Spreckley, M. and H. Kuper. Story. 2016.
Hear my story: the reflective experience of a hearing impaired researcher conducting a study on the impact of hearing loss in Guatemala.
Knowledge Management for Development Journal 11(1): 111-118
http://journal.km4dev.org/

STORY

Hear my story: the reflective experience of a hearing impaired researcher conducting a study on the impact of hearing loss in Guatemala

Mark Spreckley and Hannah Kuper

There is currently a strong emphasis on research about disability being conducted by persons with disabilities. However, to date there has been a notable lack of such research in the academic literature. With a bilateral, idiopathic hearing impairment, this reflective account explores my journey as a researcher, conducting a study on the impact of hearing loss and provision of hearing aids in Guatemala. In order to systematically explore my personal experiences of fieldwork and understand the dynamic inter-relationships, a systems-theory based conceptual framework was applied. The research identifies the practical environmental challenges and explores the academic implications such as the potential for prejudice and bias. The shared knowledge and experience of hearing loss contributed to effective research tool design, aided participant and stakeholder communication and facilitated data interpretation and analysis. This account recognises the positive contributions that such inclusive research may provide.

Keywords: research; disability; persons with disabilities; hearing impairment; hearing aids; personal knowledge; Guatemala

Introduction

After several years of receiving family member complaints that I like the television volume turned up far too loud, accusations of selective hearing and that I always punctuate a conversation with the word ‘pardon’, I was finally coerced into having a hearing test. Following a series of diagnostic tests, at the age of 42 and for no obvious reason, I was diagnosed with moderate bilateral hearing loss, to which there is no cure, but may be improved by wearing hearing aids. Now, permanently wearing two discrete in-the-ear devices, the television is much quieter, conversations are more interactive and engaging, and the world has become a much noisier place to live.

At around the same time, I embarked on the Doctor of Public Health Programme at the

London School of Hygiene and Tropical Medicine, based within the International Centre for Evidence in Disability. As part of my studies, an exciting opportunity arose for undertaking my doctoral research based on the impact of hearing loss in adults living in Guatemala. A subject area which has become of great personal interest and a challenging experience.

In line with the spirit of the disability movement, 'Nothing about us without us!' there is currently a strong emphasis on research about disability being conducted by persons with disabilities. Nind et al. (2013) proposes that engaging in such inclusive research accesses participants, communities and cultural knowledge in ways that other research cannot. This empathy and 'insider connection' may generate richer, more credible data. However, to date there has been a notable lack of such research in the academic literature. For example, Tregaskis (2004) reports that traditionally disabled people's experiences of conducting disability research has focused on reporting their research findings and not openly discussing personal disability issues that may affect the disabled researcher.

The key objective of my doctoral research is to understand the impact of hearing disabilities in Guatemala. With the completion of phase one of the fieldwork, this personal account seeks to capture my research journey. This paper critically reflects on the role and experiences of a researcher with a similar disability in a different socio-economic, cultural and linguistic context. The practical challenges are identified, the academic implications examined and the positive contributions that such inclusive research may provide are explored.

Conceptual framework

In order to systematically explore my personal experiences of fieldwork, a hybrid, systems theory based conceptual framework has been applied. According to Mele et al, systems theory is:

> 'A theoretical perspective that analyzes a phenomenon seen as a whole and not as simply the sum of elementary parts. The focus is on the interactions and on the relationships between parts in order to understand an entity's organization, functioning and outcomes' (2010: 127).

By utilising a concentric rings model, adapted from an ergonomic systems framework, (Figure 1.0) my personal experiences as a researcher engaging in fieldwork may be captured and the dynamic and complex inter-relationships of these key elements may be identified and mapped at each level. For instance, the communication challenges associated with using hearing aids whilst interviewing a participant within a noisy home environment. Table 2.0 defines the key elements of the systems framework.

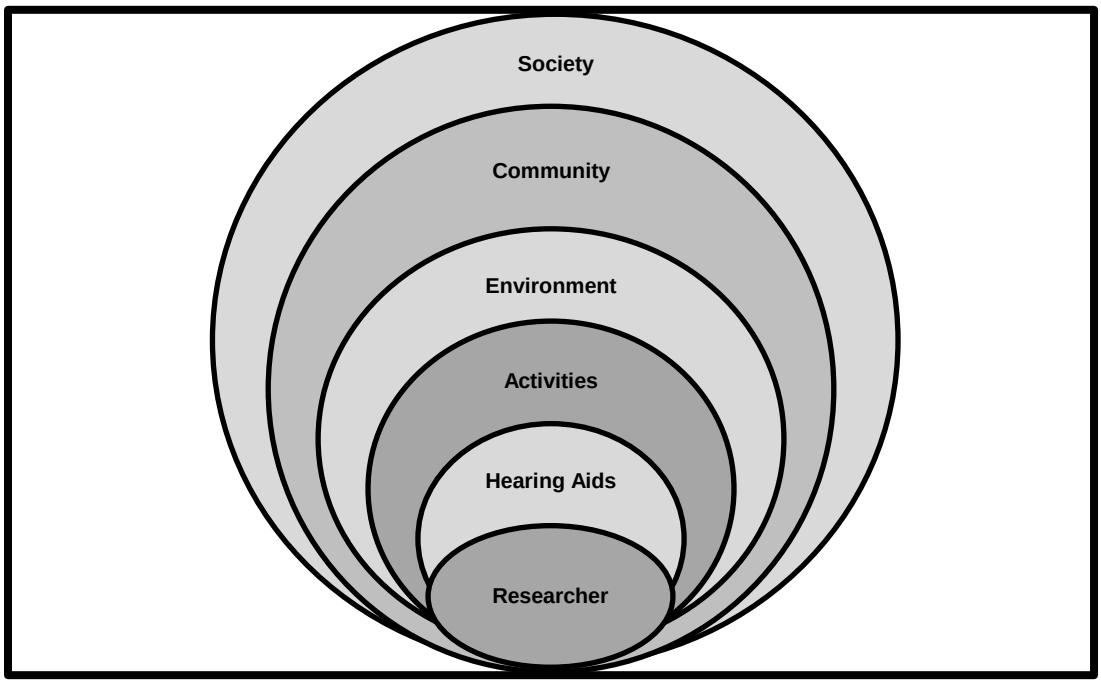

Figure 1.0: Systems Framework

Research project

In terms of scale, globally hearing impairment is a major source of morbidity and disability. The WHO estimated that in 2013 there were 360 million people worldwide with disabling hearing loss, the vast majority of whom live in low and middle income countries. Historically, few studies have been undertaken to assess the impact that hearing loss has in people's lives, or whether this can be overcome through provision of hearing aids. Of the studies that have been conducted in low and middle income countries, the findings suggest that hearing impairment is linked to poverty, impaired activities of daily living and employment. It has also been seen as a cause of stigma, reduced quality of life and well-being.

The aim of my doctoral research project was to assess the impact of hearing impairment and the provision of hearing aids on poverty, mental health, quality of life and activity participation among adults in Guatemala. This included exploring the barriers and facilitators to uptake and usage of hearing aids and assessing patient satisfaction with such devices. It is hoped that the outcomes from this research project will inform audiology outreach screening programmes, advocacy initiatives and guide diagnostic and clinical service planning and development.

Following a UK based project planning phase, the baseline fieldwork was undertaken in September-December 2015 and the post-intervention fieldwork in July-August 2016. Within Guatemala, my role was to appoint, train and manage a team of fieldworkers who conducted face to face interviews and hearing tests with more than 300 participants across both urban and rural areas of the country. Assisted by an experienced Spanish translator and project aide, I coordinated and operationally managed the team activities, project resources and stakeholder communications. I also conducted in-depth interviews with adults diagnosed with moderate-severe hearing impairment to understand how this impacted on them.

Reflective practice

Up until now, my reflective practice experience has been confined to either an academic activity as part of a professional development exercise or on a sub-conscious level, reviewing, analysing and learning from past experience. Whilst in Guatemala, I had to think on my feet, reflect on how I would have tackled a specific challenge in a resource-rich, supportive environment and then adapt and apply the same principles within an unknown and socially complex territory. The reflective techniques I employed involved writing notes, keeping a fieldwork log, composing descriptive e-mails and interacting with my Language Teacher and Research Lead. Based on this approach and the 'hearing aid-activity-environment' interface identified as integral components of the systems framework, the following practical challenges have been identified.

As part of the fieldwork, I was engaged in a series of activities which required effective communication with key stakeholders. These activities were undertaken under a broad range of environmental conditions. Such interactions included, learning Spanish within a language school, teaching research methodology within a classroom setting, supporting and guiding the team of fieldworkers and conducting in-depth interviews within patient homes. The area of greatest challenge to me was learning Spanish, in particular the correct pronunciation, though whether this was due to my hearing impairment or lack of cognitive-linguistic skills is hard to know.

Unfortunately, high humidity levels affected my hearing aid functionality and caused intermittent device failure. By acting as a physical obstruction and ear plug, conversational amplification was further reduced. Under such circumstances, I had to discretely remove the device and the translated conversation was reduced to a whisper. Equally, I found that background noise within participant homes, such as the television and family member conversations provided unwanted competing noise amplification and distraction. My compensatory response is usually to lip read and use non-verbal visual cues, however, due to the language barrier and required parallel side-seating configuration of the translator, this was a challenging experience. Despite these challenges, by discussing these experiences and

working in collaboration with the translator, I could introduce practical compensatory behaviors and physical adjustments. In order to maximize amplification and assist with lip reading, seating re-configuration enabled me to be in close proximity to the translator and within their line of sight and where appropriate, back ground noise was controlled by communicating with family members.

My perception was that my working relationship with the fieldworkers was enhanced by sharing my personal experience of hearing loss. The ability to respond to fieldworker questions and openly share my experience, transcended cultural and language barriers and reinforced research credibility and motivation as well as cultivating mutual understanding and respect. With the aid of a translator, I was engaged in qualitative interviews with participants who had hearing impairments. Despite the language barrier, my own, introductory disclosure of hearing loss and use of hearing aids, provided a relaxed, open setting from which to draw upon my own experience and ask personal questions related to such themes as family relationships, work and mental health. Furthermore, my own use of hearing aids demonstrated my personal interest and long-term project commitment.

During this process, some participants shared their experiences of hearing loss, expressing a sense of shame, lack of support, concerns of being a burden to their family and friends and adopting reclusive behaviors. In contrast, I privately reflected on my own experience of living with such a disability in the UK, including the practical inconveniences of hearing loss, access to a comprehensive network of support and guidance, cultural acceptance and social inclusion. Within the UK hearing loss prevention, detection and management measures are accessible and freely obtainable. In Guatemala, for most people, such ear health management strategies remain largely unknown, out of reach and economically unobtainable.

From a societal perspective, with the prevalence of poverty, political corruption and limited social infrastructure, Guatemala has a reputation for gang related violent crime and robbery. Under these environmental conditions, whilst travelling and working within most areas of the country, we adopted a range of personal safety and security measures. These are universal precautions, recommended for all, however, with my sensory impairment that affects spatial orientation and my ability to hear, such vulnerabilities require heightened awareness and situation avoidance tactics to be employed.

The academic implications

Undertaking qualitative research with people with hearing impairments is challenging for various practical reasons as a range of linguistic barriers were encountered. Longer duration interviews were necessary in order to fully capture the views of the person with hearing difficulties. In addition, there was often a reliance on family members for communication,

Table 2.0: Systems Framework Application

Domain	Description	Application
Researcher	Researcher Characteristics	The researcher has bilateral, idiopathic hearing loss of moderate severity.
Hearing Aids	Hearing Aid Description	The researcher used discrete, bilateral in-the-ear devices.
Activities	Key tasks & work activities	Within a broad range of environments, including office, home and class room settings and involving a varied number of participants. The key activities requiring effective communication skills were: ▪ Teaching (Via Translation) ▪ Language Lessons ▪ Participant Interviews (Via Translation) ▪ Fieldworker Support and Guidance (Via Translation) ▪ Engagement with Project Stakeholders
Environment	The surrounding area, room or work space	▪ High temperature & humidity levels ▪ Background Noise: Participant home television/family member conversation ▪ Interaction with remote tele-communication devices
Community	The wider neighborhood, street or Zone Conceptual Academic Community	Sourcing of repair services, hearing aid batteries and consumables Researcher Bias & Influence Impact of Hearing Loss Disclosure
Society	The urban and rural areas of Guatemala	Traveling within Guatemala, personal safety and security awareness

which made it more difficult to elicit the views of the individual. Specifically adapted communication skills, such as voice projection and visual cues as well as the attributes of patience and sensitivity were consequently needed and applied by the fieldworkers. These issues were further enhanced by the fact that I myself, also have a hearing impairment. One concern is that close association and personal experience of hearing loss may prejudice the research results. For example, I may assume that with the existence of background noise, all participants experience communication difficulties. Such assumptions may be formulated by me, based on my experience and may not be representative of the situational reality. Such unconscious bias may misrepresent the impact of the disability and provide an exaggerated account or potential under reporting. In this research study, such research bias was managed and controlled as far as possible by introducing such measures as pre-formatted and structured question sets, recorded and transcribed in-depth interviews and fieldwork awareness training.

Despite these practical challenges and academic considerations, this research project has also enabled significant, positive contributions to be identified. The benefits of inclusive research may be demonstrated in the planning and preparation phase of the project, whereby background knowledge and personal experience could help me in the composition, structure and formatting of the research tools. The methodological decision making process can be informed by knowing what questions to ask and why. For example, based on my own experience, a specific question that was included in the questionnaire was 'At home or at work, how often has your hearing problem potentially caused or contributed to a safety or security concern? Please explain what happened?' Such inclusion ensures that the research tools reflect the dynamic and real-life stories of the target population, eliciting rich and meaningful data that positively contributes to the research aim and objectives.

With performing in-depth interviews, I was acutely aware that I might be told what a respondent thinks I want to hear. However, I believe that by informing the participant that I had a hearing impairment myself, they were persuaded of my empathy and deep understanding of their situation. Such disclosure was met positively with eye contact, openness, a sharing of situational examples and rich in-depth responses.

Conclusions

I encountered a broad range of practical challenges as a result of my hearing impairment. These included the effect of environmental humidity on hearing aid function, communication constraints and the impact on personal safety and security awareness. On the positive side, my personal experience of hearing loss and the benefits of hearing aids helped me throughout the planning and implementation phase of this research project, as shared knowledge and experience of hearing loss enhanced the design of the research tools, aided stakeholder communication and management and facilitated data interpretation and analysis. Furthermore,

I attempted as far as possible to maintain awareness of the academic and professional implications of my personal situation and the impact of disability disclosure and researcher bias. These personal experiences encountered during the fieldwork in Guatemala demonstrated to me that challenges to participation can be addressed, academic implications can be managed and the wide-ranging benefits of inclusive research can be realised.

References

Crowther, N. (2007) 'Nothing Without Us or Nothing About Us?' Equality & Human Rights Commission, Disability & Society. Taylor & Francis. Number 7.

Mele, C. et al. (2009) 'A Brief Review of Systems Theories and Their Managerial Applications' Service Science 2(1-2), 126 – 135.

Moon, J. (2010). 'Reflection'. Study Guides: Learning Development with Plymouth University. www.learningdevelopment.plymouth.ac.uk

Nind, M and Vinha, H (2013) 'Building an Inclusive Research Community: The Challenges and Benefits.' Learning Disability Today.

Olusanya, B. et al. (2004) 'Self-Reported Outcomes of Aural Rehabilitation in a Developing Country' International Journal of Audiology, 2004; 43-563-571.

Paterson, C., & Chapman, J. (2013) 'Enhancing Skills of Critical Reflection to Evidence Learning in Professional Practice', Physical Therapy in Sport; 2013.03.004

Piennar, E. et al. (2010) 'Self-reported Outcomes of Aural Rehabilitation for Adult Hearing Aid Users in a South African Context' South African Journal of Communication Disorders. Volume 57. December 2010.

Tregaskis, C. (2004) Identity, Positionality and Power: Issues for Disabled Researchers. A Response Paper to Broun and Heshusius. Disability Studies Quarterly. Spring 2004, Volume 24, No. 2.

WHO (2012) 'Global Estimates on Prevalence of Hearing Loss' Mortality & Burden of Diseases & Prevention of Blindness & Deafness. Geneva.

About the authors

Mark Spreckley has a clinical background in Physiotherapy and Master's degree's in Business Administration (MBA) and Research (MRes). He has extensive experience in healthcare management and has undertaken research in a range of national and international public health settings. He is currently a Student Doctor of Public Health within the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine (LSHTM). Email: mark.spreckley@lshtm.ac.uk

Hannah Kuper is co-director of the International Centre for Evidence in Disability and works to expand the research and teaching activities of LSHTM in the field of global disability. Her main research interest is disability in low and middle income countries, with a particular focus on older people. Email: Hannah.kuper@lshtm.ac.uk