# Changing what it Means to be ... "Normal": A Grounded Theory Study of the Mobility Choices of People who are Blind or Visually Impaired

Elizabeth M. Ball and Colette Nicolle

## Abstract

Introduction: The ability to get out and about is important to social inclusion and quality of life and it is one of the most significant challenges for people who are blind or visually impaired. There has been little research into the underlying concerns of people who are blind or visually impaired when making decisions about mobility.

Method: This grounded theory study explored the main mobility-related concerns of people who are blind or visually impaired. It uses qualitative data, drawn from a combination of online discussions, face-to-face, telephone and email interviews, and focus groups with people who are blind or visually impaired and rehabilitation practitioners.

Results: The primary concern of people who are blind or visually impaired when making choices about where to go, and when and how to do so, was a desire to see oneself and to be seen by others as "normal". Self-identity and perceived "normality" are subjective and changeable and are continually internally co-reconstructed to achieve congruence between them. The mobility strategies used are those that are perceived as most "normal". Discussion: Perceived "normality" has a powerful influence on behaviour. By harnessing this, rehabilitation services may be better able to promote autonomy and self-reliance.

Implications for Practitioners: To promote independence, rehabilitation services must change people's perception of what is "normal". People must be supported to come to perceive fulfilment of valued social roles, autonomy and self-reliance as "normal".

#### Introduction

Orientation and mobility, that is the ability to get safely and efficiently from place to place, is important to social inclusion and quality of life. Difficulty with getting out and about curtails many activities, including employment (Coffey, Coufopoulos, & Kinghorn, 2014), leisure (Berger, 2012), and social activities (Smith, 2012). Conversely, the ability to travel enables participation in valued activities and social roles (Kendrick, 2011) and has a positive impact on the overall quality of life (La Grow et al., 2011; Yeung et al., 2011).

Independent travel is one of the biggest challenges for people who are blind or visually impaired (Diamond, 2012, Cimarolli et al., 2012). Research into orientation and mobility has largely focused upon tools and techniques to promote independent travel (Arditi & Tian, 2013; Kim & Wall Emerson, 2014; Lloyd et al., 2009, Williams et al., 2011; Wright, Harris, & Sticken, 2010), environmental influences (Deverell, 2011; Scott et al., 2011) and Rehabilitation programmes (Alma et al., 2013; Perla, 2013; Zijlstra, Ballemans, & Kempen, 2013). However, little research has explored the underlying concerns of people who are blind or visually impaired when making choices about mobility, and the roles these may play in the persistence of low rates of independent travel amongst this population.

This study explores these issues from the perspective of people who are blind or visually impaired. Persistently low rates of independent travel (Clark-Carter et al., 1981; Gray and 2

Todd, 1967; Shimizu, 2009), combined with calls for emancipatory disability research (McColl et al., 2013; Oliver, 2002; Petersen, 2011), pointed strongly to the need to adopt a generative methodology that would enable the researchers to break free of preconceptions and the history and politics of the field, generate conceptual theory that would be relevant to researchers, practitioners and people who are blind or visually impaired, and that could incorporate any factors, individual, social or political, that emerged as relevant.

### Methodology

This study used the grounded theory methodology (Glaser & Strauss, 1967; Glaser, 1998) to explore the main concerns of people who are blind or visually impaired in relation to independent travel, and how they resolve these.

Grounded theory is a generative methodology that explores the latent patterns in data, avoids preconceived research questions and generates conceptual theory. It can be used with any type of data, qualitative, quantitative or mixed, although in this study the data was qualitative, and it allows for triangulation of data from multiple sources.

Incidents within the data, i.e. a unit of data where a concern and resolution are expressed, are compared to each other, and to emerging categories and properties, in a process known as constant comparisons. Categories and their properties are derived directly from the data, and so may be revised as new data are analysed. Preconceived frameworks of categories and properties are avoided, as is the automatic collection of data relating to variables, such as age and gender, which are often presumed to be of importance, unless they emerge as relevant to the developing theory.

Coding of data progresses from open coding, where everything is included, to selective coding, where only that which relates to the emerging core category is coded, and finally to theoretical coding, where the relationships between categories and properties are explained.

During analysis, only three questions are asked: what is the main concern, how is this being resolved, and what category, or property of a category, does the comparison represent (Glaser, 1998).

In grounded theory, the researcher begins with a research area, but without specific research questions, and initial data collection is unstructured. Participants are encouraged to talk around the area, raising the concerns and resolutions they see as important.

In this study, initial data collection involved a series of twenty-one email interviews, thirteen with people who are blind or visually impaired and eight with rehabilitation professionals, with informed consent obtained from each participant. Although these yielded useful data, it was felt that the asynchronous, and non-contact, nature of email made it difficult to encourage participants to talk without the researcher asking specific questions and that it would be beneficial to make use of naturally occurring discussions between participants, where the researcher played little or no part in those discussions.

For this reason, most of the data for this research was obtained from publicly available online discussion forums where the topic of orientation and mobility is frequently discussed. This 4

ensured that the issues raised were those of importance to participants and that the researcher was not influencing these through preconceived questions. Permission was sought from the owner or moderator of each forum. In total, two hundred and thirty-eight conversations (or threads), with a median number of contributions per thread of eighteen, were analysed.

In grounded theory, analysis begins as soon as the first data are collected. Subsequent data are selected to help saturate categories and their properties, in a process known as theoretical sampling. Unlike many other research methods, grounded theory does not attempt to select a sample that is representative of the target population, or to specify the sample at the start of the research. Instead, participants and data are selected that provide comparisons that emerge as useful during the research. In this research, theoretical sampling guided the selection of online discussion forum threads, as well as leading to three further email interviews, four face-to-face, one telephone and one textphone interviews, and three face-to-face focus groups with four, six and seven visually impaired participants. Two of these focus groups were convened for a different purpose but became relevant, so permission to use the data was obtained.

Theoretical sampling led to participants and data being selected to enable comparisons involving access to different types and amounts of information about visual impairment and blindness (online and offline), cultural backgrounds (individualistic and collaborative), additional impairments (including hearing, physical and cognitive impairments), age (18 to 98 years), timing of onset of visual impairment or blindness (congenital and acquired) and the amount and type of orientation and mobility training that had been received (residential, domiciliary, and in different countries).

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This research followed the British Psychological Society's (2013) Ethical Guidelines on Internet Mediated Research. The use of online forums and email interviews gave rise to particular challenges in adhering to ethical principles, especially maintaining anonymity and confidentiality. As suggested by the guidelines, the decision was taken not to reveal the names of online discussion forums and, where quotes are traceable using a search engine, to paraphrase these in all publications. In this paper, therefore, paraphrasing is indicated by single quotation marks, as opposed to double quotation marks which are used to indicate verbatim quotes from emails which are not traceable. Pseudonyms are used to differentiate quotations from different participants. Ethical approval for the study was obtained from Loughborough University's Ethical Advisory Committee.

#### **The Theory**

Four distinct patterns of mobility-related behaviours, or strategies, emerged from the data: patientising, passing, adapting, and representing. These were each associated with specific concerns, or foci of attention: personal characteristics, mode of operation, social roles, and social groups.

Patientising involves a refocusing on personal, biological and physical characteristics and needs, on visual impairment or blindness as a characteristic that sets them apart from sighted people, on physical risk, and on meeting personal care needs such as the need for food. Their approach to mobility is to use a person who is sighted as a guide or to avoid going out.

Patientising is about surviving and coping and this pattern of refocusing and strategising was referred to as 'surviving and coping' when it emerged from the data. It was renamed 'patientising' only because it matches closely the established description of this in existing literature, such as Dodds (2006) who describes patientisation as "the helpless hand of incompetence fitting snugly into the glove of negative expectations" (p.73).

"I used to think it was normal for blind folks to rely on sighted helpers for everything, and to sit at home doing very little all day, and I got into the mind set of doing that." (Amanda)

"I need someone to do the shopping, to take the children to school and do other errands for me because it's just so much easier and safer. Maybe I could learn to do it myself but why should I when it is easier and safer for someone else?" (Becky)

"It's different for those of us who are blind. Sighted people can do these things quickly and easily. We can't. So it makes sense for us to ask sighted people to guide us." (Mark)

Passing involves a refocusing on how tasks are accomplished, the mode of operation. If an activity cannot be carried out in a particular way, it is generally avoided. There is concern over the expectations and attitudes of others, with the belief that any strategy that marked them out as "different" would be negative. There is often a desire to prove, to themselves and others, that they can continue to function in the same way as people who are sighted. This most commonly manifests as a refusal to use a long cane or other mobility aid, even 7

when it is clear that one would help, but it can also be more extreme. One participant, for example, talked about being so determined to fit in with friends that he did what they were doing, and drove while drunk, even though fully aware that driving, even while sober, was no longer safe because of visual impairment.

'I'd still rather stand than find my way by feeling for a chair. I think this is part of a legitimate determination to be as "normal" as possible, but somewhat out of control and beyond reason...' (Jody)

"I have enough vision not to need a cane most of the time now but I still always use it because that's what is normal for me and people expect partially sighted people to do." (Paul)

Adapting involves refocusing on social roles, such as doing a job or being a parent. How the role is carried out is unimportant, only that it is managed as well as possible. There is a refocusing on, and willingness, to learn new blindness or visual impairment skills and to seek resources to do this where necessary. There is a belief that people who are blind or visually impaired can succeed in a range of social roles and a willingness to strive towards that. Any mobility strategy may be adopted, such as using a long cane, guide dog, electronic travel aid, guide or residual vision, that facilitates fulfilment of the identified social roles. Roles and activities are not avoided and, while assistance from others may be accepted, control is maintained and participation maximised.

"To be a successful mother, I have to have the freedom to get where I want, how I want, when I want. I need to be in control of my own travel ... of everything

really. In my view, if a white cane gives a person freedom and mobility then the heck with what people think." (Natalie)

"My definition of independence allows for brief periods of ad-hoc assistance as long as I stay in control and am making that as a positive choice not being forced into it because I lack the skills to do it myself." (David)

'I used to have a guide dog but when I changed jobs and needed to be able to go into people's homes it became inconvenient so I now use a cane. It works better for me now and means I can just get on with the job rather than worrying all the time about the dog.' (John)

Representing involves a refocusing on being an ambassador for people who are blind or visually impaired. There is much overlap between adapting and representing, in that there is a focus on social roles and a belief that people who are blind or visually impaired can accomplish these. However, there are two major differences. Firstly, representing involves a refocus on visual impairment or blindness as making them part of a minority group that needs to advance its civil rights and that they represent, whereas, in adapting, while aware of other people who are blind or visually impaired as a potential resource, there is no particular feeling of being part of a minority group. Secondly, in representing, there is a desire to reach out to, and educate, people who are sighted about visual impairment or blindness or visual impairment.

'People can't understand that deafblind people can be mobile. It's only by us getting out there and educating them that they will ever come to understand. If we let these things stop us, and we stay indoors, or only go out with a communicator-guide, it will just reinforce their idea that we can't be independent, so we have to hold firm and keep doing it to educate people.' (Chris)

'One of the best things about having a guide dog for me is that it's a great conversation starter and gives me a chance to educate sighted people about blindness.' (Molly)

"The law gives us rights but it's up to us to get out there and enforce them. People have to see us travelling so that they can understand the need for reasonable adjustments that enable us to travel independently." (Derek)

People's focus can shift over time, leading to a change in the choices they make about mobility. A number of participants, for example, described initially passing, by resisting using a cane or guide dog for fear that it would mark them out as "abnormal", and instead trying to rely on residual vision, following other people or avoiding situations, and later coming to believe that the strategies they were using were marking them out as "abnormal" because they hindered the fulfilment of social roles, and that using a cane or guide dog could enable them to appear more "normal" by enabling them to achieve more.

'I used to go out, head down, looking carefully at the ground trying to avoid tripping. I knew how to use a long cane but didn't want to stand out by using it.

Then one day I nearly got hit by a bus because I was looking down at the ground.

From that day on, I have used a long cane and I know I look a lot more normal using that, moving around confidently, than I ever could have done timidly staring at the ground.' (Jenny)

Underlying the foci of attention is a desire to see oneself, and to be seen by others, as being "normal". "Normality", however, is a subjective state, that means different things to different people at different times. "Normality" is continually perceived, interpreted and reconstructed. So, too, is self-identity – the beliefs people hold about themselves, who they see themselves as being. The interpretation of both is interdependent: a change in perceived "normality" can lead to a change in self-identity and vice versa. This interdependent process of co-reconstructing "normality" and self-identity emerged as the core category and it drives the mobility choices of people who are blind or visually impaired. That is, the mobility choices made are those that facilitate the closest match between self-identity and perceived "normality".

People who are blind or visually impaired continually map their current self-identity and perceived "normality" and how they can co-reconstruct them to bring the two closer together. This process of mapping begins with a comparison of self-identity with perceived "normality", followed by a prediction about whether "normality", as currently perceived, is achievable. If this comparison between perceived "normality" and self-identity reveals an incongruence, this triggers a refocusing upon a different set of criteria, or aspects of "normality" and identity, followed by strategising to narrow the gap.

Patientisation, with its focus on personal characteristics, involves co-reconstructing "normality" and self-identity by reference to what is perceived as "normal" for blind people 11 based upon negative societal attitudes about blindness, and includes a perception of vulnerability to physical risks, a willingness to relinquish control and allow others to make decisions and undertake activities on their behalf, and is often associated with feelings of hopelessness.

The criterion on which people who are passing make their comparison between self-identity and "normality" is the mode of operation. "Normality" is assessed on whether a task is carried out in the way it always has been, in the way a sighted person would, or in the way it is believed blind people should.

People who are adapting co-reconstruct "normality" and self-identity based on what they perceive to be "normal" social roles irrespective of blindness or visual impairment.

In contrast to the other types of refocusing and strategising, in representing, with its focus on being part of a minority group and on educating others, people are actively trying to change the external, objective "normality" through advocacy, as well as co-reconstructing their own perceived self-identity and "normality".

Any event or process that disrupts the congruence between perceived "normality" and selfidentity leads to refocusing and strategising to restore congruence, and a change in mobility choices and behaviours. These triggers do not necessarily have to directly relate to visual impairment.

'Getting to know other blind people, and seeing them doing the things I used to do, such as working and raising families, made me realise blind people are just 12 normal with a few extra challenges and that I should start rebuilding a normal life for myself.' (Eloise)

'It wasn't until my grandson was born that I began to recognise the importance of adapting how I did things, so that I could be an effective granddad.' (Richard)

## Discussion

When making choices about mobility, the main concern of people who are blind or visually impaired is to see themselves, and to be seen by others as "normal". The strategies adopted are those that achieve the greatest congruence between self-identity and perceived "normality". Self-identity in people who are blind or visually impaired has received considerable research attention (Datta, 2014), as has psychological adjustment to blindness and visual impairment (Bergeron & Wanet-Defalque, 2013; Dodds, 2006; Emam, 2013; Hodge et al., 2013; Marquès-Brocksopp, 2012). The need to challenge stereotypes and to normalise people's experiences has been acknowledged by practitioners and researchers (Southwell, 2012). However, to the best of our knowledge, the influence of perceived norms on the mobility related choices and behaviours of people who are blind or visually impaired has not previously been explored.

The influence of descriptive and perceived social norms on behaviour has been studied widely in other fields as diverse as healthy eating (Stok et al., 2014), altruism (Rosenberg, 2013) and energy saving (Ayres, Raseman, & Shih, 2012). In these fields, a simple descriptive statement of a social norm, such as the amount of fruit eaten by peers (Stok et al., 13

2014) or the amount of energy used by neighbours (Ayres, Raseman, & Shih, 2012), was sufficient to influence behaviour. The situation with mobility for people who are blind or visually impaired would appear to be more complex than this. The appropriate reference group for the social norm will be different depending on which criteria for self-identity and "normality" are the focus of attention at any given time for any given individual. The complex web of explicit and implicit messages about social norms surrounding the individual needs to be understood and manipulated so that the desired social normative message can have an effect.

Rehabilitation services are based, albeit sometimes implicitly, on one of a number of models of adjustment to visual impairment and blindness. Amongst the most pervasive models are psychodynamic ones that conceptualise adjustment to visual impairment as a process of grieving a loss (Tuttle & Tuttle, 1996). Services based on such models may, inadvertently, be imparting to service users that feelings of grief, hopelessness and helplessness are "normal" and be encouraging patientisation. An alternative model, based on principles of cognitive psychology, was put forward by Dodds et al. (1993) and Dodds (2006). According to this model, through the development of skills and competence during rehabilitation training, negative patterns of thoughts and beliefs are replaced by positive ones. A third model, based on notions of empowerment, was put forward by Jernigan (1993) and built upon by Omvig (2002). According to this model, both rehabilitation training and contact with competent people who are blind or visually impaired are necessary for the development of independence. Services based on these latter two models may be "normalising" the skills needed to be an independent traveller, raising expectations of the fulfilment of valued social roles, and be encouraging adapting. Services based on the empowerment model expose users

to contact with people who are visually impaired or blind as a minority group, so promoting representing.

The criteria upon which "normality" is based varies between individuals and over time for any one individual. Incongruence between self-identity and perceived "normality" triggers a refocusing on a new set of criteria and, subsequently, to different choices being made and behaviours being practised. This has important implications for rehabilitation practice. If the aim of rehabilitation services is for people who are blind or visually impaired to change their behaviour to become as autonomous, self-reliant and self-directed as possible, then services must do everything possible to make service users view these as "normal" and to bring about a refocusing on social roles.

Further research is needed to explore how rehabilitation services can best make use of social norms, positively manipulate self-identity and perceptions of "normality" and promote refocusing upon fulfilment of valued social roles, i.e. adapting and representing, and change the perception of "normality" to one of autonomy, self-reliance and participation.

## Conclusion

This research explored the main concerns of visually impaired people in relation to mobility, which was to see oneself and to be seen by others as "normal". The mobility choices made by visually impaired people are determined by continual comparison and co-reconstruction of self-identity and perceived "normality", both of which are subjective and changeable constructs. The mobility strategies adopted are those that are perceived as making the person 15

most "normal". It is argued that, in order to increase independent travel, rehabilitation services must aim to "normalise" participation, autonomy and self-reliance.

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