



Working together
www.rcis.ro

Revista de cercetare și intervenție socială

ISSN: 1583-3410 (print), ISSN: 1584-5397 (electronic)

Selected by coverage in Social Sciences Citation Index, ISI databases

COMMUNE AND PROCEDURAL LEVEL CHALLENGES AND LIMITATIONS IN CONDUCTING SOCIAL RESEARCH IN MALAYSIA: A CASE OF DISABLED PEOPLE

*M. Rezaul ISLAM, Ștefan COJOCARU, Abu Bakar Ah SITI HAJAR,
Haris Abd WAHAB, Sabri SULAIMAN*

Revista de cercetare și intervenție socială, 2014, vol. 46, pp. 255-272

The online version of this article can be found at:
www.rcis.ro, www.doaj.org and www.scopus.com

Published by:

Expert Projects Publishing House



On behalf of:

„Alexandru Ioan Cuza” University,

Department of Sociology and Social Work

and

Holt Romania Foundation

REVISTA DE CERCETARE SI INTERVENTIE SOCIALA

is indexed by ISI Thomson Reuters - Social Sciences Citation Index

(Sociology and Social Work Domains)



Commune and Procedural Level Challenges and Limitations in Conducting Social Research in Malaysia: A Case of Disabled People

M. Rezaul ISLAM¹, Stefan COJOCARU², Abu Bakar Ah SITI HAJAR³,
Haris Abd WAHAB⁴, Sabri SULAIMAN⁵

Abstract

This paper explores the challenges and limitations in conducting social research in Malaysia with special reference to the disabled people. These challenges and limitations derived from the research entitled “Towards the Betterment of Persons with Disabilities. A Comprehensive Study”, under the sub-programme “Rights and advocacy of the Persons with Disabilities in Malaysia”. The study was commissioned by the Humanities and Ethics Research Clusters, University of Malaya, Kuala Lumpur, Malaysia. This article analyzed the challenges and limitations in collecting public views about the rights of the disabled people. The challenges and limitations are divided into two types; commune level and procedural level. The objective of this paper is to demonstrate how these challenges and limitations restricted the utilization of qualitative social research tools and techniques on this particular case study in Malaysia. The article provides a number of interesting points which would be useful guidelines to the researchers, policy makers, academics, and students who are interested in social research with the disabled people.

Keywords: social research, procedural level, challenges and limitations, disabled people, Malaysia.

¹ Institute of Social Welfare and Research, University of Dhaka, Dhaka-1205, BANGLADESH. Department of Social Administration & Justice, University of Malaya, MALAYSIA. E-mail: rezauldu@gmail.com (corresponding author)

² Alexandru Ioan Cuza University of Iasi, Department of Sociology and Social Work, ROMANIA. E-mail: contact@stefancojocar.ro

³ University of Malaya, Department of Social Administration & Justice, MALAYSIA. E-mail: shajar@um.edu.my

⁴ University of Malaya, Department of Social Administration & Justice, MALAYSIA. E-mail: haris@um.edu.my

⁵ University of Malaya, Department of Social Administration & Justice, MALAYSIA. E-mail: Ayievirgo88@gmail.com

Introduction

This paper is based on the field experience that we drew from the study: "Towards the Betterment of Persons with Disabilities. A Comprehensive Study". This is the first year research outcome of the Sub-Programme of the "Rights and advocacy of the Persons with Disabilities in Malaysia". The study underpins the legislative and policy options for the disabled people in Malaysia. The principal objective of the study was to look at the gaps between the rights of the disabled people and the practices. The study analyses the existing laws and policies including international conventions and relevant United Nations (UN) documents, and then compares with field data to identify the holes. The paper is developed from two previous published papers i.e. Islam and Banda (2011), and Islam and Siti Hajar (2013).

In term of the scope of this paper, there is limited number of scholarly articles published from the international Journals in the world. Undoubtedly, this number will be a handful in Malaysia. The history of qualitative research with the disabled people is relatively short (Gilbert, 2004). Indeed, the research-based literature rarely addresses with the rights of the disabled people. However, this paper reflects in part of our expertise, and in part of working premise. The disability right in Malaysia is one of the policy concerns to the Government. The Government introduced a number of UN conventions, formulated disability law (i.e., Persons with Disabilities Act, 2008), and policy (i.e., National Policy for Persons with Disabilities 2007). The non-governmental organizations (NGOs) are providing a variety of services i.e. vocational education, advocacy and counselling, etc. for the disabled people, but these are not at a satisfactory level. Like many other Asian countries, the disability issue in Malaysia is a highly prioritized policy concern at both global and international levels, though the concept 'disability' remained as one of the most neglected and forgotten development agenda by both the State and the non-state actors.

We used a qualitative research approach for our study, where a multi-method data collection methods i.e. semi-structured interview, focus group discussion (FGD), and documentation survey were used in order to collect data from six organizations (two governmental and four non-governmental) working in Kuala Lumpur, Malaysia. One organization was operating rehabilitation programme, one for blind, one deaf, one mental disability, one general service, and another organization was implementing community welfare for the disabled people. Most their working areas were included cash money, vocational education, motivation and counselling, advocacy and community awareness, and child education. Our respondents were the core staff members of those six organizations who have enough experience about the disability rights. We determined their experience according to their length of work. We distributed the semi-structured questionnaires (consisted both structured and unstructured) to the relevant staff

members. We arranged six FGD sessions with the staff members of those six organizations.

Methodological concerns, contextual aspect, and local perspective

The study used three interconnected concepts i.e. qualitative research, rights of the disabled people, and Malaysia that contoured a distinct academic discussion. Qualitative research is a method of choice when the research question requires an understanding of processes, events and relationships in the context of the social and cultural situation. This approach is about ‘personal meaning’ which refers to the way in which individuals subjectively perceive and explain their experiences, actions and social environments. This method is used for providing an in-depth description of procedures, beliefs and knowledge related to the particular issues, or for exploring the reasons for certain behaviours including the opinions of respondents about particular issues.

There is a growing recognition that undertaking qualitative research can pose many methodological concerns and challenges for researchers (Birch and Miller, 2000; Campbell, 2002; Ferguson, 2003; Gilbert, 2001a; Wright-Crawford, 1999; Johnson & Clarke, 2003; Liamputtong and Ezzy, 2005). Some of the challenges identified by researchers include issues related to maintaining boundaries (Dickson-Swift et al., 2006), developing rapport (Liamputtong and Ezzy, 2005), reflexivity (Ellingson, 1998; Kiesinger, 1998), and managing emotions (Gilbert, 2001b; Payne, 1994; Rager, 2005). While many of these difficulties are unique to qualitative research, they are often compounded when researching sensitive or difficult topics (Alty and Rodham, 1998; Lee and Renzetti, 1993). This type of research is often criticized as biased, small scaled, anecdotal, and lacking rigor. Validity relates to the honesty and genuineness of the research data while reliability relates to the reproducibility and stability of the data (Anderson, 2010). This method can enable one to tackle ‘sensitive’ issues, to appreciate the wider social context of people’s experiences, and to make connections across different areas of participants’ lives. However, data unruffled by this method might not generalize to other people or other settings. The findings might be unique to the relatively few people included in the research study. Due to its lack of statistical analysis, it is more difficult to test hypotheses and theories with large participant pools. Time consuming and personal biases increase the tensions in qualitative research approach.

The contextual standpoint about the rights of the disabled people is a highly sensitive and convoluted issue in social research. Disabled people have the same rights as all other people. However, for a number of reasons they often face social, legal, and practical barriers in claiming their human rights on an equal basis with others’ are a widespread assertion in disability rights. Our general motive is that

disabled people have been viewed as individuals who require societal protection and evoke sympathy rather than respect and empathy. We need to take steps towards changing the perception of disability and ensures that societies recognize that all people must be provided with the opportunities to live life to their fullest potential, whatever that may be. However, the ethos in our mind is that our initiative would be to provide them equal opportunity so that they can be developed and treated equally along with regular people. As a momentous thought, we conduct social research in this point so that our initiative can produce more success to forward the steps effectively. Social research is undertaken to expand knowledge, discover the truth and provide evidence for practitioners, policy-makers and legislators. We believe research that involves disabled people is essential in uncovering issues requiring attention; in informing policy; in evaluating programmes and services; and in tracking how social and economic changes affects to them.

There is a concern about the high expectations from the disabled people and service providing organizations, but the low expectations from the researcher are massively reflected to conduct any research in the disability field. The expectation is a fundamental contextual challenge regarding 'lack of self-determination' mainly from the disabled people and service providing organizations. Expectations of what people with disabilities are and can be and how they should be treated are socially determined perspectives that have great effects on the lives of disabled people (Smith, 2005) and their families (Green, 2007). Johnston et al., (2009) found a number of challenges to conduct research with disabled people. These include great breadth and complexity, emphasis on empowering disabled people, small sample sizes, difficulty in defining ethical and practical control group, improvement of a disabled person's chosen activities or quality of life, intervention development, or early stage clinical trials, addressing issues within large social systems that involve consideration for the social, physical, and economic environments, etc.

The local view connecting with two other concepts i.e. methodological concerns and contextual aspects discussed above can be an important aspect in such kind of discussion. In particular, the local ethical norms and linguistic issues should be taken into account when deciding on how to go about obtaining a legitimate, informed consent like disability rights. In some political and social environments, the participants should be informed about the potential dangers of involvement. Informed consent has a significant value in such local perspective. They should be given all information i.e. what the research is about, who is funding, what will be involved for participants, how the findings will be used, and possible benefits of the study and how data will be used in the future. Participants should be made aware of any dangers to which their involvement could make them vulnerable. This danger can be especially important when working with minority or dispossessed groups to whom the political regime is hostile. In

particular, any foreseeable limitations on anonymity and confidentiality should be made clear. The researcher has an obligation to ensure that participants understand the legal status that anonymity and confidentiality has in their country and any scenarios in which the researcher could be forced to reveal information.

The economic development leads to many changes in Malaysia especially in the socio-political landscape of the country vis-à-vis, the increasing income of the people, which led to better standard of living, health care, and others. The economic development has also widened the gap between the income of the rich and the poor and also caused problems to the environment and social problems. The national resources for research to view these social problems are often lacking in Malaysia compared with other sectors i.e. infrastructure, technology, etc. The organizations and community people are not very aware of the importance and practice of social research, and its ethical aspect. The research ethics exist to ensure that the principles of justice, respect and avoiding doing harm are upheld, by using agreed standards. These basic principles are universal, though there are, of course, many subtleties and diversities, and the contingent aspects of how principles are understood, interpreted and practised can vary from place to place (Ulrich, 2003). However, all variations tend to revolve around the question of how to balance the interests of the individual with those of the community/society/family and the goals of research studies (Morrow, 2009). The government as well as general people are still looking at their development through infrastructural, industrial and business expansions. The goal of Vision 2020 in Malaysia is to increase income through such kinds of economic developments. As a result, less emphasis is given to the social sector i.e. education, human rights, poverty, social exclusion, child care, humanitarian assistance, social justice, inequalities, public health care, etc. The whole gamut increases the tension of social research in Malaysia.

Field experience

This section discusses the field findings that we gathered round the project this year. The findings emphasised on the contextual limitations and challenges than the theoretical one. The weaknesses of this paper are noteworthy. We would argue that the findings regarding barriers and challenges to conduct social research in Malaysia with focusing disability rights would not be generalised with other areas. This study was conducted with a limited number of organizations in Kuala Lumpur with a particular and sensitive topic. The selection of these organizations was based on purposive sampling, and we conducted our research with limited time and resources. We would contend that if any researcher attempts to conduct other topics with other organizations, the velocity of these limitations and challenges might be different. We would squabble that these limitations and challenges

would be applicable more or less to related research projects. It is because, the findings of this paper has a strong theoretical base that we used in a number of other previous research projects successfully.

We would divide these limitations and challenges into two broad categories namely ‘commune’ level limitations and challenges and ‘procedural’ level limitations and challenges. The commune level limitations and challenges were very associated with the existing socio-economical, cultural, and political conditions of the country/community i.e. lack of research knowledge and research orientation, lack of gaining access, cultural barriers, political issues, lack of social trust about the research findings, subjective sensitivity, and non-cooperation from the operating organizations. On the other hand, the procedural level limitations and challenges are those that are considered as the inadequacies of qualitative research approach. These include reliability and validity of research findings, complexity and diversification of human behaviour, research ethics, and power-relation. It is argued here that one such limitation/challenge influences on another and gets complicated. This paper analyses these limitations and challenges with a case study.

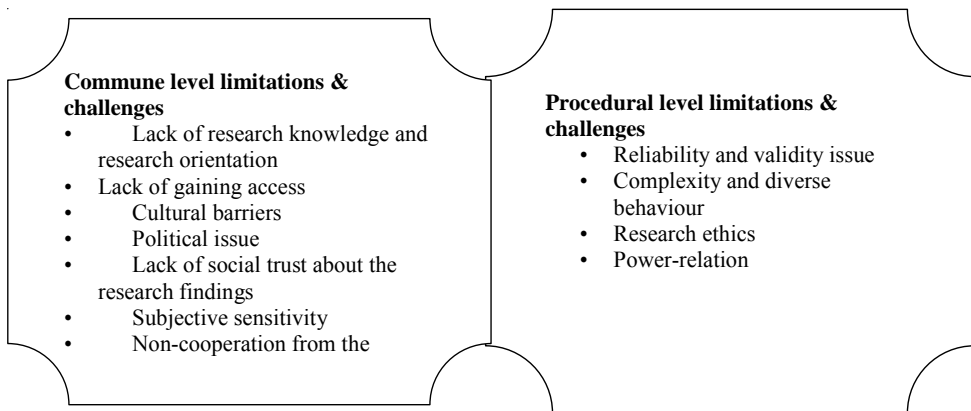


Figure 1: *Commune and procedural level limitations and challenges of social research*
 Source: *Based on Islam & Siti Hajar (2013, p. 108)*

Commune level challenges

Lack of research knowledge and research orientation

Research knowledge and research orientation to the government, implementing organizations, funding organizations, public, and respondents are very crucial. In Malaysia, the landscape of academic and professional research in social aspects is

not widely oriented, and the stakeholders are not very familiar with this. This scope is very limited to the people at an organizational level. It took a mammoth time to explain our research objectives, benefits and outcomes to the staff members. A number of organizations declined their participation due to the cause of conducting this research is prohibited in their organizations. We found a very low level of self-esteem at both organizational and individual levels.

The social and historical context is part of the methodological challenge as ‘individuals need to have self-esteem to believe that their views are valid and important [...and] to believe that they will be listened to, responded to and understood’ (Lewis & Porter, 2004, p.195). We were doubtful whether we could conduct this research. Many organizations gave us a ‘lame excuse’ that such kind of research is prohibited from their management as well as governmental level. Eventually, we could ascertain that this was due to their lack of research knowledge and research orientation.

Lack of gaining access

Gaining access is the ‘entrance door’ in any research. We understood that as qualitative researchers we must initiate a rapport-building process i.e. prior contact, continues contact, explain research objectives and its importance from their first encounter in order to build a research relationship that allows us access to that participant (Ceglowski, 2000; Goodwin et al., 2003; Liamputtong and Ezzy, 2005; Minichiello et al., 2000; Payne, 1994; Dickson-Swift et al., 2006).

Our data collection was almost dependent on the gatekeepers or facilitators, and even through a hierarchy of gatekeepers (Hood et al., 1996). Before gatekeepers are likely to help, they were needed to convince them about the benefits of this research of the disabled people. Due to their lack of research orientation and research knowledge, we failed to give them such kind of justification. We found that the gatekeepers blocked our access (Stalker, 1998; Tuffrey-Wijne et al., 2008). Our observation was that approximately 70 percent of our approaches to those organizations were blocked by the gatekeepers. Though we finally conducted our research with six organizations, in many cases we did not get much confidential information i.e. sources of funding, allocation of budget, management system, and even in some cases, the staff members denied giving us their organization’s annual report.

Cultural barriers

Cultural barrier is a very considerable challenge in qualitative research to collect valuable data (Sands et al., 2007). We mentioned earlier that difficulties in gaining access can arise when gatekeepers or participants deny access or erect physical or social barriers (Shaw, 2003). Even if physical access is granted,

participants may be reluctant to allow social access because of the interviewee's assumptions about the researcher based on his/her gender, age, status, and personal characteristics (Shaw, 2003). Similarly, interviewers may be insecure, uncomfortable or afraid to interview across class, sex, race, or ethnic lines (Rubin and Rubin, 1995; Shaw, 2003).

Interviewers with insider status in a particular culture are thought to have advantages over those with outsider status in surmounting cultural barriers. The principal investigator of this study is a foreigner. Although the language barrier was the main limitation, the staff members were instructed to speak in their local language. We observed that the staff members were overestimated about the role of the government and council to implement the legislative provisions of disability rights. We established a new challenge in qualitative research that is the fact that the participants did not want to tell negative or unsuccessful stories about their own government and organizations to the foreigner.

Political issue

The political issue has come to be one of the important aspects in social research in Malaysia. Research is a fact-finding activity. This kind of fact findings were challenging in two ways when we conducted our research. First, usually the people in Malaysia are not used to speak out about the negative roles of the government. Anti-governmental campaign is not welcomed/encouraged here. According to the latest World Press Freedom index, Malaysia has hit low ranking of 147 out of 180 countries regarding the independency of the press (Ibrahim, 2014). Secondly, the subjective locus gave us another worrying notion concerning who should own and direct research with the disabled people. It was echoed in the interface of disability politics and disability studies. Swain, Heyman and Gillman (1998) argued that research is primarily political; it has the potential to exploit vulnerable groups and further their disempowerment and oppression. For many disability theorists, including Barnes (1996), the researcher is either on the side of disabled people or one of the oppressors.

In general, qualitative research can access the perspectives and experiences of oppressed groups that lacking the power to make their voices heard through traditional academic discourse (the 'excluded voice thesis' (Booth, 1996). The academics who are expertise in disability rights have also stressed that, in the past, government social research on disability issues has failed to focus on the issues of greatest relevance to disabled people (see, for example, Barnes, 2003). According to our research proposal we only included the staff members of the organizations in our study. Failing to involve disabled people in research that concerns their experiences or to communicate research results in an accessible way could mean that research alienates disabled research participants. It could be exploitative, if data is collected from disabled people, using pre-determined

research questions that do not address the key issues they face and is then published in reports that disabled people cannot read or use. In addition, the staff member might consciously think about the potential impacts of a policy or practice from the early stages of planning, considering any risk of the adverse impact and how this might be mitigated. It also involves allowing disabled people and their organisations to have a high level of control over the research process, including both funding and the research agenda (see, for example, Barnes, 2001). It was about the problem of emancipatory research.

Lack of social trust about the research findings

‘Trust’ becomes an important element in qualitative research. It helps to develop rapport between researchers and participants in order to avail reliable and valid data. In a social context, trust has several connotations (McKnight & Chervany, 1996). Trust typically refers to a situation characterised- one party (trustor) is willing to rely on the actions of another party (trustee); the position is directed to the future. In addition, the trustor abandons control over the actions performed by the trustee. As a consequence, the trustor is uncertain about the outcome of the other’s actions; she can only develop and evaluate expectations. The uncertainty involves the risk of failure or harm to the trustor if the trustee does not behave as desired. In order for researchers to understand the experiences of the participants, they need to build a level of trust so that the participant feels safe enough to share their story (Booth and Booth, 1994; Charmaz, 1991). We took a number of initiatives to increase trust with the respondents which included show valid permission to conduct the research, explanation of our research objectives, explanations of the benefits of the research, etc. All of the factors around trust were more or less had impacts on our study. The question of trust become so much complex due the lack of research knowledge, cultural problems, and political issues. At the initial stage, the staff members asked us about our legal access to conduct this research, and then questioned if our research findings would improve the disability rights. They were also scared about the risk of data being misused.

Subjective sensitivity

The subjective sensitivity is an important aspect to qualitative researchers. They need to be able to make an assessment of the impact of the research on both the participants and themselves (Dickson-Swift et al., 2007, p. 328). In order to undertake an assessment of the potential impact, they need to be alert of the possible issues that may rise. Milling-Kinard (1996, p. 69) concluded: “Efforts to address these issues would be enhanced by more published accounts of investigators’ experiences in dealing with the effects on researchers of conducting studies on sensitive and emotionally laden topics. Too little attention is given to documenting the process of carrying out research”. We were endangered by a number

of questions from the staff members to conduct this research. These included: Who are we to do this research? What is our level of capacity to conduct this study? Why did we select the topic – ‘disability rights’? Do we know that this is related with the law? What is the confidentiality of their opinions and who will give them such guarantee? What is our benefit? Do we have any evidence of the government’s permission? etc. It is true that we did not have some evidences in our hands.

Non-cooperation from the operating organizations

Non-cooperation from the participants is one of the big dilemmas in qualitative research (Fink, 2000; Patel, 2003; Bergold and Thomas, 2012). There is a growing debate about the conflict of interest between the researchers and the funding as well as implementing organizations. This kind of non-cooperation included selection of NGOs, gaining access, participation in interview and FGD sessions, feedback, access to sensitive and confidential documents, and sharing information. Due to this non-cooperation from the agencies, we could not collect our data according to our expectations. The lack of gaining access to the relevant documents sometimes inhibited us to keep our findings ‘half-done’.

Procedural level challenges

Reliability and validity issue

There is a growing debate about the reliability and validity issue in qualitative research. The notion of validity in qualitative research has been “championed, translated, exiled, redeemed, and surpassed” (Emden and Sandelowski, 1998, p. 207). Many authors have a very restricted attempt to say that the findings of qualitative research are neither reliable nor valid. The other group of authors argued that the qualitative approach provides a very in-depth knowledge, which is unruffled with the real understanding between human behaviour and their interacting factors (Healy & Perry, 2000) as it unfolds many hiding human behaviour, which is impossible neither by quantitative nor any other option.

‘Reliability’ referred to the stability of findings, whereas ‘validity’ represented the accuracy of findings (Altheide and Johnson, 1994). However, the real meaning of validity in qualitative research is obscure, and different opinions in the literatures make the concept very complex. Numerous terms have been suggested as those working within the interpretive perspective have struggled to articulate validity criteria in qualitative research. Truth-value, credibility (Lincoln & Guba, 1985), trustworthiness (Eisner, 1991), authenticity (Guba and Lincoln, 1989), and goodness (Emden and Sandelowski, 1998; Marshall, 1990) have all been proposed

as more suitable criteria to judge the quality of qualitative research. None has been overwhelmingly supported (Whittemere et al., 2001).

Kahn (1993) discussed the implications of idiosyncratic terminology associated with the validity in qualitative research and emphasized that language should not obscure understanding. Within this compass, this case study made a number of connotations, which were difficult to fill the gaps of qualitative research. The struggles of our research were more related with stability of findings, truthfulness, credibility, trustworthiness, and authenticity. Due to the commune level limitations and challenges (discussed above), all of these criteria became very complicated to us. The ‘mindset’ of the research participants made this issue so treacherous that we could not trust ourselves to providing a reliable and valid finding to the research authority. Eventually, continuous feedbacks helped us to recover our ‘half-done’ report to ‘complete story.’

Complexity and diverse behaviour

Qualitative research comes in a variety of forms. We produce ‘qualitative data’ in the course of our attempts to understand a range of different events, processes, behaviours of people, and such data are inherently diverse, non-standardized, heterogeneous and difficult to classify. It is seen that the language barriers and use of language are other difficulties to comprehend the correct meaning of what the respondents want to express (Islam and Siti Hajar, 2013; Islam and Banda, 2011). It is neither arguable nor questionable that our research topic was complex, and we encountered diverse behaviours from different organizations and associated people. The subjective complexity i.e. rights of the disabled people in one hand, and the actual diversity of the organizations and their activities on the other gave us a nauseating situation. Sometimes, in terms of our time limit and research objective, we could not minimize all of those. We found in our FGD sessions that the staff members asked us – what are the next actions coming from the government about the laws of disability rights? We did not have a clear-cut answer to this question.

Research ethics

Now a day, it is an obvious condition that the researcher has to collect the ethical approval from the recognized ethical body to conduct any research. Ethics can be defined as a ‘set of moral principles and rules of conduct.’ It is a system of moral principles to prevent harming or wronging to other, to promote the good, to be respectful, and to be fair’ (Seiber, 1993, p. 4). We followed the principles of the ethical issue provided by Miles & Huberman (1994). These are the worthiness of the project (i.e., is my contemplated study worth doing?); competence boundaries; informed consent; benefits, costs and reciprocity; harm and risk; honesty and

trust; privacy, confidentiality and anonymity; interventions and advocacy; research integrity and quality; ownership of data and conclusions; use and misuse of results; and conflicts, dilemmas and trade-offs. Getting informed consent to participate in research has become a legal requirement as well as a moral obligation. Scott et al., (2006) outline the three key issues i.e. the person's competence to give consent, the extent to which the research is in the person's own best interests, and the balance with the public interest.

Islam and Banda (2011) found that the research ethics are western dominated which created a number of dilemmas when used in developing countries such as Bangladesh and Zambia. Like Islam & Banda, we believe that our ethical guidelines provided by the University of Malaya (UM) are based on western culture and values too. Many of these are not 'well-suited' in Malaysia. These ethics are also incomplete, and many issues that we faced during our research are not mentioned. The important aspects of ethical issues such as autonomy, justice, reciprocity, honesty and trustworthiness are not included in UM ethical guidelines. On the other hand, the ethical issues such as privacy and confidentiality, security, and benefits are not explained properly in Malaysian context.

Box 1: CODE OF RESEARCH ETHICS IN THE UNIVERSITY OF MALAYA

1. All research conducted by staff and students of the university involving human participants and the use of vertebrate animal subjects must be referred to the appropriate ethics committee.
2. These include all research, qualitative or quantitative, regardless of whether the research is funded by internal/external grants or even unfunded.
3. All research conducted by staff and students must follow codes of ethical guidelines for research involving human participants which include :
 - a) Sources of Data – The participant is subject to ethical clearance, meaning the researcher must define whether the data involves new data collection or existing data and how the data will be collected.
 - b) Risk Assessment – The researcher is required to undertake “Risk Assessment” to ensure that participants’ interests and rights are protected.
 - c) Informed Consent – The participant is given the opportunity to choose what shall or shall not happen to them, meaning the researcher should provide the participants with sufficient information using words that are easy to understand and the language/s that the participants speak.
 - d) Recorded consent other than written consent - online/email recorded response can also serve as a means of obtaining informed consent as long as it is in response to a proper information sheet.
 - e) Waiver of the Requirement of Recorded Informed Consent - participants must normally give recorded informed consent to any use of their personal

- data unless existing personal data is being used for the purposes for which they were collected or a directly related purpose.
- f) Pilot Studies – It is a must to seek consent before obtaining data in pilot studies.
 - g) Parental consent - For research involving children under 18 years old , researchers should seek written consent from parents by providing a full justification for the data collection and an information sheet.
 - h) Privacy and confidentiality of data - researchers must maintain the confidentiality of data related to individual research participants. Except by public observation, researchers should clearly indicate the purpose of the collection of data and the method to ensure the confidentiality of collected data. Researchers must also avoid the use of any personal identifiers such as individuals' names and addresses in their research reports which could lead to the human participants being identified.
 - i) Security - Information collected will not be publicly disclosed for security reason. As for private sensitive data, researchers are advised to use indirect identifiers and to keep the direct identifiers separate from the data.
 - j) Benefits - All reimbursement of expenses, such as travelling expenses, should be commensurate with standard practice and be reasonable.
 - k) Sensitive issues – The researcher should be aware of sensitive issues that are highlighted by EPU. (<http://www.epu.gov.my/undertaking>)

Power-relation

Power relation is considered as multiple ethical dilemmas and seriously methodological challenges in qualitative research (Karnieli-Miller et al., 2009). The goal of qualitative research is quite explicitly to 'ground' studies in the experience and views of respondents. The literature provides three kinds of opinions about these challenges. First, usually, the researcher determines the overall research questions, and gathers, analyses, and interprets the data and draws conclusions. Thus, it is evident that while seeking to value the experiences of people with difficulties, traditional qualitative research is likely to encompass substantial barriers between the authoritative researcher and the less influential researched (Nind, 2008). Secondly, Henry (2003) and Tang (2003) claimed that most researchers have organizational and institutional power. The researcher felt powerless while trying to recruit participants and was constantly anxious about losing their interest during the study and during the validation phase of the study. And thirdly, Reason (1994, p. 42) stated that the qualitative inquiry draws on a critical view of hierarchical relations of power between researchers and participants. He mentioned that in traditional research, the roles of researcher and subject are

mutually exclusive: the researcher alone contributes the thinking that goes into the project, and the subjects contribute the action or contents to be studied. Here, the division of roles between researcher and participant is dichotomous, unequivocal, constant, uniform, and predetermined. Reason further stated that this division follows from the positivistic worldview that sees the researcher as a neutral observer who objectively examines various human phenomena. In this regards, O'Connor & O'Neill (2004) argued that drawing predominantly on constructivist and critical paradigms of understanding, qualitative research fosters a rebalancing of power in the researcher-participant relationship and encourages a focus on marginalized understandings and skills. The use of researcher self-disclosure was reported by a number of the participant researchers. In order to ensure that the relationship between the researcher and the participant is non-hierarchical, researchers are often involved in a reciprocal sharing of their personal stories (Liamputtong and Ezzy, 2005). We agreed to all three arguments that are discussed above. We felt that our position related with the second argument though we followed the third one. Although we have institutional and organization power, we felt powerless while trying to select and recruit the staff members. We showed 'self-disclosure' and tried to minimize or power and kept ourselves neutral and in a balanced position, but many issues were unresolved such as uncertainly scheduled change, domination of higher officials in the FGD sessions, and exclusion of some staff members in interview and FGD.

Conclusions

A qualitative inquiry is the process of understanding a social or human problem, based on building complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting. This is a rapidly developing field, and a couple of decades ago the practical guidance contained in this view would not have been available. This paper highlighted a number of commune and procedural limitations and challenges. We mentioned that both levels of these limitations and challenges are interwoven with each other and across all stages of the research process. We also acknowledged that these kinds of challenges and limitations are not to be generalised. These are more or less relatable to other qualitative research projects. The communal level challenges and limitations gave substantial contextual value to this paper. These limitations and challenges are being taken up now, not just by the pioneers in the field but by a whole raft of researchers in a range of disciplines who would no longer consider conducting research on people with disability rights without, first and foremost, addressing them as human beings with something to say that is worth hearing.

Acknowledgements

This paper is based on the study 'Policy and social assessment for disabled community in a multi-culture society – Malaysia' with the funding support of the University of Malaya Research Grant (UMRG, project number RP003B-13HNE). The authors acknowledge the funding authority.

References

- Altheide, D. L., & Johnson, J. M. (1994). Criteria for assessing interpretive validity in qualitative research. In Denzin, N. K., & Lincoln, Y.S. (Eds.), *Handbook of qualitative research* (pp. 485-499). Thousand Oaks, CA: Sage.
- Alty, A., & Rodham, K. (1998). The ouch! factor: Problems in conducting sensitive Research. *Qualitative Health Research*, 8, 275-82.
- Anderson, C. (2010). Presenting and evaluating qualitative research. *American Journal of Pharmaceutical Education*, 74(8), 141.
- Barnes, C. (1996). Disability and the myth of the independent researcher. *Disability and Society*, 11 (2), 107-110.
- Barnes, C. (2001). 'Emancipatory' disability research: Project or process? Public Lecture at City Chambers, Glasgow, on 24 October 2001 (<http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/glasgow%20lecture.pdf>)
- Barnes, C. (2003). What a difference a decade makes: Reflections on doing 'emancipatory' disability research. *Disability & Society*, 18 (1), 3-17.
- Bergold, J. & Thomas, S. (2012). Participatory research methods: A methodological approach in motion, *Forum: Qualitative Social Research*, 1(3). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/1801/3334>.
- Birch, M., & Miller, T. (2000). Inviting intimacy: The interview as therapeutic opportunity. *International Journal of Social Research Methodology*, 3, 189-202.
- Booth, T. (1996). Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties. In L. Barton (ed.), *Disability and society: Emerging issues and insights* (pp. 237-55), London: Longman
- Booth, T., & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham: Open University Press.
- Campbell, R. (2002). *Emotionally involved: The impact of researching rape*. New York: Routledge.
- Ceglowski, D. (2000). Research as relationship. *Qualitative Inquiry*, 6, 88-103.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Dickson-Swift, V., James, E., Kippen, S., & Liamputtong, P. (2006). Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research*, 16, 853-371.
- Dickson-Swift, V.; James, E. L.; Kippen, S.; & Liamputtong, P. (2007). Doing sensitive research: What challenges do qualitative researchers face. *Qualitative Research*, 7(3), 327-353.

- Eisner, E. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practices*. New York: Macmillan.
- Ellingson, L. L. (1998). "Then you know how I feel": Empathy, identification and reflexivity in fieldwork. *Qualitative Inquiry*, 461(1), 492-532.
- Emden, C., & Sandelowski, M. (1999) The good, the bad and the relative. Part two: goodness and the criterion problem in qualitative research. *International Journal of Nursing Practice*, 5(1), 2-7.
- Ferguson, K. (2003). The impact of qualitative research on the researcher. Paper presented at the Association for Qualitative Research Conference. Coogee, Sydney.
- Fink, A. S. (2000). The role of the researcher in the qualitative research process. A potential barrier to archiving qualitative data. *Forum: Qualitative Social Research*, 1(3). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/1021/2201>
- Gilbert, K. R. (2001a). Introduction: Why are we interested in emotions?'. In K.R. Gilbert (ed.) *The emotional nature of qualitative research*. London: CRC.
- Gilbert, K.R. (2001b). Collateral damage? Indirect exposure of staff members to the emotions of qualitative research. In K.R. Gilbert (ed.), *The emotional nature of qualitative research*. London: CRC.
- Gilbert, T. (2004). Involving people with learning disabilities in research: Issues and possibilities, *Health and Social Care in the Community*, 12(4), 298-308.
- Goodwin, D., Pope, C., Mort, M. & Smith, A. (2003). Ethics and ethnography: An experiential account. *Qualitative Health Research*, 13, 567-577.
- Green, S. E. (2007) We're tired not sad: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64, 150-163.
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.
- Healy, M., & Perry, C. (2000). Comprehensive criteria to judge validity and reliability of qualitative research within the realism paradigm. *Qualitative Market Research*, 3(3), 118-126.
- Henry, M. G. (2003). Where are you really from?: representation, identity and power in the fieldwork experiences of a South Asian diasporic. *Qualitative Research*, 3(2), 229-242.
- Islam, M. R., & Banda, D. (2011). Cross cultural social research with indigenous knowledge: Some dilemmas and lessons. *Journal of Social Research and Policy*. 2(1), 67-82.
- Islam, M. R., & Siti Hajar, A. B. (2013). Methodological challenges on community safe motherhood: A case study on community level health monitoring and advocacy programme in Bangladesh. *Review of Research and Social Intervention*, 42, 101-119.
- Johnson, B., & Clarke, J. (2003). Collecting sensitive data: The impact on researchers. *Qualitative Health Research*, 13, 421-34.
- Johnston, M. V., Vanderheiden, G. C., Farkas, M. D., Rogers, E. S., Summers, J. A., & Westbrook, J. D. (2009). The challenge of evidence in disability and rehabilitation research and practice: A position paper. Austin, TX: SEDL.
- Kahn, D. L. (1993). Ways of discussing validity in qualitative nursing research. *Western Journal of Nursing Research*, 15, 122-126.

- Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research*, 19(2), 279-289.
- Kiesinger, C. (1998). From interview to story: Writing 'Abbie's life'. *Qualitative Inquiry*, 4, 71-96.
- Lee, R. M., & Renzetti, C. (1993). The problems of researching sensitive topics. In C.M. Renzetti & R.M. Lee (eds), *Researching sensitive topics*. Newbury Park, CA.: Sage.
- Lewis, A. & Porter, J. (2004). Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32, 191-197.
- Liamputtong, P., & Ezzy, D. (2005). *Qualitative research methods*. South Melbourne: Oxford University Press.
- Lincoln, Y. S., & Guba, E.A. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Marshall, C. (1990). Goodness criteria: Are they objective or judgement calls? In E. G. Guba (ed.), *The paradigm dialog* (pp. 188-197). Newbury Park, CA: Sage.
- McKnight, D. H., & Chervany, N. L. (1996). *The meanings of trust*. Scientific report, University of Minnesota
- Miles, M. B., & Huberman, A. M. (1994). *An expanded sourcebook: qualitative data analysis (2nd ed.)*. Thousand Oaks, CA.: Sage.
- Milling-Kinard, E. (1996). Conducting research on child maltreatment: Effects on researchers. *Violence and Victims*, 11, 65-69.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (2000) *In-depth interviewing*. Sydney: Longman.
- Morrow, V. (2009). *The ethics of social research with children and families in young lives: Practical experiences*. London: Young Lives.
- Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. ESRC National Centre for Research Methods Review Paper.
- O'Connor, D. L., & O'Neill, B. J. (2004). Toward social justice: Teaching qualitative research. *Journal of Teaching in Social Work*, 24(3/4): 19-33.
- Patel, M. X. (2003). Challenging in recruitment of research participants. *Advancing Psychiatric Treatment*, 9, 229-238.
- Payne, S. (1994). Issues for researchers using qualitative methods. *Health Psychology Update*, 16, 7-9.
- Rager, K. B. (2005). Self-care and the qualitative researcher: When collecting data can break your heart. *Educational Researcher*, 34, 23-27.
- Reason, P. (ed.). (1994). *Participation in human inquiry*. London: Sage.
- Rubin, H. J. & Rubin, I. S. (1995) *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Sands, R. G., Bourjolly, J., & Roser-Strier, D. (2007). Crossing cultural barriers in research interviewing. *Qualitative Social Work*, 6(3), 353-372.
- Scott, J. K., Wishart, J. G., & Bowyer, D. J. (2006). Do consent and confidentiality requirements impede or enhance research with children with learning disabilities, *Disability & Society*, 21(3), 273-87.
- Seiber, J. (1993) The ethics and politics of sensitive research. In C. Renzetti & R. M. Lee (eds.), *Researching sensitive topics*. London: Sage.

- Shaw I. (2003). Qualitative research and outcomes in health, social work and education. *Qualitative Research*, 3(1), 57-77.
- Stalker, K. (1998) Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society*, 13, 5-19.
- Swain, J., Heyman, B., & Gillman, M. (1998) Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability & Society*, 13, 21-36.
- Tang, N. (2002). Interviewer and interviewee relationships between women. *Sociology*, 36, 703-721.
- Tuffrey-Wijne, I., Bernal, J., & Hollins, S. (2008). Doing research on people with learning disabilities, cancer and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities*, 36(3), 185-90.
- Ulrich, G. (2003). Charges and counter-charges of ethical imperialism: Towards a situated approach to development ethics. In P. Quarles van Ufford & A.K. Giri (eds), *A moral critique of development: In search of global responsibilities*. London: Routledge.
- Whitemere, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative Health Research*, 11(4), 522-537.