

Chapter 3: Methods

Research Questions

- How do palliative care nurses perceive the death and dying experiences of their terminally ill patients?
- How does spiritual and existential experience relate to or intersect with Kübler-Ross's theory of the five stages of dying within these perceptions?

Research Design

The study used a qualitative approach, using in-depth, face-to-face, one-to-one semi-structured interviews. The design was non-experimental (Whitley, 2002; Rosnow & Rosenthal, 2005).

Procedure

The Witwatersrand Hospice in Johannesburg was approached, and permission was granted from the clinical manager to conduct the study with members of the organization. Once ethics clearance has been obtained from the university, individual nurses were contacted, told about the study and asked to participate. They were given an information sheet explaining the nature of the study. The participants were also informed verbally by the researcher of the basic interests and aims of the research. Potential participants were asked to sign a consent form to indicate their willingness to participate in the research. They had to consent to being interviewed and being recorded. If the consent form was signed (Appendix C), and written consent to be recorded was given, the interview proceeded at a time convenient to both parties, using the interview schedule (see Instrument). Interviews were held over a 2-month period, between July and August 2009. Interviews lasted between 20 and 80 minutes, and were conducted in quiet settings within the facility where the parties had a minimal chance of being disturbed. Initially, rapport was established: the researcher asked for information regarding the participant's training and motivations, to get a sense of the participant's context and beliefs. The interview was concluded when all prepared questions had been asked and answered, or when saturation has been reached. All interviews were recorded onto MP3 and stored in password-protected files on the researcher's personal computer. After all interviews had been carried out, the researcher

transcribed and analysed them. Numerical coding was used. After the research project was concluded, the data will either be destroyed, or kept for use in further research.

Participants

The researcher interviewed 10 nurses and nursing sisters working in a Hospice facility in the greater Johannesburg area. Six of these participants were home care sisters, and 4 were inpatient nurses working at the facility itself. All were female. Their work experience at Hospice ranged from 6 months to 23 years. Six of the participants were White, and 4 were Black. Most (80%) of the participants claimed to have some adherence to a sect of the Christian faith, although this dimension ranged from skeptical and doubtful to highly devoted. One of the participants self-identified as an atheist, and one as Muslim. Over the course of two months, they were interviewed individually, and asked to comment on the spiritual and emotional experiences of individuals who have been diagnosed with terminal illnesses. This sample was a convenience sample (Whitley, 2002). The sampling method followed non-probability methods, due to the qualitative method being used, which does not emphasise generalisability, but rather depth and richness of data (Davies, 2001; Parker, 1994).

Instrument (see Appendix D)

Interviews are used in qualitative research to gain a description of the subject's interpretation of an experience (Davies, 2007). It is emphasised that understanding the subject was the primary overarching goal in these interviews, even if some structure was sacrificed (Bogdan & Biklen, 2003). One semi-structured interview was conducted with each respondent. This allowed the researcher to adapt her questions and probes during the interview according to the way the participant responded (Burman, 1994), but still to retain a sense of structure and not lapse into a conversational style (Whitley, 2002).

An interview template was developed, based on the literature and structured around the research questions. It focused on two main themes: spirituality and meaning, and theories of death and dying, including Kübler-Ross's five stages of dying. The interview contained certain questions and probes, but these were structured to be relatively open-ended. For example, initial questions regarding the construct of acceptance were: "How often do people reach a stage where they are at peace with dying?" and "How would you describe the way people behave when they have accepted death?" Depending on the participant's

reply, several probes could be used to ascertain their ideas of acceptance, such as, “Do you think accepting death means not struggling with it anymore?” It was hoped that these questions would serve to open up new avenues of questioning, which were pursued as far as possible within the interview structure and research aims. Because of the flexible nature of qualitative interviews, the subject was given space to shape the interview to a certain extent (Bogdan & Biklen, 2003).

Data Analysis

This research aims to approach the notion from the bottom up: by taking the constructions of individuals as some form of subjective ‘truth’. A phenomenographic approach was thus used to analyse the data. The particular strategy utilised was interpretative phenomenological analysis (IPA), a method which not only seeks to represent the voices of those it investigates, but also aims to explore and understand these unique viewpoints (Larkin, Watts & Clifton, 2006). It uses an idiographic template, in that it works at an individual level, but this does not imply that it is limited to analysis at the individual, intrapsychic level; though subjective experience is its focus, it is nearly impossible for it not to take into account situation, context and construction. Nonetheless, it involves a richly detailed account of a small number of individuals’ experience, after which themes or “patterns of meaning” are extracted (Larkin et al, 2006, p104).

Interpretive phenomenology follows Husserl and Heidegger in assuming that the individual is a part of material reality, even as it studies human consciousness (Larkin et al, 2006). This is a rejection of the dualism often found in modernism that claims that subjective and objective reality can be separated (Giorgi & Giorgi, 2008). Situations cannot be disentangled from our “active intellectual construction” of them (Prigogine & Stengers, 1984 in Larkin et al, 2006, p106). Thus, even though the aim of the research was primarily to gain insight into the subjective experiences of the participants, the way they construct the world, and how it is constructed for them through language, was also considered. The first goal of IPA is thus to try to understand, and give an account of, what living in the participant’s world is like. This comes with the rider that the ‘true’, unvarnished experience of another can never be fully accounted for: it is constantly being constructed by the person themselves, then reconstructed by the researcher (Larkin et al, 2006). This is usually termed a “double hermeneutic” (Smith & Eatough, 2007), but in this case a third level of interpretation is added here, since nurses are also making meaning of

the experiences of others, i.e. the individuals with terminal illnesses whom they are in contact with. Thus, three levels of experience are being interrogated. The second aim of IPA is to position the description within a particular sociocultural and situational milieu, thus adding an interpretative dimension, and sometimes linking the data to existing theoretical frameworks (Larkin et al, 2006).

IPA is, however, more a perspective on research than a method of analysis (Larkin et al, 2006). Thus, within the interpretive phenomenological framework, the technique of thematic content analysis was used. In this method, the researcher used coding procedures to isolate themes which recurred in the text, and thus attempted to decode “messages, meanings [and] symbols” (Neuman, 1994, p.262). Though qualitative content analysis is not seen as useful by most positivist researchers, it is a flexible tool which allows for rich, nuanced readings of data (Braun & Clarke, 2006). It is also well suited to interpretivist methodologies, given its usefulness in revealing non-obvious implications in data (Neuman, 1994). The basic analytic procedure followed Braun & Clarke’s (2006) steps. Data was transcribed and the researcher familiarised herself with it, by re-reading transcripts several times. A coding system was developed, and interesting or relevant features of the data were coded, which provided a framework to determine the frequency, direction, intensity and space occupied by the units of analysis (in this case, themes) (Neuman, 1994). Latent coding, or coding of underlying meanings, was implemented: the researcher attempted as far as possible to interpret the unsaid as well as what was said. Codes were then grouped into potential themes, after which the coded data was revisited in order to see if it collated with the themes. The researcher then, through thorough analysis, defined and named themes, and selected the most pertinent and interesting to report in the final written research (Braun & Clarke, 2006). Themes were determined using both a theoretical or top-down approach (Braun & Clarke, 2006), given the basis of the research in Kübler-Ross’s stages of dying, and allowing for new and unexpected themes to emerge through a bottom-up approach. Thus, the approach to identification of themes was theoretically guided, but still open to taking advantage of the generativity of semi-structured interviews.

The assumptions of this research were thus located in an interpretive framework, with a descriptive leaning, and this was appropriate given the aims of the study: to take the experiences of those caring for dying patients as a text, as their own truth, and work within that paradigm to explore issues and theoretical clashes. Commonalities and contrasts in

narratives were identified: the gaps or discordant elements are often as important as themes which unite narratives (Breakwell, 2000). This technique also works particularly well with the data collection technique of a few semi-structured interviews, which provides rich text data which can be explored in-depth. Although the research questions and instrument were drawn from theory and research, there was a hope that the research would be, to an extent, generative.

As always with qualitative research, it is acknowledged that neutrality and objectivity in the traditional Western positivist framework are impossible. Context and participant factors are thus not necessarily extraneous variables which contaminate the research, but rather important factors, unique to the particular setting and moment, which are inextricable parts of the research (Parker, 1994). Given the philosophical and epistemological assumptions of interpretive phenomenological research, what is found in research is necessarily a function of the interaction between the researcher and the subject (Larkin et al, 2006). Interviews set up an inescapable power dynamic between researcher and participant (Burman, 1994). In analysis, too, the researcher decides which themes are important, what themes are, and how they are defined (Braun & Clarke, 2006). It is acknowledged that the researcher is always a co-constructor of knowledge, and is inseparable from it (Snyman & Fasser, 2004). The role of the researcher must thus be acknowledged and explored, and this is especially pertinent in a one-on-one, face-to-face interview situation (Burman, 1994). The ways in which the researcher has determined and changed the research was thus carefully documented in a research journal, which detailed the researcher's subjective experience of the research, including how she was affected by the research and how she may have been affecting it. It included both descriptive notes on the context and subjects themselves, and reflections on the researcher's method, analysis, ethical dilemmas and frame of mind (Bogdan & Biklen, 2003). This served as a way to control for inevitable researcher biases (Bogdan & Biklen, 2003).

Ethical Considerations

This study was, by nature, ethically sensitive. It is acknowledged that the subject of dying is traumatic to many people, especially the patients themselves. This is exacerbated by society's general resistance to dealing with death directly (Govender, 2006). However, nurses are constantly confronted with patients who are at a crisis point in their lives, and are thus thoroughly and intensively trained by their institution in end-of-life care issues

and counselling. There was thus very little, if any, risk that the research itself could traumatise or re-traumatise participants, as they possessed both training and experience. The research was thus far more viable than it would be using most other respondents, as the response group was necessarily somewhat desensitised to the topic of death. This way of studying the important issues around spirituality and dying was perhaps the least risky method possible.

The researcher explained the purpose of the study and the method which would be used to the participants. She emphasised that participation was voluntary, and that they could withdraw at any time with no negative consequences. Additionally, no benefit was given to participants. The researcher also clarified that anonymity was assured, and that even though quotes would be used and themes discussed, no identifying information would be used in the written report. Interview raw data was seen by the researcher and her supervisor. The results of the study would be made available to the respondents in the form of an executive summary to the institution, and a list of counselling services, both in person and telephonic, was provided in case of any negative emotional reaction.

All ethical and procedural information was provided in a consent form which the participants were asked to sign in order to participate. They were also presented with a form giving consent to the researcher to record all proceedings and use quotations, which was always signed before the interview could begin. After the interview was concluded, the participant was again informed that if they had any concerns or felt they needed any help or counselling as a result of what had happened during the research process, the researcher would assist them in any way possible. This included recommending the counselling services at the Emthonjeni Centre at the University of the Witwatersrand, providing the telephone numbers of Lifeline and the South African Depression and Anxiety Group, and informing them how they could access the counselling facilities at Hospice itself.

Total anonymity could not be guaranteed, given the face-to-face nature of interviews: the researcher needed to access participants' names and contact details for practical reasons. However, privacy was ensured, as the researcher did not request, record or use surnames, birthdates, or any other identifying information. Participants are referred to in the written report by numbers, e.g. Participant 7. Confidentiality was ensured, since only the researcher and supervisor of the project had access to the data.