A View of Quality of Life

for a Sample of Irish Adults

with Physical Disabilities
DECLARATION

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Sue Kraftsoff, Author
SUMMARY

There is limited existing research that provides a personal view of quality of life for people with disabilities. This qualitative study aimed to explore the subjective meanings and influences on the quality of life for a small sample of adults with physical disabilities using lightly structured interviews. Snowball sampling technique was used to access the sample of seven adults with physical and neurological disabilities who were living independently in the community. Grounded theory approach was the research design that guided data collection and analysis, which run concurrently. This approach uses a constant comparison analysis, which facilitates emergence of theory from data through comparison of common codes or categories, and the broader increasingly abstract themes. Memo writing – or reflection on the part of the researcher ensured that the emerging themes arise from the data aids the process of construction of the theory. The themes were then re-constructed into a model with a main concept to represent influences on quality of life for this population sample. The main concept was the quality of life, with its influences and subjective meanings for the sample of seven adults with disabilities. The model is represented by three categories: person, participation and society/environment, which interact with each other, and contain components, such as independence, access, employment, and others. All of these impact on the personal identity, which forms part of the personal quality of life. These concepts, grounded in the findings of the study are the personal meanings and influences on the quality of life. When reviewed in the light of existing literature, these findings were mostly consistent with other qualitative studies carried out in the area of quality of life. However, further research into subjective and interpretive meanings of quality of life using qualitative approach is needed.
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DEDICATION

The author would like to dedicate this work to her parents, Tamara and Anatoli, as a small gesture of her deepest appreciation for their love, continued support and encouragement during this MSc.

Without you, none of this would have been possible.
1. INTRODUCTION

1.1 Introduction

This chapter introduces the concept of disability and places it within the context of modern Ireland, providing an overview of where people with disabilities are within the overall population using some statistical references. The terms ‘disability’ and ‘quality of life’ are defined in relation to their use within the wider academic research and for the purpose of this study. Quality of life for Irish people with physical disabilities is discussed as an area of focus of this study and its aims, together with the rationale for the choice of methodology are provided.

1.2 Disability in Irish society

In the Irish legal context, disability has been defined as “a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment” (Disability Act 2005). According to this definition, impairment causes the restriction of personal capacity, which results in a disability. While this is a somewhat improved definition of disability since its former version in the National Disability Authority Act (1999) whereby disability was a “substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment”, where the key changes are: the elaboration of the meaning of ‘economic life’ and addition of ‘emotional’ impairment. However, the definition remains rooted in the traditional medical
model view of disability, whereby the impairment has a disabling effect on the individual, as opposed to his environment, which is what is ultimately disabling the individual, which is the view of the social model of disability.

In order to get a brief overview of the importance and presence of disability in modern Irish society, it may be helpful to envisage people with disabilities as part of the overall population in statistical terms. Thus, there were 345,024 people with disabilities living in Ireland on census night in 2006, of which 177,085 identified themselves as having a condition that substantially limits one or more basic physical activities (Central Statistics Office, 2006).

While the majority of people with disabilities (266,688) were not in the labour force; 77,800 people with disabilities over 15 years of age were in employment in 2006; with the top occupations being in the sectors of ‘Sales Occupations’, ‘Personal Service and Childcare Workers’, ‘Clerical and Office Workers’, and ‘Other Gainful Occupations, including not stated’ (Central Statistics Office, 2006). Another 16,922 people with disabilities identified themselves as students (Central Statistics Office, 2006).

The above statistical references give an overview of the position of people with disabilities within the whole population in Ireland. The majority of people with disabilities are not part of the labour force, however those who are – tend to be in administrative and service sectors of employment, as well as a smaller number who are in education.

Overall, little is known about the quality of life (QOL) of people with disabilities identified by these statistics and what is attributed to having a QOL by an active, independent and employed population of people with disabilities themselves.
1.3 Defining quality of life for people with disabilities

QOL is a complex, yet commonly referred to concept in literature and practice. Particularly in health and social sciences, this concept is usually talked about in terms of its relation to health, as health-related QOL, which is usually measured using survey methods in empirical studies. However, this approach has been described as being limited to the view of health and health-related QOL as seen by the medical professionals for the purposes of health planning (Koch, 2000), and although more recent studies have attempted to go beyond measuring function, it can be argued that this way of measuring quality of life still remains within the medical model view of disability (Charmaz, 1996).

Therefore a broader definition, which is more holistic and, therefore, encompassing of the complexity of QOL, one that attempts to highlight the relationship between its components, which influence QOL while giving voice to those whose primary experiences are being studied, is needed. Among QOL’s frequently described features are its ‘multidimensionality’ and its ‘subjectivity’ – describing the concept’s physical, functional, social and emotional areas as well as the importance of the personal opinion of their QOL (Cella, 1994).

For the purpose of this study, one particular definition was found to be most appropriate, highlighting the components, which this study aims to explore; Peter (pg. 27, as cited in Brown, 1997) described QOL in relation to “aspects of one’s life or lifestyle that contribute to, or the absence of those things that diminish, one’s well being” with “opportunities to fulfil one’s needs.. grow and learn..and become a participant or contributor within the larger society”. It is this definition’s conceptualisation of the complex and interdependent nature of its components that makes it relevant to this study. In particular, qualitative research appears to be best suited to reveal these complexities and relationships between the
components of the nature, or as Peter calls them, ‘ambiguities’ within somebody’s lifestyle that make up their quality of life (as cited in Brown, 1997). He also points out the importance of participant-led line of qualitative inquiry and its power to hone in on the most relevant personal experiences, while providing a holistic view of a person with disability (Peter, as cited in Brown, 1997).

1.4 Conclusion

Although there are models of quality of life in existence, such as Parmenter’s (1988) ‘Model of quality of life for people with disabilities’ (as cited in Brown, 1997), this small-scale exploratory study aimed to develop its own model using the grounded theory approach, which was rooted in the environmental, cultural, political and social context surrounding people with physical disabilities living in Ireland. Exploring the aspects or areas of lifestyles of this particular group of people and what affects the quality of their lives through open, lightly structured interviews, which provide the milieu for discussion of this complex and subjective concept was the overall aim of this inquiry. Use of a qualitative method is key for this enquiry to get to the essence of the personal meaning and influence of QOL to a person with a disability.
2. Literature Review

2.1 Introduction

Having stated the research question and the aim of this study, it is important to refer to the empirical studies whose purpose was to investigate the quality of life (QOL) of people with disabilities and the place this study might take among existing body of work on this topic. The literature review was conducted using a number of research databases, including PsychInfo and PsychArticles, ScienceDirect, EBSCOHost and electronic journals, such as Disability and Health. Main literature source for this chapter was the book Quality of Life for People with Disabilities, 2nd edition, (Brown, 1997).

As mentioned previously, the concept of QOL has its broad uses not only in the description of a certain standard of living, but more prominently in health care planning, provision and evaluation using several different instruments for this purpose. Use of instruments versus use of qualitative measures, such as interviews is discussed with reference to previous studies, international and domestic, conducted with the aim of defining and identifying meaning of QOL.

2.2 Researching Quality of Life

Farquhar (1995) wrote of the importance of distinguishing between the definitions and synonyms of QOL before engaging in researching them, as this affects the method chosen for the purpose of such research.
2.2.1 Subjective versus objective measures of quality of life

Some of the research has been done to identify subjective perceptions of QOL, such as Hall’s (1975) study ‘Subjective measures of quality of life in Britain: 1971 to 1975’ in which participants identified the family, home life and marriage in a single major category, while some reported being happy and content without defining QOL further. The decision between the most suitable measure to describe QOL – whether subjective or objective, relies on the type of information being sought; thus objective measures, usually surveys in the form of questionnaires seek to obtain norm-referenced information, while subjective measure look for personal perceptions of well-being (Cummins, as cited in Brown, 1997). Qualitative approach is particularly well suited to delve into the complex subjective perceptions of an individual’s QOL. Interviewing people with physical disabilities about their QOL and related concepts, several authors successfully engaged their participants using this method of data collection and obtained responses that explained participants’ views, represented in a complex matrix of subjective perceptions of well-being (Velde, as cited in Brown, 1997).

Both subjective and objective measures used in empirical studies since the concept of QOL has been researched, have contributed to a body of knowledge, which was has been organised into models and domains to describe QOL. Most of these theoretical structures include some or all of the areas of well-being, which constitute QOL for a person with or without a disability, such as physical, material, social, emotional and productive well-being (Felce and Perry, as cited in Brown, 1997).
2.2.2 Using a qualitative approach

Albrecht and Devlieger (1999) used a qualitative approach to develop an understanding of the disability paradox (whereby people with disabilities report high quality of life, while it would not be seen as such to their observers) with 153 participants using semi-structured interviews. The interviews took place in the community and a snowball sampling strategy was used to reach the participants in the community networks of groups of people with disabilities. Following qualitative analysis, it was found that 54.3% of participants with serious disabilities reported ‘excellent’ or ‘good’ QOL (Albrecht & Devlieger, 1999). Among the identified factors that contributed to high quality of life, as reported by the participants, were: being in control over their bodies, minds and lives with a ‘can do’ approach to life, giving an example of being able to drive a car, as being in control of the body. Participants also identified faith or spirituality, emotional connectedness to others, and gaining a balanced perspective of life as a result of disability experiences, as well as success and achievement in their job or other meaningful tasks, as other factors, which resulted in high QOL. Those 45% of the participants who reported their QOL as ‘poor’ or ‘fair’ identified experiences of pain, fatigue, losing control over body’s an mind’s functions and discrepancy between their former abilities and current abilities among the contributing factors to their QOL (Albrecht & Devlieger, 1999). This study was conducted as a part of a bigger research project on the experience of living with a disability. The researchers adapted Antonovsky’s salutogenic model and dynamic theory of the concept of coherence, in relation to chaos, ambiguity and meaningfulness, to the idea of balance between body, mind and spirit in the context of disability for the purpose of eliciting personal factors that predict QOL for individuals from 11 different social networks for people with disabilities from six informal
disability communities in four ethnic community groups. Data analysis, following semi-structured interviews, included primary and secondary stages as well as a higher level of concept analysis. Some of the findings were calculated statistically (how high QOL was rated by the respondents) in order to be compared with the general population statistical data. The findings supported the disability paradox, and a framework was provided to explain it. However the authors conceded that the framework provides only partial explanation for this paradox, and offer four sets of further research questions that will examine various aspects of this phenomenon. This was one of the few large-scale qualitative studies that attempted to address the complexity of the concept of QOL, and it provided a valuable starting point in review of literature for this study. The authors may have achieved data saturation with the large sample, although they do not state so explicitly, but state that a higher level of analysis was possible with the available categories and sub-categories of data. The researchers refer to the some of the authors and proponents of grounded theory, such as Strauss and Corbin, in relation to their analytical approach to data collection and analysis, however they do not name grounded theory as their research design, although it appears to be prominent in their methodology. Good descriptive clarity was provided during the data collection stage, with a clear description of site, participants and role/biases of the researchers (Letts et al, 2007). While evidence of analytical rigour was presented with a brief reference to analyses conducted, overall trustworthiness, in relation to the four components, was not discussed. Overall, this study provided a good basis for further research, in particular, by specifying sets of research questions that need to be asked to achieve a good grasp of the complex concept of QOL.
2.2.3 Using a mixed methods approach

Montazeri et al (1996) interviewed 200 lung cancer patients using open-ended questionnaires, seeking to find out how this sample population defined QOL in general and how they identified a good QOL in relation to themselves. Using content analysis the researchers were able to categorise responses into eight areas, which included ability to do what one wants to do/work, enjoyment of life, family life, financial security, happiness, health, living longer and social life/leisure activities; of these health, enjoyment of life and family life were the areas most used to define QOL (Montazeri et al, 1996). Participants identified family life, health and social life as the main contributors to having a good quality of life. This study claimed to go beyond measuring health-related QOL by allowing the participants the freedom to define QOL subjectively without the constraints of an objective measure; however a questionnaire was used to identify the subjective meaning of QOL.

Thus, there appears to be limited scope for generating rich, qualitative data consistently as a mixed method design was employed in this case, and it seems unclear the extent to which each of the measures – interviews and questionnaires were used. Qualitative descriptions of subjective definitions were analyzed using content analysis and ranked data of meaning of QOL areas and their importance were statistically analysed. The authors suggested that among the key findings was the discrepancy between the participants’ definition of QOL and its meaning as applied to themselves; they conclude with the discussion by stating that including participants’ views in identifying QOL ensures the validity and thus the strength of the instrument, measuring QOL (Montazeri et al, 1996). However, available qualitative literature provides evidence for an even stronger internal validity of qualitative research, as well as other benefits of this type of research to encourage the participant to take on a
leading role in the discourse, and providing a holistic view within a cultural and social context (Peter, as cited in Brown, 1997).

Farquhar (1995) conducted a study with a sample of 210 older people living at home to identify lay definitions of QOL and evaluate effectiveness of measures of QOL. The participants were asked to complete a set of scales in pairs, with the rationale that scales are one of the common methods to evaluate QOL; a sub-sample of 70 participants were additionally asked open questions about their QOL, for example ‘How would you describe your quality of life?’, ‘What would make your quality of life better or worse?’, etc. (Farquhar, 1995). The findings revealed that older people spoke willingly about this topic and provided a depth of detail sought by the researcher in an unstructured interview format. The author acknowledges the limitation of the sample population as not representative of the whole older population and states that future analyses are needed in order to draw further comparisons between data collected using interviews and scales, and to clarify the model of quality of life (Farquhar, 1995). This is another study, which uses mixed methods design, combining unstructured interviews of the sub-sample at the second stage to support the scales completed by the sample at the first stage of the research. The findings are supported by other empirical studies, as was the case in the aforementioned study.

2.3 Disability and Quality of Life research in Ireland

There are few empirical studies researching QOL for Irish people with disabilities, however as can be seen from the description of the two Irish studies cited below, there is some
attempt to use qualitative measures to explore this concept, as well as those studies following the predominant trend of health-related QOL.

2.3.1 Using a qualitative approach

Among the most recent studies, Murphy et al. (2009) applied the grounded theory approach to identify the determinants of QOL for older people with disabilities in the community. They interviewed a large sample of 122 people across all disability groups in their homes and analysed the data as it reached saturation; following a two-stage analysis process, informed by grounded theory, four foundation factors were established as main determinants of QOL for this population sample – ‘my health’, ‘social connectedness’, ‘being myself’ and ‘financial security’, which were in a complex relationship with mediating, facilitating and constraining factors (Murphy et al, 2009). The authors acknowledge the limitations of the chosen sampling technique and its consequences in terms of transferability of the study’s findings. However, they do not state researchers’ affiliations and biases until the end of the study, whereby they implicate the findings in relation to future nursing practice. Finally, although criteria to ensure rigour in the study were reported to have been used, there was no description given as to how this may have been ensured, other than experts in the field confirming the consistency of the findings, which were reported.
2.3.2 Using a mixed methods approach

Boland, Daly and Staines (2009) conducted a study using face-to-face interviews with 247 adults with intellectual disabilities and 180 adults with physical or sensory disabilities who were in receipt of services in South Dublin/Wicklow areas. The study aimed at exploring self-rated health and quality of life for this population, as part of a larger national study on health promotion needs assessment. A random, representative sample of clients was interviewed using interviewer-directed questionnaires, based on a culturally sensitive measure of health-related behaviour (SLAN) and a generic quality of life measure, which includes description of the concept in five areas (mobility, self-care, activities, pain or discomfort and anxiety or depression) (EQ-5D); both measures were adapted for participants with intellectual disabilities (Boland, Daly and Staines, 2009). Statistical analysis was used to make data comparisons. Results of the study indicated a high response rate, a slightly greater number of people with intellectual disabilities in comparison to people with physical or sensory disabilities; in addition those in the latter group were significantly older than those in the former. People with intellectual disabilities rated their quality of life (response to “Do you enjoy life?” question on a four point Likert scale) significantly higher than the other group, who reported greater difficulties in mobility, self care and carrying out usual activities, as well as reporting more pain and anxiety than the other group and overall poorer QOL (Boland, Daly and Staines, 2009). The authors acknowledge the limitations in transferability of QOL measures, such as the ones used in the study, as providing a partial overview of the concept in relation to the surveyed population; they recommend mixed methods longitudinal design for further research (Boland, Daly, and Staines, 2009). One of the possible critiques of this well-constructed study is while the authors recommend that
qualitative as well as quantitative methods are used to measure subjective parameters of QOL for a complete ‘picture’, this study uses a questionnaire to measure health-related quality of life as well as a health-related questionnaire, both quantitative tools that measure objective, norm-references parameters, such as mobility, participation, self-care. Therefore, it may have been more appropriate to have referred to the concept of health-related QOL rather than QOL, which is a more complex and holistic concept, encompassing a greater number of both subjective and objective areas.

2.4 Identifying an area for research

While the above is not an exhaustive list of empirical studies on quality of life, it provides a relevant backdrop to the type of studies that are prevalent in this area – mixed methods or quantitative, focusing on measuring objective, norm-referenced measures of health-related QOL for the purpose of health care planning and policy making. There is a need for a more personal, subjective, and qualitative focus on QOL in this area, particularly domestically, to provide a balanced view of the phenomenon of quality of life for people with disabilities.

2.5 Conclusion

Hence, the research statement for this study is ‘Exploring personal meanings of quality of life for adults with physical disabilities, who have meaningful roles and live independently in Ireland’. The principal aim of this study is to explore in a subjective, inductive and interpretative way the meaning the concept of QOL holds for a particular group of people with disabilities using a qualitative approach and grounded theory design.
3. Research Methodology

3.1 Introduction

This chapter begins by outlining the aim of the study and stating the research question that it attempts to answer. Key terms of the research are defined here to provide the context and background to the study. Grounded theory approach was chosen as the most suitable research design to answer the research question using a qualitative method of inquiry, specifically, open, lightly structured interviews using constant comparative method of data analysis. The study’s theoretical stance is noted as being in agreement with Strauss and Corbin’s view on grounded theory theoretical position. A detailed description of the population sample, consisting of seven people with physical disabilities living in Ireland and the snowball sampling technique is provided. Finally, follows an outline of how rigour was ensured, according to the criteria set out by Guba and Lincoln (1994), with possible limitations and attempts to overcome them in this study, with appropriate ethical considerations, including ethical approval to conduct this study.

3.2 Aim and Research Question

The aim of this study was exploratory in nature, to gain an understanding of the personal meanings, influences and attributes attached to the concept of quality of life for a small sample of adults with physical disabilities living in Ireland, and gather its implications and influences for this group of people. This study aimed to do this by exploring their opinions and personal experiences in everyday life, with possible discussion of the topics, such as employment, socialising, access and other relevant influences.
The research question was: what do the participants see as the personal meanings and influences on the quality of life for them, as adults with physical difficulties who live independently and engage in productive occupations in Ireland?

### 3.3 Definitions of terms

*Quality of life* is defined in many ways in the literature. The description of quality of life that was used for the purpose of this study may include many different aspects, such as socialising, physical or mental well-being, independence and many others, depending on the personal interpretation of the concept for each participant. Throughout the data collection, in which open interviews were used, participants were encouraged to explore through discussion what personal meaning ‘quality of life’ holds for them, as well as its implications and influences on their everyday life.

*Adults with physical disabilities* refers to people over 18 years of age who have identified themselves as having a physical disability with an underlying neurological or neuromuscular (physical) condition or impairment.

*Live independently* refers to adults living in their own accommodation or in the family home, with parents and with or without siblings. Participants may avail of personal assistance services (PA’s) or assistive technology to increase their level of independence further.

*Engage in productive occupations* refers to participation in (full-time or part-time) employment or education or a combination of both (training with work experience), or disability activism (dealing with local authorities regarding disability issues as a member of the public).
3.4 Research Design

Grounded theory design was chosen for this study due to its fit with the exploratory aim of the research question. Grounded theory is an approach to research, which seeks to generate theory from data using specific techniques. Its authors, Glazer and Strauss, had attempted to create a new method of inquiry that was intended to go beyond either qualitative or quantitative approach, had succeeded in creating a methodological and theoretical approach, which may be complex and contradictory at times, but provides a novel way to generating and grounding theory (Dey, 2008). One of its key features is a constant comparative method, it aims to relate theoretical concepts or categories emerging from the data by comparing codes or themes within the data on an ongoing basis, which forms the analysis of the data (Glaser and Strauss, 1967). Other features of grounded theory approach, such as theoretical sampling, whereby the researcher is not only engaged in constant comparative method of data analysis but is also flexible about sampling new populations in order to gain richer material, and using a variety of sources, such as interviews, documents and observations, were not applied in this study, mostly due to time constraints and limitations in the sample selection. However, most requirements for data collection according to the grounded theory approach were met, as open, lightly structured interviews were used to collect data, which satisfied the approach’s qualitative and unstructured requirements, and a dialogue between data and analysis was developed (Dey, 2008). This dialogue, as described by Dey (2008) involved re-focusing of the initial ideas generated from the first unstructured interviews following analysis, and making them more specific in the subsequent interviews. This was done through writing of memoranda or memo-writing, which facilitated coding of data, especially in the higher level of data analysis
as the categories became more abstract and encouraged reflection on the relationship between the categories, which was later illustrated in the structure of the model, which emerged from the data (Chen & Boore, 2009).

3.5 Theoretical Perspective

While there appears to be little agreement on the philosophical position of grounded theory among its leading proponents, as positivist, phenomenological positions and even a complex four-fold combination of positivist, post-positivist, critical theory and constructivist perspectives have been argued (Charmaz, 1990; Glazer and Strauss, 1967; Annels, 1996).

This study appears to have a better fit with Strauss and Corbin’s view of interactive, inductive and interpretive view of grounded theory, whereby the researcher plays an active role in interactions with participants as well as data, interpreting the reality and verifying the generated theory through researching it using a qualitative approach (Annells, 1996). Symbolic interaction has a good fit with grounded theory as guided by both, the researchers attempt to explain a phenomenon based on evidence from data and through development of theory, by assuming that people create their reality from interaction with their surroundings (Chen & Boore, 2009). Thus, this study attempted to explain the concept of QOL through identifying common patterns or themes as reported by the participants, whose reality of the concept of QOL is constructed by their interaction with their surroundings.
3.6 Data Collection Methods

Open, lightly structured interviews were used in this small-scale study to gather empirical data. As the aim was to explore an area with few empirical studies, with a particular population sample, interviews were chosen a method of inquiry to uncover rich, new data on the topic by following the participant’s answers to the introduced topic and seek new personal meanings and perspectives, contained in it (Kvale and Brinkmann, 2009). Furthermore, used with the grounded theory approach, open interviews are an appropriate method of eliciting and developing categories and theoretical concepts (Bryman, 2008; Kvale and Brinkmann, 2009). Lightly structured, or unstructured interviews with few questions and several prompts were used to encourage the participants to explore the topic freely, leading discussion through lived experiences and values, meaningful and personal to them. The researcher’s role was to guide the participant in their search for new meanings, and encourage the participants to consider the main idea of quality of life from other possible angles, while maintaining the established personal connection with the topic.

Seven participants were interviewed using an open, lightly structured interview approach. The duration of interviews was from approximately 50 minutes to 100 minutes. Please refer to the Appendices for the Interview Guide, containing questions and prompts, that was used throughout the interviews. All interviews were digitally recorded using a digital recorder and transcribed verbatim by the researcher.
3.7 Population and Sample

Sample population consisted of seven people, five females and two males, aged between 23 and 45 years of age who themselves identified as having a physical disability. All of them lived independently, either on their own or with family and engaged in productive occupations, such as education or employment. All of the participants resided in the greater Dublin and Wicklow areas, and of Irish descent. Some of the participants were availing of the PA service. For detailed demographic descriptions, please refer to Table 1.

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Disability</th>
<th>Occupation (work or education)</th>
<th>Living situation</th>
<th>Personal Assistance (PA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anne</td>
<td>Female</td>
<td>27</td>
<td>Physical</td>
<td>Full time</td>
<td>Family home</td>
<td>No</td>
</tr>
<tr>
<td>Mary</td>
<td>Female</td>
<td>32</td>
<td>Physical</td>
<td>Part time</td>
<td>Own accommodation</td>
<td>Yes</td>
</tr>
<tr>
<td>John</td>
<td>Male</td>
<td>45</td>
<td>Physical</td>
<td>Part time</td>
<td>Own accommodation</td>
<td>No</td>
</tr>
<tr>
<td>Jack</td>
<td>Male</td>
<td>30</td>
<td>Neurological</td>
<td>Full time</td>
<td>Family home, awaiting move to own accommodation</td>
<td>No</td>
</tr>
<tr>
<td>Charlie</td>
<td>Female</td>
<td>23</td>
<td>Physical</td>
<td>Full time</td>
<td>Family home</td>
<td>No</td>
</tr>
<tr>
<td>Jane</td>
<td>Female</td>
<td>37</td>
<td>Neurological</td>
<td>Full time</td>
<td>Own accommodation</td>
<td>No</td>
</tr>
<tr>
<td>Katie</td>
<td>Female</td>
<td>37</td>
<td>Physical</td>
<td>Full time</td>
<td>Own accommodation</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Table 1. Demographic description of population sample

Snowball sampling technique was used to recruit the participants for this study. Three of the participants were known to the researcher, two of them through a common school friend and one as a work colleague in a satellite office. The remaining participants contacted the researcher, having learned about the study through university colleagues, work colleagues and friends of the researcher. One other potential participant had made contact with the
researcher through one of the participants; however she withdrew after the deliberation period, citing current emotional vulnerability, which would place her at risk if she were to discuss personal circumstances, pertaining to her quality of life.

Snowball sampling is a type of purposive sampling, and although one of its weaknesses is that the sample is not representative of the population, Bryman (2008) suggests that this ability to generalise does not hold the same important in qualitative research as it does for quantitative research. He suggests that snowball sampling has similarities with theoretical sampling, proposed by Glazer and Strauss (1967) as one of the key aspects of the grounded theory approach (Bryman, 2008).

The sample size of this study may be considered small for an in-depth qualitative inquiry, however, Kvale and Brinkmann (2009) suggest that sample size depends on the purpose of the study, and in this case, the exploratory nature of the study allows for the current sample size. Additionally, data saturation may have been reached as it had appeared that little or no new perspectives on common codes or categories had emerged by the final interview within this particular population sample.

3.8 Data Analysis

Grounded theory approach provided several techniques to conduct data analysis in accordance with it, including the constant comparative method, mentioned previously, which involved several parts of generating new theory. In order to achieve this, analysis of gathered quantitative data underwent the following processes: identifying or coding ‘incidents’, integrating codes through establishing their similarities and differences, and
when this was completed and ‘theoretical saturation’ was completed, e.g. no new ideas could emerge from existing or new data, the theory would emerge with core and peripheral concepts as a result of the analysis, and memo writing to support this analysis (Dey, 2008). Consulting available literature, including empirical studies and writing of the literature review was done throughout the data analysis in accordance with the instruction to generate new theory as consistent as possible with the grounded theory approach. The coding process underwent open and selective coding stages, similar to substantive and theoretical coding, outlined by Chen and Boore (2009), although perhaps not as thorough, as mentioned above, due to time constraints affecting the study. However, a two-tier or stage coding and analysis took place, as initial codes were assigned in text, followed by shortening of codes and developing categories, within individual sets of data (each interview) before they were compared with other sets of data and other connections were established. These connections were revised as further data was collected and coded, new connections were developed, supported by memo writing and theoretical sensitivity (the researcher referred to existing empirical studies on the topic of quality of life and the themes, which had been identified, while not being guided by them for data collection). This was done until the core concepts and their connections were established, which can be observed in the final model (Fig. 1).

This new model, which contained three categories and their subsets, influencing the core concept of personal identity, which in turn formed part of the greater concept of QOL, illustrated the interactive relationship between the data and represented the findings from the study. Existing models and frameworks of QOL were used to inform the model in this study.
The reason this type of approach and analysis was chosen as it can be used to explore the topic of research with few empirical studies were done, particularly in the Irish context, and this inductive method of enquiry and analysis would be a good starting point for further research within disability field, by providing an outline of influences on the quality of life and its meaning to this particular sample population.

3.9 Rigour

Trustworthiness and authenticity have been put forward by Guba (1985), Guba and Lincoln (1994), as alternative means to reliability and validity concepts, to establish whether a piece of qualitative research is of adequate standard; this was done to provide an alternative way of ensuring quality of qualitative research, which did not rely realist perspective of a single reality (Bryman, 2008).

Trustworthiness consists of transferability, dependability, credibility and confirmability. In this study, the sampling technique has affected the transferability of the findings to a wider population of people with disabilities, however, by providing a ‘thick description’ (Geertz, as cited in Bryman, 2008), i.e., a detailed background of the sample population and other relevant aspects of the study, which would promote an understanding of the findings in other settings. Fieldwork journal, interview transcripts and analysis memos and codes were kept and are available for peer inspection to establish a degree of dependability. Credibility has been addressed by providing the participants with full transcripts of their interviews on request, as well as abstracts, containing their quotes and interpretation to ensure respondent validation, whereby the participants reserve the right to withdraw or amend the
information they have provided at the time of the interview. Finally, confirmability was approached through reflexive use of a fieldwork journal and bearing in mind the purpose of the research and the research question during data collection and analysis stages.

Authenticity refers to the impact the research might have on a social and political level, and includes criteria, which relative to fairness in representing viewpoints of the participants, ontological understanding by the participants of their social position, education in relation to others’ viewpoints, as a catalyst to promote action to change circumstances and empowerment to take this action (Bryman, 2008). In relation to this study, it may help to promote understanding of influences on the quality of life for this group of participants, both for themselves, and for the wider academic community, which may be achieved with publication of findings. It may also promote further research in the area, which may galvanise action for change to improve the standard, and therefore affect the quality of life for people with disabilities in the long term.

3.10 Ethical Considerations

Ethical approval for this study was granted by the Research Ethical Approval Committee at School of Social Work and Social Policy, Trinity College Dublin. Participants were provided with written information sheets about the study and their entitlements as their research participants, a consent form was attached to the information sheets, which the participants were asked to sign and return to the researcher prior to the interview. Participants were asked to choose a first name pseudonym for themselves prior to the interview and sign the consent form using the pseudonym. After a deliberation period they had contacted the
researcher to take part in the study and consented to this in writing. Confidentiality measures were upheld by using pseudonyms throughout data collection, data records, storage of anonymised transcriptions and audio files in a password-protected file on the researcher’s private computer and hard copies of the consent forms are stored in a locked, fireproof cabinet.

3.11 Conclusion

Thus, using a qualitative approach, informed by grounded theory research design, this study was well placed to engage a small sample of participants in an exploratory, subjective discussion about what they hold to mean quality of life, from an inductive, interactionist and positivist theoretical perspective.
4. Findings

4.1 Introduction

This chapter provides a detailed description of themes or categories, which emerged from the data following multiple step analysis. Following categorisation, the themes were structured into a model, which was used to illustrate the overview of the themes and their components as three categories and the interactive nature of their relationship, as well as their influence on the concepts of identity and quality of life.

4.2 Emergence of new model of quality of life

Following data collection and analysis, which ran concurrently, several themes or categories identified by the participants, emerged as influential or holding a particular meaning to them in relation to their quality of life. These categories were constructed into a model, which contains interrelated components, which is presented in Figure 1 overleaf.
4.3 Structure of the model

Three broad categories were formed by grouping common meanings reported by the participants of this study about the person (themselves) and their personal characteristics, participation in productive occupations, such as work, study or activism, within the context of the society or environment (physical and social). The three categories have a reciprocal relationship with each other, facilitated or inhibited by a range of influences, which can be the components within the categories themselves (for example, access to buildings or information, service provisions, such as Personal Assistant (PA) service). All of the components within the categories, and thus, the categories themselves, contribute the
concept of personal identity for the participants, and together they form their personal influences and meanings of their quality of life.

4.3.1 Person

The person category reflects broad individual characteristics, identified by the participants. They all spoke of the current level of independence, both in a broad sense of living independently, and in relation to personal mobility. This was at times compared with past level of independence, in particular if some of the participants had experienced a change, such as transition to a wheelchair from walking, which have had an effect on perception of own abilities, and self-esteem. For example, John, a 45 year old man with a physical disability described transitioning from using the crutches to using the wheelchair seven years ago as negatively impacting on his quality of life due to decreased socialising with friends as a result of fear of limited or impossible access to local pubs, anxiety about ‘accidents’ with his urostomy bag in the case that wheelchair toilets were not accessible and wheelchair accessible taxis not stopping for him: “...it's a totally different ballgame to walking and it's... people see you differently than like friends and stuff”. He explained how such experiences have affected him emotionally: “You get that depression, you feel inferior, you know”.

Katie, a 37 year old woman, who became a wheelchair user several years ago as her physical disability progressed. She spoke of her own self-esteem being affected as a result of her doctors’ decision to advise her to use the wheelchair permanently to ensure safety in her mobility:
“My own doctor said to me I’m a danger – ‘Your legs, you’ll break your arms. You have to think, you have to think about this NOW’. You know. So (inaudible) it depressed me, it really depressed me, it really.. because, you know... ehm like when doctors were making this decision for me and.. you know?”

Such decisions have the potential to impact greatly on a person’s self-esteem, and in addition, others’ perceptions also have an effect on the person’s identity.

John provided an example about others’ perceptions of him in the chair, which he reported were not existent when he was using crutches for mobility, such as this encounter with a mother’s acquaintance:

“I was going down the road with the mother, in the power chair and "How’s John doing?" you know, "Haven’t seen John in ages"... "I’m sitting in the bloody wheelchair" and your one’s talking to my mother and little John was looking up: "I’m down here, talk to me, ask me how I’m doing!"”
A similar experience of others’ mistaken perceptions was somewhat echoed by another wheelchair user, Mary (32), who spoke of her experience in her job, where she holds a senior role, with non-disabled people carers:

“‘And the carers can say: ‘Oh, you’re here for the day, isn’t that lovely?’ [Mary:] ‘Ah yeah, it should be a good day for the residents’ [Carers:] ‘Oh, so you’re not a resident?’ [Mary:] ‘No, I’m working here’ [Carers:] ‘Oh God! Sorry’”

She saw such instances from a different perspective, as an opportunity to educate people about the possible abilities and roles of people with disabilities: “But it’s good, because, again, you’re changing perspectives, because you’re sitting down that you can’t be as equally in authority as people that are standing up”.

On the contrary, Jack (30), also a wheelchair user spoke about his entirely positive experiences of using a wheelchair in public, both in Ireland and when travelling abroad:

“I find people very, very nice, like I haven’t come across anyone that’s like, that’s looked disapprovingly or…hasn’t treated me well because of the wheelchair, everyone treats me extremely well. Em, like, to random strangers, to everyone, really.”
Another participant, Jane (37) who has a neurological condition but does not use a wheelchair, recalled one of the instances, when she was treated and regarded differently, because of her appearance on an airplane flight:

“I was going over to Paris, and we wanted a seat in the emergency isle, front row, and I sat down, she [air hostess] said “you can’t sit there,” so I went down and I- I came back up and said “why can’t I sit there” –[...] I just felt, you know, that, they looked at me, thought that I was a person with a disability, that I couldn’t sit in the emergency seats and they made a judgement but, you know, you could be somebody who has a weak arm, who won’t be able to open the emergency isle seats. But they’re not going to stop you ‘cause the way that you, you look, you know what I mean?”

However, Jane concluded that this kind of ‘judgment’ was very rare, in fact she only felt that she was different for the first time at 11 years of age, when her appearance was pointed out to her by a boy at a school dance. Everything about Jane’s upbringing, including school, college, social circles, was, as she describes, ‘normal’. Her attitude towards people noticing her disability could be described as laid back, as it does not affect her quality of day-to-day life: “Sometimes people just look at you because, the moment I open my mouth people notice a difference, and they notice the, [appearance], but you get to a stage in life where
you, sort of you get over it, you know what I mean”. Having a philosophical or positive outlook may be an important contributing factor to the overall perception of such experiences. Being perceived by others negatively or positively, was one of the components of the society/environment category that together through interaction with the person’s perception of self can impact on the person’s identity.

Further in his interview, Jack discussed his personality and outlook, as perceived by others and him:

“My brother tends to say it to me quite a lot..he says that my attitude is great... in the last ten years, there’s been such change, and I’ve take it all in my stride, like yeah, it’s annoying, but em..it’s kind of one of these things you have to either get on with it or..”

While this kind of coping attitude may not come as naturally to John, who has reported that he has had mental health difficulties, in particular depression, in the past, since the breakdown of his engagement and relationship, which led him to avoid future relationships and limited his socialising, in particular, other romantic relationships: “I stayed in my room for years and years and years, almost nine years and I used to only come out for mealtimes” (John). It was not until he made a decision to move out, he was able to regain interest in life, however, he is cautious about striking up a deep friendship or a romantic relationship as “I still have this depression, and if I get too close to somebody...’cause people come and go,
people change, people get married, move on, whatever. And that’s a big problem with me, because when I was a child, that happened a lot” (John).

Katie expressed her sadness at the loss of her ability to walk and loss of independence due to the progressive nature of her condition, which necessitated her to become a wheelchair user:

“That frustrates me, I just hate doing that because I loved my own. I loved my own independence, and ehm, I, ehm, you know, I was able to do everything. It would be different, now, it would be different, if... if I was born in a wheelchair. [...]

But, the fact that I know what it was like when I was walking... it really hurts, you know?”

However, she is coming to terms with her new identity as a wheelchair user and has taken on an active role in campaigning for wheelchair access in her local area, as discussed later in this chapter.

Finally, being in a romantic relationship was one of the important aspects of two (female) participants’ lives. Jane told the researcher that her and her boyfriend would like to get married some day, after financial and living circumstances are decided. And Katie, who has been married for two years, also spoke about the progressive nature of her disability and her concern about her husband taking on caring for her in the future, as her next of kin: “My
husband might, just, might have to wash me, might have to dress me, might have to change me, might have to feed me. Might have to talk for me.” In her marriage, Katie’s husband took on the caring role, which was previously fulfilled by her parents when she lived in parental home.

When the male participants spoke about romantic relationships, John said: “I’d love to be married and have children but it’s not gonna happen, so you just get on with it” and expressed a wish for a companion instead – someone “to laugh with, to joke with”. He described his nephews and nieces as “..[they are] my children too”; Jack had a similar opinion about children in his family: “I have my nephews and my niece, and I see them a good bit, so yeah, it’s like I’ve got my fair share of kids!”, he acknowledged that if he were to have children, it would place a lot of responsibility on his partner. Thus, it was male participants and two female participants, who spoke about sexuality and relationships as part of their being, whether in relation to past, present or possible future relationships or in terms of having children.

4.3.2 Participation

This was a very large area of the reported meanings of QOL, as all participants were able to identify with participating in meaningful occupations, such as employment or education, in daily life. Frequently, there was some blurring of the roles, particularly between socialising and work, as several people reported that their work colleagues were a part of their social circle. Family relationships were among key features in this category, as one of the most commonly reported roles were those as an immediate family member – a son or daughter, a
sibling, an aunt or an uncle and for two of the female participants, also a wife and a girlfriend. All the participants reported that most of their families, in particularly, parents, were supportive of them and their life choices throughout their lives - when moving out of the family home, attending a new project, starting a new job, as well as being a constant source of support in everyday activities, facilitating fulfilment of the chosen roles, like walking the daughter to her Luas stop every day as part of her journey to work, to provide her with physical stability to aid her mobility. John spoke of his mother as having to ‘fight’ for services for her son when he was a child, as his QOL was her priority:

“When I was a child, the mother would have to go from a Social Worker to a Social Worker; she’d have to fight to get me, just like, callipers or boots, or even bags, nappies, anything! Some sort of...to improve MY quality of life, you know that kind of way?”

He reflected that to fight became his role as he progressed into adulthood, as he now continues his mother’s role of fighting for service provision, in particular PA service.

Friendship was another area cited by all participants, which was equally important to them and had a great influence on the overall identity and quality of life. As Jack described the importance of friends beyond socialising, but also as a support network to facilitate him to overcome barriers posed by limited access to transport or public places in the physical environment:
“My friends...constantly say if I ever want anything, no problem in giving a shout, and there was one incident where I was actually stuck out in Slane a few years ago. I rang this guy and he was out drinking so he couldn’t come get me so he rang another guy, and your man came to collect me and it was just that whole aspect of friends and, it’s great to have them and be able to rely on them.”

As well as being helpful, friends were credited with providing the motivation needed to make a life changing decision, and improve a person’s QOL through increased independence, such as moving out of the family home: “And my two friends, who are OT’s when I first started the job ENCOURAGED me to move out of the family home and go on, on your own, you know, get your independence back, because I just had everything handed to me [at home]” (John).

Work colleagues, were described by several people as friends, either as a main group of friends or an additional circle of friends. For John, who was encouraged to move out of his family home, his work colleagues became his main group of friends when he started a new job and he replaced his old friends or acquaintances, who he felt were a negative influence on him, with a supportive circle of friends. Similarly, for other participants, one of whom works in a community organisation, and another participant, who attends a training centre, work friends or student friends make up their main social circle.
Mary, who works with non-disabled people in a community non-governmental organisation, spoke about the difficulty that is forming lasting friendships for people with disabilities: “because most friends want to go to the cinema or going out to a club, or whatever. And if you’re living with a disability you mightn’t be able to get [there]”. However, she emphasised that her main group of friends, made up of colleagues with whom she has worked for over several years:

“really changed..the quality of life, because, like, it was the first people I went to a nightclub with. What I love about [the job] is there’s no real ‘Oh we have Mary in the chair, and Joe Bloggs in the chair, it’s just..yeah, we’re all going and that’s the end of it’. [..] You’re just one of the gang, you know”.

Spontaneous socialising with friends has become part of her life: “..now it’s the norm for me to say: ‘Oh, we’re going to the pub’, but two, three years ago it wouldn’t have been the norm, ‘cause I wouldn’t have had that circle of friends”.

Another participant, Charlie, 23, spoke about her circle of friends in the training centre for people with disabilities that she attends, some of whom she has known since attending a special school, and all of whom attend her respite centre: “I have a best friend, we’ve been friends for 14 years. I meet her every day, she’s in the same respite centre as me. [..] if we go into respite, we go together”. Charlie spoke about the social opportunities presented by
respite services and training centre, like socials and outings; she also stated that as another
training centre uses the same respite facility, it was also a way of meeting new people, as
was joining community organisations and clubs also through friends.

For other participants, like Jack and Jane, who attended mainstream primary, secondary
education and went on to third level universities, before gaining employment, their work
colleagues are one part of several groups of friends, adding to the existing childhood and
college friends:

“Em.. I suppose it’s kind of groups of friends, I’d have,
let’s say I’ve my group that I know from home, then I
have another group, that’d be my college friends, then
I’d have another group that I have that are made up of
people from home, that went to the same college as
me, then my work friends.”

They appeared to have a multi-layered network of friends from different social
environments, which provide supports to facilitate socialisation and thus, participation.

While all of the participants participated in productive occupations, either as a worker or as
a student (past, present or future), some spoke about their roles of disability activists of
sorts, which went beyond their usual occupational roles. Katie, 37, a wheelchair user,
discussed the struggles she faced in everyday life getting around her local area and the steps
she took to address this challenge: “I was very frustrated that it wasn’t accessible. I, actually,
took to ring people, and eh..I was in touch with, [local authorities] and I had to actually meet [local representatives], go around [the town] in my wheelchair up and down steps with [them]”.

While changing the physical environment is vital for all the members of the community, one of the participants, Mary felt passionately about changing people’s perspectives on disability, which she saw as her unofficial role, while being in a senior role as part of her job in a community organisation:

“..my role is to change perspectives, ‘cause the people that come down and they’re like: ‘Ah, yeah! Give them [the participants] a ground auld holiday!’ and it is a holiday..but there’s more psychological benefits that there would be physical benefits”

Mary also spoke about supporting the participants with disabilities challenging themselves by participating in the activities they may never had the opportunity to do before, like rock climbing:

“[the participant] would be quite similar to me, but absolutely terrified of going up a wall and I was like: ‘Ah, give it a bash there! We’re not going to be here again. If I
can do it, you can do it’ and because I’m so used to the equipment that they use for going up the wall, I always tell the person: ‘It’s just like being in a hoist. If you’re secure in a hoist – you’re secure going up a wall’.”

For other participants, raising awareness or education others about disability, was at the familial level, as Jack described educating his nephews and niece about his disability:

“..they ask questions, the odd time, but they’re totally accepting, like my oldest nephew, he’s ten..the second he saw me in a wheelchair, he said: ‘Daddy, can I get one of them?’ and I’m like: ‘mm-kay’”.

Children in the immediate and extended family were reported to be generally accepting of their relatives with physical disabilities, and the participants, for whom this was the case, expressed their hope that as they grow up, these children will continue to be accepting and understanding of disability when they reach adulthood.

4.3.3 Society/Environment

This category holds components, which participants have identified as impacting on their everyday life in a variety of ways. Access was a particularly key area, which affected
participation, mainly socialising, mentioned previously, which all of the participants with reduced mobility, in particular wheelchair users, identified with very strongly.

Anne, a 27 year old woman with reduced mobility, and is able to walk, spoke about what her quality of life would be like, if access was not an issue: “it would mean I could live like everyone else lives, I could go out and socialise, not be limited to what I can do or where I could go”. She described that she relies on her father to walk her to the Luas stop every day to go to work and back, due to poor quality of paths in her area. Her main concern was the access to infrastructure of the paths and roads outside of buildings: “I think the shops and places inside like shops and things like that they’re OK. But outside is not so good. So I think the people should improve the outsides of buildings.” These issues are more important for wheelchair users, who require the physical structures, like ramps and slopes in place to provide access to the environment. In addition, limiting access also affects participation and person categories, as the participants have reported not being able to access pubs or other premises to socialise with friends, accessible toilets that are not, in fact, accessible, or buses that will not have enough turnaround space for a larger powered chair.

Mary also raised an important point, which she considers among the key quality of life issues, which is related to personal dignity – wheelchair users having to resort to using incontinence sheets due to lack of accessible toilet facilities or for safety reasons, which were identified by the service provider: “And then they’re saying, ‘Ah, yeah, but it’s to do with your quality’, it’s NOT, if you’re asking me to go back into pads at 32 to suit the employer, you know”. In addition, she mentioned that she was told that a person with a disability is entitled to three pads a day, which she described as ‘inhumane’ and argued
further, that “if a baby was left in a pad for 8-10 hours, the parent would, quite rightly, be up for neglect!”.

In relation to service provision and entitlements, both Mary and John identified the need for a PA services for people with physical disabilities to suit the needs they may have and facilitate independence in a chosen area. Mary has access to a PA service, and John is on a two-year waiting list for a PA. Mary advocated very strongly for a need for PA provided at 16 years of age, at the time of early importance social development and participation, and that it ultimately “does improve the quality of life for EVERYBODY, because there is people earning employment, you are more in control of what’s going on.” She emphasised that PA services promote a person’s quality of life:

“It’s all about what they’ve done for their 30 or 40 years. It’s not the length of time they got to stay on the earth it’s what they done in them times. So that’s a REALLY big part of why I think for ALL people with disabilities it should be have a right to have a PA”.

John spoke about being on a waiting list for a PA as he required assistance with some areas like washing, ensuring safety in the shower, dressing, getting ready for work, as it currently takes him around two hours to get ready for work in the mornings. He said: “If I got those little bits of hand..help with the things that I need, that are very, very small , I would have more energy to do a lot more things, you know? And even just...I wouldn’t be so tired all the
time”. Increased energy and independence would mean an improvement in his quality of life, similarly to what Mary has reported, “So that has REALLY helped like every aspects of my..quality of life has REALLY increased because I now feel as though I can do stuff I couldn’t necessarily do before, like, do you know?”. She also added that having a PA decreases a person with disability having to rely on the family for assistance in everyday things, like travel, dressing, help around the house, which also impacts on the family’s quality of life. This is a point that can apply to others like Anne, whose father provides assistance to get to work by walking her to the Luas stop every morning; Charlie, who also relies on physical support of her family members when going socialising with friends and help from family in everyday things at home, and Katie, who spoke about her and her husband receiving personal care, which, due to staff shortages, can mean that she may have to wait up to 30 minutes to use the toilet with care assistance. PA service was reported a key provision in improving a person’s independence for participants of this study.

Transport was another area that participants spoke about that enhanced their sense of independence and freedom in getting around. Jack spoke about the value of being able to drive his automatic car in getting to different places, like work, cinema: “. the car makes things a lot easier, getting around, like little things like going to the shop”, “the car is a big thing being able to get around”. Mary, whose PA drives her car, spoke about its importance:

“I think the car is as equally important as my chair, ‘cause without that I can’t go anywhere. (Reseacher: ‘Yeah’) You know, you can be in your lovely house or your lovely apartment but you can’t access school or work. You know?
And there’s only so much telly and internet you can do in any one given day. And believe me, I’ve a lot of books, and having a car affects the quality of my life.”

Anne, who was learning to drive at the time of the interview, also recognised the freedom that driving would give her in her everyday life: “That would mean that I could go wherever I want to and I wouldn’t have to sit and wait and think of how I’m going to get down there and how I’m gonna get back...yeah.”

John, who uses accessible community transport company for his travel needs to work and outside of work, which he described as “God’s gift”. Katie spoke about considering buying a family car, which her husband would drive, which would enhance their ability to get from A to B without having to rely on the service’s transport or be affected by staff shortages.

Such supports and provisions were reported by the participants to have a great effect on their independence in everyday life, they facilitate participation in meaningful occupations and add to the personal sense of self-worth, which impacts positively on the overall quality of life for this group of people.

4.4 Conclusion

The above findings illustrate the personal meanings and influences on the quality of life for this group of people with physical disabilities, as reported by them. The model in Fig. 1 was
used to illustrate the relationship between the categories and their components, as identified by the participants.
5. Discussion

5.1 Introduction

Having described the findings of the study and illustrated them in a model of quality of life, this chapter will take a closer look at the themes, in relation to the literature discussed in earlier and attempt to interpret the findings. A review of the research question and it was sufficiently answered by the findings will be provided. Finally, a reflection on the learning arising from this research project will conclude this chapter.

5.2 Use of a qualitative approach

This was preliminary study with the aim of exploring personal meanings, interpretations and influences on the quality of life for a sample of Irish people with physical disabilities. The study used a qualitative approach, guided by grounded theory design, to elicit detailed and personal interpretations of what QOL may hold for the participants. This was a departure from the apparently dominant approach used by medical and allied health professions, who design their research around a health-related QOL with clients using survey design or a mixed methods approach.

5.3 Models of quality of life

The findings of this study were grouped into three categories for the purpose of illustration using a model, which was informed by existing structures, such as a multidimensional framework discussed by Felce and Perry (1997, as cited in Brown). This framework focuses
on the concept of QOL, as influenced by personal values, in turn influenced by several areas of personal well-being (physical, material, social, emotional and productive), which are under the influence of both objective and subjective assessments of life conditions and satisfaction (Felce and Perry, 1997, as cited in Brown). This was represented as a hierarchical structure with QOL being the outcome of all the other categories, however, the others make a point about the interconnectedness of the objective, subjective assessment and satisfaction with QOL with personal values, with any one dimension potentially affecting the others.

Another model of quality of life for people with disabilities, proposed by Parmenter, 1988 (as cited in Brown 1997) had the person or personal identity, or self, in an interactive relationship with societal influences and functional behaviours, with the overall theoretical underpinnings of symbolic interactionism (Parmenter & Donnelly, as cited in Brown, 1997). The model in this study was largely informed by Parmenter’s model, in particularly its interactionist nature and emphasis placed on the subjective components within the functional behaviours and self categories, in particular. The sub categories or components of the model in this study emerged from the data, and it can be seen that they fall within the sub categories proposed by both theoretical structures in the literature, and as such are confirmed as relevant to the overall concept of QOL, even as a small-scale, purposive sample study.
5.4 Comparison with existing studies

When compared to other empirical research, this study’s findings revealed that its participants’ meanings and influences on their QOL are generally similar to participants in other studies, as their identified areas of friends and family, socialising, work, access and supports and provisions echoed the findings by Montazeri et al. (1996) and Murphy et al. (2009). However, there was much less emphasis placed by participants of this study on health, financial security or age-related areas, which were among the key themes in findings in the above studies. A possible explanation for this may be the fact that this small-scale qualitative study used an open, lightly structured interview approach to gathering data, rather than scales to measure QOL, as used by Montazeri et al. (1996) and there were no older adults in this small sample, whereas the focus of the study conducted by Murphy et al. (2009) interviewed the sample population of older adults.

Another finding of this study, the references to previous experiences of walking and using crutches for mobility in comparison to current experiences of using a wheelchair were made by three of the participants, who underwent the transition to using the wheelchair. Two of participants described having a better quality of life, related to being more independent in their mobility and personal care, as well as access and therefore socialising were not issues when they were walking or using crutches, which is in some accordance with the findings by Boland et al (2009) of their sample of people with physical disabilities reporting a poorer quality of life, as related to reduced functioning and anxiety in relation to this.

While this study took the grounded theory approach of allowing the theory to emerge from the data, thus allowing the participants to dictate the discussion on their personal meanings and influences on their quality of life, the findings had resonated with those of Albrecht and
Devlieger’s (1999), who addressed a very similar question on the factors of QOL for people with disabilities with a large sample of participants, using a specific theoretical model (Antonovsky’s coherence model). One of the discrepancies, which may be attributed to the lightly structured style of interviewing or a general model structure in the study, the participants reported both positive and negative experiences and attributes of their QOL in everyday life. For example, John, while describing being happy and overall reporting a good QOL, which he attributed to his living situation and social supports, also reported underlying depression, decreased mobility and fatigue. Sense of control over one’s body, living in a supportive social world and having a sense of ‘can do’ attitude was also seen in the responses of the participants, as Jack spoke about his sense of freedom from driving a car, reducing barriers of access in his environment by having a layered and extremely supportive social network of friends and family. It was observed that as Jack and Jane both attended schools and universities and work in the environment where they are the only disabled people, they had built a strong and lasting network of school, college and work friends, which remains their core social network, while other people with disabilities are considered as acquaintances. Whereas, John, Katie and Charlie, who have attended special schools, work or attend training, or live in social environments whose main purpose is to support people with disabilities, their social supports outside of the disability aimed environments consist mainly of family, as the rest of their lives exist within the disability aimed environment, which may be limiting the extent of their overall involvement and impact they could have on the greater society.
5.5 Limitations of the study

Thus, this study attempted to explore the concept of quality of life, its meaning, implications and influences for a small group of adults with physical disabilities. While it has limitations in terms of its transferability due to small purposive sample, it fulfilled its purpose in being a stepping stone to further qualitative research, at the core of which, are people’s own view and perspectives on disability, whereby they themselves ascribe personal meanings and values on their quality of life.

5.6 Conclusion

This study attempted to contribute to the greater body of literature on the topic of subjective QOL for people with disabilities in Ireland by exploring personal meanings and influences of QOL for a small sample of adults with physical disabilities. Findings suggested that these meanings and influences for the participants of the study can be compared with the findings of existing empirical studies, and have common themes, such as personal control, positive outlook or a ‘can do’ attitude, as well as other areas outside of personal control, such as access, which can be impacted on by social support networks, consisting of family and friends.
6. Conclusion

6.1 Introduction

This study was conducted as part of a MSc. in Disability Studies and was chosen by the researcher, who identified a need for an exploratory, preliminary study to be carried out in the field of quality of life for people with disabilities in Ireland. The findings were consistent with some of the existing empirical studies, however it must be noted that due to the nature of sampling technique and the sample size, this study’s findings are only illustrative of the personal viewpoints of QOL of its participants.

6.2 Reflective summary of the learning process

Throughout the process of conducting the study, including the preliminary preparations, data collection and analysis and its writing up into a dissertation, the researcher has progressed through a personal learning journey. The challenge of extracting the most of the project, from participant interviews, analysis of themes, selection of research design and methods has been not an easy, yet a rewarding one. Much personal reflection, discussion in supervision of the appropriate approach to answer a research question, which itself underwent further specification and re-focusing, has assisted in this task.

Keeping a research journal for reflection during the data collection, to note the seemingly insignificant, yet influential details, such as the environmental and personal circumstances of the interviews, together with researcher’s own aims, hopes and biases, has been found quite beneficial during the data analysis stage. Memo writing, which served a similar
purpose during higher levels of data analysis, had continued to uphold the reflective purpose of the journal in the latter stages of the study.

The time constraints of this project proved to be more challenging than expected, as concurrent data collection and analysis took place within three weeks’ time, with the most time consuming parts being the transcription of the raw data and the coding using the constant comparative analysis. However, this ensured that the content was quite familiar to the researcher, which facilitated the writing up of the dissertation in a much more efficient and effective manner.

Finally, due to the specific nature of the research question, searching for the appropriately suitable background literature for the literature review, including available empirical research as well as the literature discussing the research design was more time consuming than expected.

However, having completed the review of evidence, data collection and analysis, the study was written up in a format, consistent with university requirements, which required ongoing revision to reflect the work that was done by the researcher and acknowledging the vital role of the participants. Here, the final challenge was to present the study in a way, which illustrated the importance of such study in today’s society.

6.3 Implications for future research

This study has provided an answer to the question it posed at the beginning, which aimed to explore personal meanings held by a small sample of Irish adults with physical disabilities about their QOL. It aimed to frame the answer in a format of a model and thus, provide a
stepping stone for further research in the area of subjective view of QOL for people with physical disabilities in Ireland.

Many more questions may arise from this piece of research, all of which can provide answers and a fragment of the complex concept of QOL from the personal and subjective point of view, which needs to be highlighted just as relevant as the dominant professional concept of health-related QOL in existing research. Literature suggests that a balanced viewpoint, encompassing both subjective and objective elements of QOL is needed to inform policy making and service provision.

6.4 Conclusion

This study illustrates the importance of further exploration of the concept of QOL, particularly in the light of upcoming changes in the Irish policy and practice as relevant to service provision for people with disabilities, such as direct payments, an increase of the independent living philosophy, guiding centres for independent living, as well as other services providers. Providing a subjective viewpoint using a qualitative, semi- or unstructured approach allows people with disabilities a common voice and freedom to explore what having a good QOL means to them and what they need to achieve it. This is consistent with the social model of disability and disability rights, which underpin our societal values.
REFERENCES


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APPENDICES

Appendix 1

Interview Guide

1. What constitutes ‘being well’ or having a ‘good quality of life’ to the participant?

2. How does the participant evaluate his/her life (quality of life) to be in general? How satisfied is he/she with his/her life at present?
   a. Past experiences
   b. Personality
   c. Knowledge

3. What are the influences to having a good quality of life or being well? *(They may emerge as the areas below are explored in more detail)*

4. How does the participant describe their physical, mental and emotional health?

5. How would he/she describe himself/herself in comparison to others (in the same situation)?

6. Living arrangements - Physical environment – home, community, getting out and about, getting things done

7. Social environment and supports – family, relationships, friendships, wider community groups (work, leisure, spirituality)

8. Participation in education, employment or leisure

9. Financial situation/economic status

10. What is important to the participant in his/her life? Values.
Appendix 2

Information Sheet and Consent Form

About the researcher:

My name is Sue Kraftsoff, I am an MSc student studying Disability Studies at Trinity College Dublin. I work in the area of disability as an Occupational therapist and I am interested in researching the experiences of people with disabilities, particularly people with physical disabilities. I wish to explore understanding of the people’s personal understandings and experiences of quality of life. This study is part of dissertation for the Masters in Disability Studies course in Trinity College Dublin.

About this study:

There is little research done about people with disabilities and their opinions on their quality of life, particularly in Ireland. I would like to explore this area further and give voice to you, as a group of people with disabilities living in Ireland, to tell your story and talk about what you think are important influences on the quality of your lives. If you allow me, I would like to share this information with policy makers and service providers, through publication of an academic paper or sharing the results of the study. If you would like to participate in this study, you will be given an opportunity to review your direct quotations from the interview that are used in the final draft of the study to ensure they reflect the intended meaning. This study will try to encourage discussion about the quality of life in general and relevant topics, which may include health, employment, standard of living, relationships, and others.
**Participating in the study:**

I hope to find out about your opinions on the quality of your life and related issues through one-to-one interviews in person, which would last about an hour to an hour and a half. I will be recording the interviews digitally.

I will ask you for your permission to contact you by telephone or email after the interviews if I need to clarify anything you have told me. If you decide to participate in this study I will ask you to let me know by X (at least one week for considering participation will be given).

**Confidentiality:**

Before the interviews I will ask you to pick a name for yourself to protect your identity and use that name throughout the interview. I will use the name you choose to store any information you will have provided, such as responses from the interviews and when publishing the findings of the study. Any information about you will be accessible only to me in a password protected file on my computer.

**Risks and Benefits:**

Due to the sensitive nature of the topic, exploring personal experiences of living with disability, you may experience anxiety, distress or discomfort when asked questions about your personal experiences. You may choose not to answer these questions. I will provide information about available support agencies should you wish to access such services for support.

By participating in the study, you will be contributing to the understanding of experiences of living with disability in Ireland and influences on the quality of life.
Participants’ entitlement

It is your right as a research participant to withdraw from the study at any time, or withdraw any information previously provided or omit responses without penalty.

You will be asked to verify you responses when provided with a written draft of the findings with direct quotes and responses, and you can request to change the responses if you so wish.

You will be given copies of your responses, as recorded, on request.

If you have any further questions about participating in the study, please contact me at kraftss@tcd.ie or on 086 1275521.

If you would like to participate in the study, you will be asked to sign the consent form below before the interview.

CONSENT FORM

By signing this consent form, I acknowledge that I consent to the following:

- I am over 18 years of age
- I was provided with information about the study and an opportunity to ask questions and find out more about the study and can contact the researcher if I need more information
- I am aware that I can withdraw from the study at any time, withdraw or amend any provided information and I will be given an opportunity to do so when I am provided with a final written draft of the findings, containing direct quotes and responses
- I am aware that I can access the information about me at any time under the Freedom of Information Act
- I can request to keep a signed copy of this form for my records

By signing this consent form, you indicate that you are voluntarily choosing to take part in this research.

___________________  __________
Signature of Participant   Date

(Pseudonym)