ACCEPTING WHEELCHAIR USE

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Introduction

Wheelchair use takes many forms. A wheelchair may replace walking for a temporary period following an injury that quickly heals. This would be called full time, temporary wheelchair use. Permanent wheelchair use might be an elderly person who finds walking out of doors is no longer safe and uses a chair always when out of doors, however, not indoors. This is part-time, permanent wheelchair use. For others, who have never walked or who lost the ability, wheelchair use is permanent and full time. This research explored the experiences of a group of people who are all full time, permanent wheelchair users. It was prompted by my occupational involvement with wheelchair users over more than thirty years of practice as a physiotherapist mainly concerned with rehabilitation and latterly working in the NHS wheelchair service.

Summary

Statutory wheelchair provision in England and Wales has been equipment led since its inception in 1990. However, users are reported to be dissatisfied with the service and a reorganisation of provision is underway that purports, in accordance with recent Government advice (DOH, 2012), to make the wheelchair user central to the supply process. However, little is known about wheelchair users perspectives of the equipment that they use to inform this process.

This study seeks to enter the world of permanent, full time wheelchair users, exploring their perspectives on their wheelchair; how these were formed and what affected their attitude towards the mobility equipment that they used. A theoretical model of accepting wheelchair use was developed out of the data to explain the social process that the participants described.

Adopting an interpretivist perspective and a theoretical framework based on symbolic interactionism a group of ten permanent, full time wheelchair users were interviewed. These took the form of unstructured one to two hour, in-depth conversations with the participants about their experience of wheelchair use. The first four participants were selected by purposive sampling. This sampling method is reported to increase the significance of the findings even in small samples (Merriam, 2001). Following this, data analysis informed theoretical sampling of six further participants to maximise variation in cases. Digital audio-recordings were made of each interview and transcribed.

Dimensional Analysis, a second generation (Morse et al, 2009) method of grounding theory in the data, was then applied. All of the dimensions of the texts were identified and analysed. Using constant comparative method shared patterns of behaviour were recognised and further analysis enabled an understanding of the social process of being a wheelchair user to be constructed.

Participants were understood to fall into one of a number of groups who had different approaches to wheelchair use. The first group were those who were lifelong wheelchair users. They had not experienced change in their abilities having never walked and their attitude to wheelchair mobility was formed on the basis of a consistent approach to equipment use. The second group had become wheelchair users later in life, having walked for some period.

Analysis revealed that the perspective of the user, on adopting wheeled mobility, affected their attitude to wheelchair use and ultimately their level of independence. For those who acquired their disabilities later in life, engagement in the process of becoming a wheelchair user was essential for them to form a new understanding of themselves from the standpoint of their altered mobility. This process was conceptualised as a transition from walker to wheelchair user and this was considered to comprise a number of stages. These were becoming, embracing and being. The participants were at different places in the process and the reasons for this were explored. A number of pre-existing contextual and biographical features affected each participant's response to wheelchair use. These and other factors moderated the process of change for each individual. Maximum independence was determined to be achieved when the participant embraced the wheelchair into their lifestyle, irrespective of their level of disability. This required that they made practical, psychological and emotional changes in their lives.

This study was timely in the light of the latest proposal to reorganise wheelchair provision. The findings show that the majority of wheelchair users are able to assess their needs and access the wheelchair that they require, having undergone rehabilitation or special schooling. These users have developed a lifestyle as wheelchair users. However, there are a number who come later to wheelchair use and are not offered specialist training. For them, transition into being a wheelchair user may never be completed and they make concessions to their disabilities that result in increasing social isolation and dependency. Further work is required to determine the best way of identifying these individuals and providing support.

The individual's reaction to becoming a wheelchair user has been explored and a theory of phased transition to acceptance identified. The contribution that this study makes to our understanding of accepting wheelchair use may assist in shaping therapists' approach to wheelchair assessment, provision and skills training.

Synopsis

The following synopsis provides a chapter by chapter guide to the full thesis which is available for download at https://cris.brighton.ac.uk/ws/portalfiles/portal/4759415/ACCEPTINGWHEELCHAIRUSE-LINDAWALKER-27MARCH2014.pdf.

Chapter 1: Background and context

This chapter describes the motivation for this study and outlines the context by introducing the wheelchair and the changing pattern of its provision over the last century in England and Wales. Once statutory provision was established for all citizens through the Department of Health and Social Security wheelchair users began to express concerns about the chairs that were supplied. The chapter explains why in order to address this criticism the role of statutory provider was transferred to the NHS, and the expectations that accompanied this change.

Within the context of the NHS, the wheelchair is identified as a piece of medical equipment and delivered in such a manner. The use of an outcome measure was thought to be required following two reports from the Audit Commission (2000, 2003) in which it was reported that user satisfaction with the service and the wheelchairs supplied was poor. This prompted a search for an outcome measure to record wheelchair user's satisfaction with the equipment that was supplied. However, more recent Government initiates have moved the emphasis away from managerialism in the NHS to patient centred initiatives being implemented to offer choice and involvement in their own care (DOH, 2006; 2009; 2010; 2011; 2012).

The wheelchair has become more than purely functional: a piece of equipment that facilitates movement for those who cannot walk. It is now perceived in many different ways which are explored through the stories of three individuals.

Whilst the search for an outcome measure continues the focus of concern has changed. Wheelchair provision services should be more responsive to the user's needs. The wheelchair is no longer understood as a medical device or a functional item to assist with task completion. Improvement in the equipment available and social attitudes mean that the wheelchair is now understood differently and an alternative more contemporary framework should be found for the wheelchair service in order to meet the demands of the present service users.

Chapter 2: Disability

This chapter presents the contextual background to the study. First the question of normality in our society is presented. In this context the historical and cultural changes in attitudes towards what constitutes disability are then discussed. The discourses on disability are offered to contextualise the experience of people with impairments in this society. The different models of disability are discussed. The wheelchair is understood as a universal symbol of disability; the implications of becoming a wheelchair user are explored in terms of biographical disruption and change, labelling and identity.

At the end of this chapter a research question would normally be set. However, this is not the case in the present study. In exploring the complexity of the contextual issues surrounding wheelchair use it became clear that to set a research question at the start of the research might limit all that was there from being revealed. The study was, therefore, designed to explore an area of interest, the experience of wheelchair use, in which there was a dearth of published research. By entering the field with no preconceptions I remained open to attending to all the concerns of the participants. This is a topical subject with reorganisation of statutory wheelchair provision in England and Wales presently being explored and so the study is timely. The suggestion is that wheelchair provision should be moved away from the NHS to social enterprise and the commercial sector. Understanding the service users' perspectives will be helpful in informing decisions about changes to the supply process.

Patient experience is a current issue following advice from the Department of Health (2012) and it is anticipated that the findings of this research will inform the debate when restructuring of supply processes are taking place by suggesting an alternative way of understanding wheelchair use. In understanding wheelchair use from an alternative perspective, those who are planning services may be able to improve the experience of wheelchair provision for the service users.

Chapter 3: Methodology

This chapter sets the research within the theoretical framework that guided the study. The decisions that were made with regards to methodology in relation to the area of interest of the research are explained. The data were collected and understood using a symbolic interactionist perspective (Blumer, 1969). Reality was considered as being formed in the minds of the participants of the study and developed through their experiences. The wheelchair was understood as having no innate meaning in itself. Each individual was thought to create a symbolic meaning through interaction with others. All perspectives expressed were of the moment informed by experience, time in history and culture and were subject to change. I joined the participants in their world and sitting beside them we co-constructed a shared understanding of their perspectives of wheelchair use.

A Classic Grounded Theory approach (Glaser and Strauss, 1967) to the research was considered most appropriate to provide the overarching theoretical framework for this study in that it allowed understanding to emerge from the participants' narratives. Since its inception, through repeated use worldwide, different variations of this classic approach have been developed. These were explored before the decision was made to use a second generation of this methodology (Morse et al, 2009), Dimensional Analysis (Schatzman, 1991). This methodology was selected as it provided a structured framework, akin to naturally learned decision making, for the novice researcher to follow. The chapter describes the stages of Dimensional Analysis and then compares some aspects of this research with Classic Grounded Theory Method.

Researcher bias is a factor in a study so closely related to the researcher's occupational area of interest. The chapter continues by exploring how strategies to ensure the trustworthiness and authenticity of this research were used.

Chapter 4: Methods

This chapter explains the decisions that were made regarding the design of the study, the researcher's relationship with the participants and their recruitment, data collection and analysis.

Ten permanent, fulltime wheelchair users took part in in-depth interviews with the researcher. These lasted from 1-2 hours and were wide ranging conversations that were led by the concerns of the participants. They took place at a time and venue of the participants choosing and were digitally recorded and transcribed on completion. They were initiated by the request,

Please tell me about your life as a wheelchair user?

Ethical issues relating to the research are addressed. This includes permission from Ethics Committees, the place of anonymity and consent in the research and strategies that were used to enhance auditability and demonstrate reliability to the reader of the thesis.

The chapter then explains how Dimensional Analysis was used in the study with examples of how the stages were implemented. An explanatory matrix emerged from the data and this was used as the foundation to the theory of accepting wheelchair use that is presented in Chapter 6. Finally, writing and theoretical sufficiency are addressed.

Chapter 5: Participant profiles

This chapter gives an overview of the participants of the study. It is intended as background information that will enable the reader to form their own impressions of the world of each of the participants. This was considered to be important in a study of this type that explored the perspectives of ten different wheelchair users. It also sets out the participants socio-biographical data collected at the start of my interactions with them presented as Tables that may be referred to and assist the reader when addressing the detailed findings that follow.

Chapter 6: Findings

This chapter presented the findings of the data analysis. Initially, the explanatory matrix of the social process formed from the dimensions that emerged is presented. The data were understood as describing a social process of accepting wheelchair use which is presented as a phased transition from walking to wheelchair use. The stages of this process are explained as becoming, embracing and being. Each stage is modified for the individual by their contextual conditions. The individual's level of independence and autonomy was found to be changed by their progress through the model that was developed.

The body of the chapter explains, using the participants own words, their experiences of wheelchair use. The participants presented not as one group of people who use wheelchairs for all of their mobility but in a number of different ways dependent upon how wheelchair use was adopted, naturally, suddenly or gradually. Their reaction to the onset of immobility and their adaptation to wheeled mobility is explored and supported by evidence from the interviews.

A number of different stages were identified that were required to be completed in order for the participant to accept wheelchair use. The understanding of these developed out of the narratives of those participants with lifelong conditions who had never walked and had accepted a wheelchair as a necessary part of their lives from an early age. This was developed into a process of transition which was used to compare and contrast the narratives of all of the other participants who had walked for a period of their lives.

It was the individual contextual factors of each participant that made their journey unique. However, successful completion of each stage in the process was found to facilitate wheelchair independence and acceptance. A change in the self-identity of the participant from walker to being a wheelchair user took place as the process unfolded. Those who were found to have fully embraced wheelchair use and adjusted their identity were able to form new life maps and to become independent, autonomous participants in society regardless of their level of disability.

Some of the literature, relating to acceptance of disability (Gibson, 2006), identity change in chronic illness (Allen and van de Vliert, 1984; Charmaz, 1987) and research with groups of elderly people with acquired disability (Barker et al, 2004) was included in this chapter. This illustrated how others had found similar evidence that was compared with the findings of this study and used to clarify how individual contextual factors changed the transitional process for individuals.

A theoretical model of the social process of accepting wheelchair use emerged and was presented in the following chapter as the substantive theory of accepting wheelchair use.

Chapter 7: Discussion

This chapter presented the substantive theory of accepting wheelchair use which is discussed with reference to the formal theories that informed the theoretical sensitivity of the researcher and shaped the writing of the substantive theory.

Initially, human reaction to change and the process known as adaptation are explored tracing development from Spencer, Durkheim and Parsons to recently published work from Papadimitriou (2008). These are compared with the findings and the use of practical, cognitive-behavioural, psychodynamic and interpersonal approaches to the development of coping strategies are mentioned.

The chapter then moves on to identity theory. The overlap between sociological approaches to identity theory and psychological frameworks are discussed through use of the self (Goffman, 1959) and the movement of thinking from macro to micro sociological settings. The important part that reflection plays on life and its trajectories is introduced (Giddens, 1991 and 1992). Finally, symbolic interactionism (Blumer, 1969) is included in the discussion on the formation of understanding of oneself. Charmaz, (1987) connected chronic illness with identity hierarchies and preferential identities that no longer relate to present life experiences. Evidence to support this was found in the current study.

In locating the substantive theory devised in this study with formal theory the chapter discussed the findings in relation to changes in the wheelchair service and implications for practice. Finally, the chapter discusses my experience of and reflections on the research process and makes recommendations for further research. It also acknowledges the limitations of the present study.

The limited geographical area in which participants were recruited may limit the data provided. The use of only interview data and a supplementary socio-biographical survey may limit understanding through the use of language. These were the findings from the narratives of this group of individuals provided at a moment in history. The possibility is that the theory may not generalise to populations outside the southeast of England.

The thesis is drawn to a close with a concluding statement of personal observations. This is a first attempt to link the different components of wheelchair use, replacement of a lost function, ability to complete tasks, fitting the wheelchair into the environment, coping with wheeled mobility in a disabling environment with the psychological and emotional adjustment that is required to make the change of identity that is essential for personal autonomy and independence as a wheelchair user.

Finally, the journey of the individual from walking to being a wheelchair user is compared with that of the therapist moving from clinical concerns to researcher: my lived experience of completing this research study and writing the thesis.

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