planning of health and education services at all levels, but what this data does not do, is provide information about the variations within the target population and the extremes that are likely to exist. Such studies tend to ignore the socio-cultural context as determinants of health and educational status and the fact that political problems are socially constructed (26). A study by the author and colleagues in Uganda (in press) has looked at the perception of stakeholders towards the implementation of policy relating to disabled people. The results highlight the interactive, iterative relationship between the development of policy and existing practice, and challenge the more linear view of cause and effect, that might have been predicted. This study provides the evidence to support policy development through participation with practitioners. This concept can be utilised in other settings around the world.

2. TOGETHER WITH QUANTITATIVE RESEARCH

Qualitative data can be a prerequisite for good quantitative research in a number of ways. For example, increasing the validity of measuring tools by providing culturally relevant information about the issues that require to be measured. Black (1) says 'It is better to measure what is relevant inaccurately than to measure accurately what is irrelevant', but it is even better to measure accurately what is relevant.

In the initial stages of an on going study by the author and colleagues in Kenya, the local perceptions of the quality of life of disabled children and their families, have been explored in a qualitative study. This information has been used to develop a survey questionnaire, which is presently being used to measure the impact of an intervention utilising women's groups.

Qualitative research can also be used for providing possible explanations for quantitative survey results, which would be otherwise un-explicable. A quantitative study in Kenya, has recently revealed that a large proportion of children with epilepsy, do not avail themselves of medical treatment, even though this treatment is known to have the capacity to improve their condition considerably and is easily available. The reason for this under-utilisation was unknown and so a qualitative study has now examined the reasons for this (27). The Childhood Blindness Project in Bangladesh [CBPB] revealed that the leading cause of blindness in children was congenital/developmental cataract, contributing to 31% of all blindness in children. As cataract blindness in children is completely curable, a qualitative study is currently underway to identify the barriers of uptake of cataract surgery for children in Bangladesh. CBPB also identified about 100 families in which multiple members are affected by unoperated congenital/developmental cataract who never avail themselves for surgery. The qualitative study revealed that the community members perceived familial blindness from cataract as a curse on the family. There was a widespread belief that this type of blindness is incurable which prevented them from going to the eye care facilities for treatment.

What skills are needed by a researcher to carry out qualitative studies?

As qualitative studies rely on collecting data from participants in their natural settings and most of the data are usually non-numeric, unstructured textual data, a high level of linguistic skills are required. Quality and relevance of interview and focus group data largely depends on the linguistic skill of the researcher. Excellent verbal and written communication skill are required to collect qualitative data and to analyse and disseminate the results of qualitative study.

It is also important to appreciate that the ability of formulating open-ended questions and facilitating discussions in a non-directional manner, needs detailed planning, adequate practice and an understanding about the study participants and the environment in which they live. Qualitative research relies heavily on the empathy, commitment and involvement of the researcher. It needs prolonged contact with the community and the people to understand the inner meaning of the qualitative data.

Continuous reflection by the researcher is also required throughout a qualitative study to modify the focus (when required) and to accommodate the initial findings into the subsequent data collection. Involvement with the study participants and with the process or topic under investigation is needed to analyse the qualitative data in a meaningful way. Emotional intelligence and an open mind to learn from the participants are vital in qualitative research, as the whole purpose is to learn the participant's perspective on a given topic.

Qualitative research requires a considerable time by the research team. Quite often, researchers, who are new in the qualitative research, underestimate the amount of time

required to transcribe, translate [if required], transcribe in the second language, and to conduct the data analysis. In the absence of adequate time, good quality data can end up in sloppy analysis and without any meaningful and valid results.

All research requires excellent planning and management skills but in qualitative research changes to the research structure can be made in response to new data at any stage in the process in an iterative way.

Another important skill required by a good qualitative researcher is the ability to listen carefully to better understand other people's views. Qualitative researchers need to learn not to judge people as that can create a communication barrier between researcher and the participants. Facilitating skills are required particularly to conduct focus group discussions.

It is important to consider the skills that are required when recruiting interviewers for a qualitative study and also to provide training in interview techniques and facilitating skills. Most of the skills can be developed and enhanced through active training, regular practice and sharing the experience with other researchers.

WHAT CAN QUANTITATIVE RESEARCHERS LEARN FROM INCORPORATING QUALITATIVE ASPECTS TO THEIR RESEARCH?

There is a growing interest about qualitative research methods among the quantitative researchers. More and more researchers are incorporating qualitative components as part of larger quantitative studies. There are many benefits in doing this. Most of the quantitative research provides very limited opportunity to interact and learn from the study participants on a one to one basis. On the other hand, qualitative research methods can educate the quantitative researchers about the 'people' and their perception, beliefs and practices. They can get a better and broader idea about the lives of the people from whom they are collecting quantitative data. It helps the researchers not only to better understand their data but also to understand the implications of the results and interventions on the people, at a more individual level. Qualitative studies can act as a catalyst for reorientation of the researcher and may lead to more action research to initiate real change in people's lives. It may also illuminate the gap between the 'professional's' view and the participants view on a given topic which may help to interpret the data. By combining quantitative and qualitative methods, researchers will be able to get a holistic view on the research topic.

THE WAY FORWARD

There is a real need for researchers to take a more holistic view in order to make research more ethical by having a closer relationship with the people and their needs. This requires more emphasis on action research with participation of disabled people at all stages of the research. Qualitative research methods can contribute to improving the validity and ethics of

research in general and at the same time offer a method of investigating topics, which are difficult to research using a more quantitative approach. They have much to offer in the area of disability studies worldwide because of the need to examine the effect of the socio-cultural environment and reflect a comprehensive view of disability. Also to examine how this view impacts on service provision, policy and planning. Qualitative research has a particularly valuable role to play in the development of relevant research about disability in majority world countries by virtue of the fact that little is known about this area and that the stakeholders are a very vulnerable group.

Researchers need to acquire qualitative research skills, or employ someone on their research teams to carry out this aspect of the research. There is also a need for people engaged in qualitative research to be prepared to defend their activities against the positivists view and to conduct research in a rigorous fashion with commitment and integrity so that their work can be shared in the public area and take a credible place beside and together with, other research methods.

*Senior Research Fellow
Institute of Child Health, London
30 Guilford Street, London WC1N 1EH
email: S.Hartley@ich.ucl.ac.uk

**Clinical Research Fellow
London School of Hygiene & Tropical Medicine, London.
email: Mohammad.Muhit@lshtm.ac.uk

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