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Navigating the Process of Ethical Approval: A methodological note

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Abstract

Classic grounded theory (CGT) methodology is a general methodology whereby the researcher aims to develop an emergent conceptual theory from empirical data collected by the researcher during the research study. Gaining ethical approval from relevant ethics committees to access such data is the starting point for processing a CGT study. The adoption of the Universal Declaration on Bioethics and Human Rights (UNESCO, 2005) is an indication of global consensus on the importance of research ethics. There is, however, a wide variation of health research systems across countries and disciplines (Hearnshaw 2004). Institutional Research Boards (IRB) or Research Ethics Committees (REC) have been established in many countries to regulate ethical research ensuring that researchers agree to, and adhere to, specific ethical and methodological conditions prior to ethical approval being granted. Interestingly, both the processes and outcomes through which the methodological aspects pertinent to CGT studies are agreed between the researcher and ethics committee remain largely ambiguous and vague. Therefore, meeting the requirements for ethical approval from ethics committees, while enlisting the CGT methodology as a chosen research approach, can be daunting for novice researchers embarking upon their first CGT study.

This article has been written in response to the main challenges encountered by the author from an Irish perspective when seeking ethical approval to undertake a CGT research study with adults with intellectual disabilities. The emphasis on ethical specifications meant that the CGT author had to balance ethical principles and rules with issues of 'not knowing before one is in a position to know' and 'trusting in emergence'. Ethical prescription challenged the emergence inherent within CGT methodology. While acknowledging the need for ethical requirements, this paper is intended in particular to illuminate methodological challenges which may confront novice classic grounded theorists,

and offer some insight into the practicalities of balancing the requirements of ethics committees with the requirements of the CGT methodology. The author demonstrates that the meticulous nature of the CGT methodology must not be overshadowed when meeting the requirements of ethics committees. The author seeks to encourage novice classic grounded theorists to approach ethics committees with research proposals which reflect the fundamental principles of CGT methodology while challenging experienced classic grounded theorists researchers to stand firm on ethics committees supporting such proposals.

Introduction

In Ireland in 2009, there were 26,066 people registered on the National Intellectual Disability Database (NIDD, 2010). Of the above figures 25, 556 people with intellectual disability are in receipt of services, 98% of the total population registered on the NIDD (NIDD, 2010). The current focus of Irish service delivery when working with and for this group of people is Person Centred Planning (PCP). The National Standards for Disability Services define a person centred service as one which is designed, organised and provided around what is important to the person from his or her perspective (NDA, 2004). CGT methodology fits closely with some of the principles of person centred planning in that it focuses on explaining what the main issue of concern for the person is and how he/she continually resolves this concern. Currently, in Ireland, there is a dearth of research representing what is actually happening in the lives of people with intellectual disabilities. CGT methodology is particularly suited to looking at rarely explored phenomena where extant theory would not be appropriate. In such situations, a grounded theory building approach is anticipated to generate novel and accurate insights into the phenomenon under study (Glaser and Strauss, 1967).

In Ireland, national and international policy and legislation such as the United Nations Convention on the Rights of Persons with Disabilities (2006) have driven the inclusive research agenda for people with intellectual disability from a human rights based perspective. However despite the innovative approaches, research seeking the views and experience of people with intellectual disabilities is still in its infancy. The need to include people with intellectual disabilities in research is important, however, the more vulnerable research participants are perceived to be, the greater the potential for exploitation and so, greater

research ethical regulations are required (Ramcharan, 2006). What is evident from the literature is that many researchers have acquired ethical approval for CGT studies; what is not clear is what the agreed processes and subsequent outcomes involved and as highlighted by Breckenridge and Jones (2009), without being able to refer to useful exemplars of CGT studies it is difficult for a novice CGT researcher to understand and prepare for the practicalities of carrying out one's own CGT research. The purpose of this article is thus to highlight the importance of research ethics and the value of CGT; to acknowledge possible methodological challenges and opportunities for a novice CGT researcher when submitting a research proposal; and, to provide some practical suggestions which may help the novice grounded theorist to meet the challenges and optimise the opportunities when navigating the process of ethical approval.

The Importance of Research Ethics

The first international code of ethics, The Nuremberg Code in 1949, was established to protect the rights of people from research abuse. Examples of such abuse can be viewed in Beauchamp, Walters, Kahn, and Mastroianni (2008): The Tuskegee Syphilis Study (1930-1972), Nazi Experiments (1939-1945), Human Radiation Research (1944-1974), Deception Research, (most notably Stanley Milgram's studies of obedience in the early 1960s'), and the Jewish Chronic Disease Hospital (1963). The central declaration of The Nuremberg Code was that the voluntary consent of every human subject would be obtained (Beauchamp et al 2008). In 1964, The Declaration of Helsinki devised by the World Medical Association in response to the Nuremberg code advocated for independent committees to review research protocols prior to research being undertaken, as well as making explicit provision for participation in research by legally incompetent persons. In the United States research ethics policy focused on the risks rather than the benefits of research, and on preventing subjects from being exposed to unacceptable or exploitive levels of risk, not to enable autonomous choice about participation (Fadan and Beauchamp, 1986). Later on, the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research in their Belmont Report (1978) outlined what they considered to be the three most important ethical principles (respect for persons, beneficence, and justice) that should govern the conduct of research with human beings. This paved the way for the research regulatory culture

that had emphasized protection from risk in the 1970s to shift towards principles of inclusion. Researchers were and are now required to include representative populations of women and minority groups such as people with intellectual disabilities in their protocols unless there is a specific rationale for exclusion.

The research agenda in Ireland has been led by the international developments on research ethics, by the magnitude and pace of recent technological advancement, by changes in the Irish culture from a mono culture society to a multicultural society as well as other influencing factors relevant to the ethics of human relationships such as moral issues, limits of confidentiality and truth telling. The Irish Council for Bioethics was set up by the Government in 2002. In 2004 they published guidelines for Research Ethics Committees (REC) (TICB, 2004). The current standards of research ethics in Irish society are driven by such widespread social phenomena as the increasing demand, modelled on the civil rights movement, for patients' rights to information and healthcare; the growing distrust of professional privilege; women's critiques of male dominance within medicine; and the assimilation of medicine to our consumerist and entrepreneurial culture. Research ethics specifically pertaining to people with intellectual disabilities are embedded in human rights issues.

Research Ethics Pertaining to People with Intellectual Disabilities

National and international policy and legislation have driven the research agenda for people with disabilities including people with intellectual disability. The International Association for the Scientific Study of Intellectual Disabilities (IASSID) produced ethical guidelines for conducting research with people with intellectual disabilities. Currently in Ireland, there is no central office for research ethics committees governing research for people with intellectual disabilities. Therefore each university institution and each service for people with intellectual disability regulates its own ethics committee. The National Disability Authority (NDA) (2005) provides guidelines for research practice and believes that quality research and ethical research are synonymous, so that adhering to ethical good practice is a quality assurance issue. In 2005 promoting the inclusion in research of people with intellectual disability the NDA (2005) declared ethics to be "a set of standards by which a particular group or

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community decides to regulate its behaviour – to distinguish what is legitimate or acceptable in pursuit of their aims from what is not”(Flew, 1979:112)

The following are core values of ethical research as stipulated by NDA (2009):

- Promote the wellbeing of those participating, involved in or affected by the research process
- Respect the dignity, autonomy, equality and diversity of all those involved in the research process (p.19)

As the field of disability research in Ireland expands, it is vital that the above ethical values be ensured. In addition the author believes that quality research methodology and CGT are synonymous so adhering to the rigorous nature of the CGT methodology is a quality assurance mechanism. Adhering to these general core ethical values, however, presents some specific challenges for the classic grounded theorist undertaking research in the field of intellectual disability. The following section provides an overview of the importance of CGT as a general methodology.

The Importance of Grounded Theory as a General Methodology

Since its inception in 1964 with identification of the importance of the *constant comparative method* (Glaser, 1964) CGT has opened the floodgates for the legitimacy and acceptance of naturalistic research methods as scientific methods of inquiry (Glaser 1964, Glaser & Strauss, 1967). In 1965, it was the disenchantment of Barney Glaser and Anslem Strauss with logico-deductive emphasis on theory verification, inherent in social science research which promoted their development of the CGT methodology as an alternative to the verificational research tradition (Glaser & Strauss, 1967). While promoting naturalistic research as a scientific method of inquiry it is important to recognise CGT as a methodology which is distinctly different from other qualitative research approaches. Many qualitative and quantitative approaches to research have different philosophical perspectives. CGT is a general methodology, which can accommodate any of these perspectives (Holton, 2008). CGT relies on abstract conceptualizations and conceptual relationships while avoiding contextual descriptions and descriptive

interpretations of the empirical data, whereas, other qualitative research approaches focus on in-depth descriptions. Interestingly, it is those very qualitative descriptive approaches that have presented the greatest challenges to the authenticity of the CGT methodology today, by eroding the very nature of the initial general methodology which provided them with legitimacy to exist (Glaser, 2009). Therefore it is now more important than ever, for CGT researchers and ethic committee forums to work together to find ways to address challenges and promote opportunities for researchers to undertake rigorous CGT studies.

The Challenges and Opportunities for Novice CGT Researchers

From the experience of the author the CGT methodology in its own right did not present as an issue for the ethics committees; rather the concerns raised by the ethics committees focused on the protection of the participants. Thus, the main subject of concern was of an ethical nature rather than a methodological one, however, the ethical concerns affected the author's ability to employ CGT methodology in its truest sense. Universities overseeing research and organisations providing services to people with intellectual disabilities are accountable for the protection of research participants. Having had the experience of being a clinician in practice, the author could well understand the conditions required by service ethics committees so that managers or administrators: a) fulfil their responsibilities in an organisation providing a service for people with intellectual disabilities, b) facilitate the running of the normal day to day activities of the service and c) oversee the role of gatekeeper for the research purpose by communicating with people with intellectual disabilities and their families about the procedures associated with the research. The challenges lie in addressing the expectations of ethics committees to know all that the researcher intends to have happen during the study; managers are expected to know all that is going on in their organisation whereas the CGT researcher is expected not to know what is going on until it emerges from empirical data collected during the course of the study.

Being expected to know before one is in a position to know

The core principles of the CGT methodology ensure that the theory developed is both grounded in and guided by the data. Thus in CGT a definite plan relating to the research design,

process and number of groups to be examined is challenging to present at the outset of the research study (Glaser and Strauss 1967). Glaser (2001) proposes that the CGT proposal should be simple and compiled into two pages. All that is needed is an area of interest of some relevance and a site or population where it can be studied (Glaser 2001 pg 111). The methodological aspects of the CGT approach indicate that the researcher should not declare that they know before they are in a position to know. Christiansen (2008) advises the CGT researcher to abstain from making any pre-framings or pre-conceptions, as this indicates that the researcher is stating he/she “*knows*” before he/she is in a position to “*know*”.

In contrast, the requirements as stipulated by the research ethics committees encountered by the author meant the completion of a detailed seventy-one page proposal incorporating appendices (interview schedules, briefing sheets, questionnaires, consent forms, time schedules, etc.) relevant to the study. In order to promote the well-being and ensure the protection of research participants, ethics committees require to know exactly what a researcher intends to do in a field prior to providing ethical approval. While it was possible for the author to present an overview of the proposed study, presentation of exact details of what the study would involve was challenging. While meeting the requirements of the ethics committee, the author was challenged to create opportunities which would allow for the development of conceptual theory through theoretical sampling and constant comparison.

Having to declare rather than trusting in emergence

Ethical requirements stipulated that the author declare the aim and objectives of the proposed study. In order to protect research participants, ethics committees seek specific information in relation to exactly what the researcher aims to do and how the researcher aims to do it. The author developed a research proposal to ensure a broad area of interest was a starting point for the research and committed to entering the research site without any preconceived ideas but instead with the ‘abstract wonderment’ of what is going on with the aim of developing a conceptual theory explaining the main issue of concern for adults with intellectual disabilities.

Observation and interview schedules

The ethics committee required observation, interview and questionnaire guides to be submitted with the research application form. As further protection of research participants, the committees also required information as to the intended primary locations of research, the questions to be asked, and what was to be observed. Furthermore, they wanted to ensure that each participant would be afforded the opportunity to read a transcript of the interview. The challenge for the author was to formulate the necessary forms to provide the required descriptive information while remaining free from preconceived ideas and loyal to the CGT approach. Glaser (2009) contends that qualitative data analysis requirements that focus on collecting data by interview guides with specific populations, audio-taping interviews and returning the transcripts to the participants for verification to increase accuracy in the study result in the researcher becoming overwhelmed with descriptive data which does nothing to aid the generation of theory. According to Glaser (2009), the collection of descriptive data is jargonized as grounded theory which it is not.

On the observation guide, the author first declared her intentions as classical grounded theorist observer indicating that she intended to write analytical notes of her own thoughts and feelings about what was happening in the research setting. This would include notes of first impressions of her observations of each incident, also the general feel of the group/individuals doing the activity and observed relationships between people. In addition, she declared intent to record additional data in order to maintain the observational record as events happen. Glaser (1978, p.74) has advised to elaborate on the six C's (causes, contexts, contingencies, consequences, covariances and conditions) when a researcher is required to preconceive data. Therefore, the author incorporated the six C's and declared her intentions to observe for the occurrence of particular phenomena and occurrence of specific behaviours to reflect the phenomena. The observation guide also included requirements and these were accounted for by Spradley (1986) who focuses on qualitative descriptive accounts such as people, places and things, all of which Glaser would say are transcended in CGT but yet this was a requirement for the ethics committee.

Likewise, the interview guide held a similar classic grounded

theorist declaration that in keeping with a CGT approach, the interview topic guide would be kept general and open as interviews would rely on the emergent data to stimulate and generate discussion on the topic as relevant and important to participant. Reflecting the initial broad area of interest, the interview guide incorporated questions on the topic and asked questions in relation to how this might happen in the lives of adults with intellectual disabilities. The interview would be completed with provision for obtaining permission from the participant to return for another interview, if required.

It was agreed with the ethics committee that access to documentation and photography would be guided by theoretical sampling. The PhotoVoice Manual (Dahan, Dick, Moll, Salwach, Sherman, Vengris, & Selman, 2009) provided ethical guidelines to incorporate the use of photography with marginalised groups of people; interestingly, its questioning fits with the principles of CGT: *What is really happening here?*

Recruitment and theoretical sampling

Recruitment is a crucial and fundamental part of research and one that poses various degrees of difficulty (Chiang, Keatinge, Williams, 2001). This is particularly so when the area of research is one that is either highly sensitive, or that involves participants who are deemed to be particularly vulnerable such as adults with intellectual disabilities. Fortunately, a basic tenet of CGT is that “all is data” (Glaser, 1998, p. 8). In alignment with this tenet, and acknowledging the need to optimise opportunities for data collection and theoretical sampling within a customised research proposal, the author proposed that data would be collected from adults with intellectual disabilities through observations, meetings and informal discussions, in various locations and at various activities. The author also optimised opportunities for the participants to discuss their main issue of concern by proposing to request access to documentation and to use photography which would be guided by theoretical sampling. Any requirements for further theoretical sampling would be negotiated with the gatekeeper.

Maltby, Williams, McGarry, and Day (2010) state that research using grounded theory does not start with a predefined sample. The challenge for the author was that a population and sample size was required by the ethics committee. In CGT, specific identification of the number of people to be invited to

participate in the research is challenging, as the theoretical sampling that is intrinsic to CGT is unknown at the beginning. Glaser (1978) suggests that initial data should be gathered from the individuals who are the best informants in that area. Routine qualitative data analysis requirements are contrary to the flexibility that theoretical sampling requires (Glaser, 2001). In order to gather data from the best informants and to meet the criteria as required by the research ethics committee, the author proposed that the research study would commence with a purposeful sample of participants. Taking into account the nature of the constant comparative method and the need for the researcher to optimise opportunities to avail of theoretical sampling, the author proposed to avail of comparison groups in different services where each of the services catered for individuals with different needs. It was proposed that a purposeful sample would initially be selected and it was agreed with the ethics committee that further theoretical sampling would be negotiated with the gatekeeper.

Consent: informed and voluntary

Informed and voluntary consent has been a foremost requirement from ethics committees to grant approval to a researcher who can subsequently gain access to people with intellectual disabilities. Siminoff (2003) argues that conceptually, a standard bioethics principal-based framework does not provide guidance as to how the process of informed consent should be operationalised. Often consent from people with intellectual disabilities means more than a single act of giving consent. It may mean an on-going negotiated process through the various stages of the research project. Glaser (2001) acknowledges the constraint which the human subjects' requirement for informed consent places on theoretical sampling. The challenge to the classic grounded theorist is balancing the need to provide accessible and specific information to the person about what would be expected of him/her in the study with the requirement for a classic grounded theorist to stay open and to be guided from what is emerging from the data. As the core principles of CGT, which focus on explaining the main issue of concern for participants, are closely linked with the principles of person centred planning which identifies what is most important for the person, it was easy to submit templates to the ethics committee of how the author would provide accessible information to the participants informing them that they would be able to focus on

their main issue of concern. What was more challenging was providing specific descriptive details of how and when and where this would be done and what exactly the focus would be or the exact time the person would be involved in the study. Glaser (2009) directs the CGT researcher to collect and simultaneously analyze data from the outset of the research study with the emerging theory dictating to the researcher where to look next for data. The author presented samples to the research ethics committees of locations where observations and interviews might take place declaring that these were not definitive but rather would be led by theoretical sampling.

Conclusion

CGT has the power to generate a conceptual theory explaining the main issue of concern for the participants and how they resolve this main issue of concern. This is closely linked to the current paradigm of person centred planning service provision for people with intellectual disabilities. While, in Ireland, research in the field of intellectual disabilities is novel, and requirements stringent from ethics committees, CGT researchers need to continually optimise opportunities to creatively find ways to open avenues for theoretical sampling, conceptualisation, and constant comparisons when writing research proposals. For CGT methodology, a theory is abstract of time, place and people; to focus on these very aspects countermands the value of the methodology and its' conceptual ability to generate theory. Yet it is these very aspects which are crucial for the ethics committee governance in ensuring that research participants are protected. Ethics committees appear to be oblivious to the constraints being placed on CGT researchers (Glaser 2009). Breckenridge and Jones (2009) encourage novice classic grounded theorists to be mindful that the methodology should not be subject to generic 'qualitative' guidelines. The author advocates that more classic grounded theorists need to stand firm on ethics committees and recommends the creation of discussion forums to address the ethical and methodological concerns pertinent to CGT researchers undertaking research with people with intellectual disabilities.

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