Exploring researchers' experiences of working with people with acquired brain injury

Andrea Greenwood[1], Alice Theadom[1,2], Paula Kersten[1], Kathryn M McPherson[1]

[1] Person Centred Research Centre, Health and Rehabilitation Institute, Auckland University of Technology, Auckland

[2] National Institute for Stroke and Applied Neuroscience, Auckland University of Technology, Auckland

Keywords: qualitative descriptive, experience, brain injury, participation researcher–subject relations

Corresponding author:

Alice Theadom, PhD.

National Institute for Stroke and Applied Neurosciences, Faculty of Health and Environmental Studies, Auckland University of Technology, AA254C, 90 Akoranga Dr, Northcote 0627, Private Bag 92006, Auckland 1142, New Zealand.

Telephone: +64 9 921 9999 x7805; Fax: +64 9 921 9620;

Email: alice.theadom@aut.ac.nz

Abstract

Purpose: This study aimed to investigate the challenges and positive experiences of researchers who work with people who have experienced an acquired brain injury and their families.

Method: People who were currently or had previously worked as a researcher in the field of acquired brain injury (using either quantitative or qualitative methods) were invited to participate in a focus group or individual interview about their experiences. An expert reference group meeting was held to discuss strategies that could be implemented to enhance the researcher experience based on the interview data.

Results: A total of 19 researchers who worked across 4 different research teams took part in the study. Six interconnected themes were identified: researcher motivation, meaning and fulfillment; human connection; knowing and understanding the role; complexity of brain injury in the research context; the research process; state of the researcher. A number of recommendations for supporting researchers more effectively were identified.

Discussion: Researchers described a number of positive aspects as well as tensions they encountered in their role. The findings highlight the need to ensure researchers are supported effectively to ensure quality of research studies in the field of brain injury.

Introduction

Acquired brain injury (ABI) is now recognized as an increasing public health concern, [1, 2] with projections that ABI will become one of the main causes of global disease burden by 2020. Traumatic brain injury and stroke are the most prevalent causes of acquired brain injury [3] with approximately 1.7 million people sustaining a traumatic brain injury and more than 750,000 people in the US experiencing a stroke annually [4]. In addition to the high frequency, the impact of ABI can be devastating, including physical disability [5], cognitive difficulties [6], fatigue [7-13], loss of sense of self [14] and depression [15] that can make everyday activities extremely challenging both for the affected person and their family/whānau (whānau is a Māori-language word for extended family) [16].

Recognition of the importance of preventing injury and improving the quality of life for people who experience ABI, has led to a rapid increase in research to document people's experiences, the recovery process and to develop new rehabilitation methods [17, 18]. A variety of qualitative and quantitative methods are used to collect data from participants, including cross sectional and repeated in-depth interviews using detailed questionnaires, functional assessments and semi-structured interviews [19, 20]. Research staff play an important role in facilitating participant recruitment and ensuring a high quality of data is collected which are critical components to the success of research studies. Consequently, it is important to understand factors researchers find challenging and rewarding about their role in order to support researchers most effectively. Further, by ensuring researchers are supported and research systems are functioning well, this will optimize performance through facilitating collection of complete and valid data, increase adherence to research protocols and have a positive impact on the engagement participants with ABI in the research process.

Several studies have explored the experiences of those being studied in research, finding that research participation is associated with both benefits and burden [21-24]. However, despite playing a crucial role in ensuring the validity research studies, relatively little attention has been given to the explicit study of the experience of individual researchers and research team members in conducting research in people with ABI.

In the wider health field, a recent study by Derrett & Colhoun [25] explored the positive aspects and difficulties faced by quantitative researchers when interviewing people with a wide range of accidental injuries. This study revealed that researchers found it challenging to balance the expectations of the project, whilst being sensitive to the needs of patients and their families, difficulties in managing when participants did not attend arranged appointments, and not feeling able to respond to mental health concerns effectively were issues that were also identified. This study suggested there is a very real need for additional supports to be put into place for staff to assist staff to manage these challenges experienced in the researcher role.

Paterson, Gregory & Thorne [26] highlight the importance of protecting researcher safety and note that the number and seriousness of risks researchers face are often not acknowledged, with researchers describing experiences of being stalked, threatened or frightened while conducting research. More recently, Parker & O’Reilly [27] noted that researchers are presented with a number of safety risks even when following prescribed safety protocols, thus researchers must be cautious in the field. The reflective nature of the research process can also evoke potentially highly emotional responses in the participants, family and others involved in research [28]. Wray, Markovich & Manderson [29] note that conducting emotion-laden research (e.g. with people experiencing disability, terminal illness, or death and dying) involves researchers being immersed spatially, emotionally and indeed repeatedly in people's stories through data collection, transcription and data analysis. This involvement may impact on researcher wellbeing, as researchers are required to manage their own emotions as well as those of participants.

Working with people who have experienced a brain injury and associated complex difficulties may therefore have the potential to place an emotional burden for researchers in this field, in addition to risks to personal safety. A recent paper reflecting on the personal case stories of two researchers working in ABI [30] revealed that specific skills were needed by researchers interviewing participants after ABI, due to the difficulties participants experienced in their ability to recall information, concentrate on the interview questions, and articulate their experiences and feelings. Interviewers need to be vigilant for signs of distress and fatigue and ensure participants understood what they were being asked, in addition to managing the challenges of 'conducting an interview' and expectations of the project. These findings highlight that there are a number of unique challenges that researchers are likely to encounter when working with people who have experienced an ABI and their families. Consequently it is important to understand the wider experience of the researcher working in this field.

It is also noted that previous research has focused predominantly on the negative aspects of the researcher role. There is a need to explore the positive aspects that have been found to help balance out any negative aspects of the role [25] as well the commonalities and differences between using different research designs. As job satisfaction and wellbeing have been widely linked to job performance [31], it is important to be able to understand the broader experience of the researcher in order to provide the appropriate supports to optimize the researcher's well being and resulting quality of the data collected across research teams. This study aimed to investigate the challenges and positive experiences of conducting qualitative and quantitative research with people who have experienced an acquired brain injury and their families.

Methods

A qualitative descriptive study [32] was conducted to identify the positive and challenging aspects of the researcher role when gathering data from people with ABI within the research context. The study also aimed to identify the strategies they had developed or would recommend to help them manage the challenges more effectively in the future. Ethical approval was obtained from the Auckland University of Technology Ethics Committee (AUTEC) Ref 12/75.

Participants

We refer to the participants of our study as 'researchers' throughout this paper. We highlight this point to avoid any confusion, when we use the term 'participants' to refer to people with ABI and their families that the researcher worked with. Researchers were eligible for inclusion if they had within the prior 24 months collected data (quantitative or qualitative) with people who had experienced an acquired brain injury (including stroke and traumatic brain injury) and/or their families. Recruitment took place in a large tertiary institution undertaking multiple projects in acquired and traumatic brain injury. Information sheets were sent to those who were eligible to participate by a self-nominated member of each research team known to be carrying out the relevant research. Those who were interested in taking part ere able to contact a member of the research team who was not involved in the line management of any research staff. Permission from managers for the data collection to occur during work time was obtained before recruitment. This process was established to protect researcher confidentiality and to prevent any perceived coercion or uncomfortable feeling in talking about their experience. This also meant research team managers were unaware of who was taking part. The methods of this study were developed in consultation with staff across research teams to ensure that they were comfortable with the processes involved to protect their privacy. Researchers were asked to provide written consent before commencing the interview (in the case of telephone interviews, consent forms were posted back before the interview was conducted).

A total of 19 researchers who worked across 4 different research teams took part in the study. All researchers who expressed interest in the study were interviewed.

Data collection

Researchers were able to take part in a focus group or individual interview based on personal preference. Semi-structured interviews were conducted following the same interview guide (see table 1) for both focus groups and individual interviews. The interview guide included topics such as: initial expectations of the role, positives, challenges, strategies developed, and changes one would suggest. The interview was administered flexibly to ensure issues of importance to the researchers were discussed.

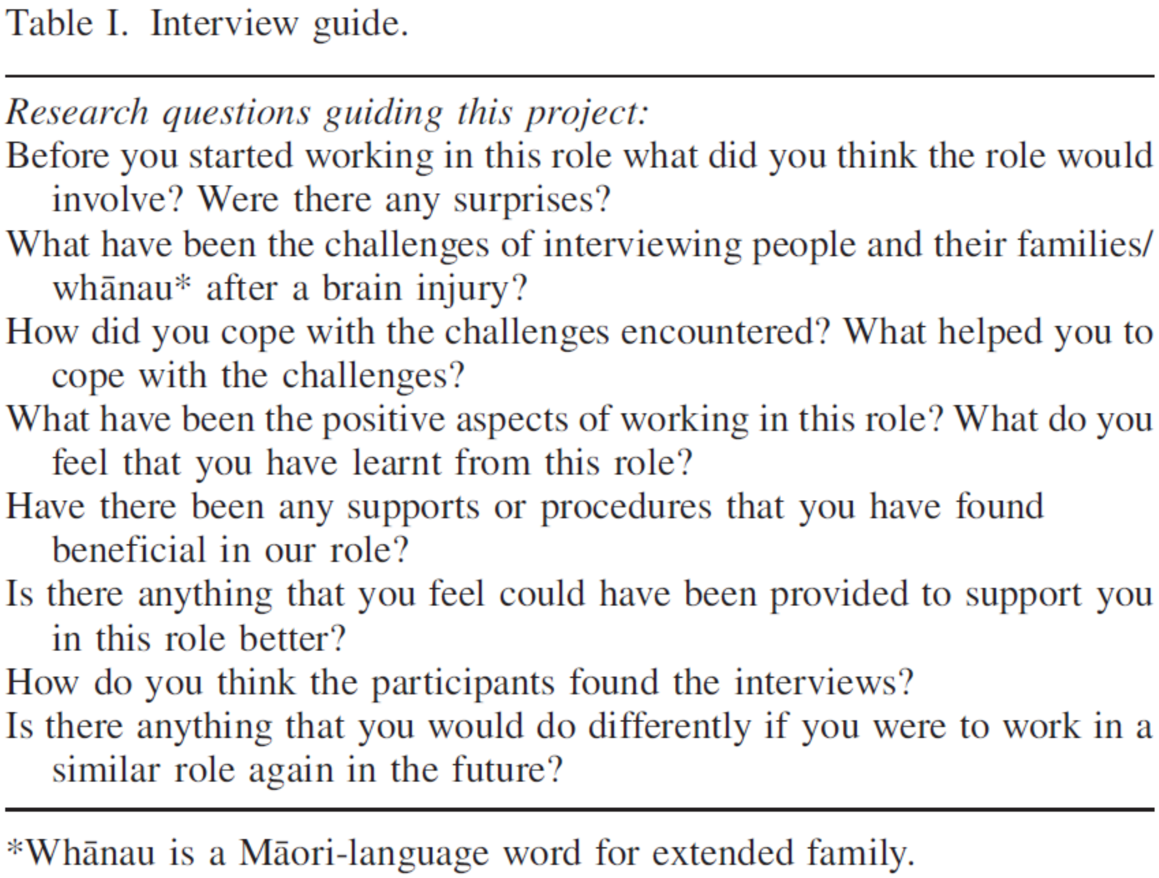

Table I. Interview guide.

Research questions guiding this project:
Before you started working in this role what did you think the role would involve? Were there any surprises?
What have been the challenges of interviewing people and their families/ whānau* after a brain injury?
How did you cope with the challenges encountered? What helped you to cope with the challenges?
What have been the positive aspects of working in this role? What do you feel that you have learnt from this role?
Have there been any supports or procedures that you have found beneficial in our role?
Is there anything that you feel could have been provided to support you in this role better?
How do you think the participants found the interviews?
Is there anything that you would do differently if you were to work in a similar role again in the future?

*Whānau is a Māori-language word for extended family.

Three focus groups were conducted, each facilitated by two interviewers (GS and AG or KM) with a maximum of six researchers per group. Focus groups included a range of between 3 and 5 researchers. Eight individual interviews were also conducted by an experienced interviewer (GS) either in person or over the phone (if the researcher had moved away from the immediate study area). The interviewers were selected for any one focus group or interview based on them being external to the research teams involved in the study to enable the researchers to talk openly about their experiences. The focus groups and individual interviews were held away from the researchers’ work place to help protect anonymity.

The qualitative descriptive approach was chosen for this study as this approach provides a rich description of an experience or an event using language similar to that used by informants. Further, when analyzing qualitative descriptive data there are no theoretical strings attached, therefore results stay close to the data and the informants' point of view [33].

Data analysis

The focus groups and individual interviews were audio-recorded and transcribed verbatim. All identifying details (such as study names, job titles and references to gender) were removed from the written transcripts by the interviewers before analysis. The written transcripts were individually coded by two researchers to ensure rigor (AG and AT). Codes were grouped into themes through discussion and final data themes were refined with insight from other team members. The constant comparative method [34] was used to identify patterns, highlight key points and to refine the findings. As described by Taylor & Bogdan [35] the constant comparative methods allows researchers to simultaneously code and analyze data in order to develop themes. The continual comparison of specific findings in the data allows themes and their boundaries to be refined, enabling researchers to explore the relationship between themes and integrate them into a coherent explanatory model. Finally, salient quotes were identified to illustrate the identified themes. Quotes are reported by researcher number only, without demographic identifiers (such as age or gender) to preserve the anonymity of researchers.

Expert Reference Group

The findings were presented to a group of nine senior investigators and study managers from across the participating research teams, to facilitate the identification of practical strategies that could be implemented to support researchers based on their experiences. The aim of the meeting was to give attendees the opportunity to discuss findings, and identify practical suggestions that could be implemented that provide better support for researchers.

Results

Researchers had been involved in different research projects using a range of research designs including quantitative epidemiological studies, questionnaire studies, clinical trials and qualitative projects. Some researchers were new to research (having been in the role for only a few months and with no prior research experience) and others had been involved in several research roles within the field of brain injury over several years, and had experience of working on projects with different research designs.

Six interconnected themes were identified relating to researchers' experiences of conducting research with people with ABI. Themes were:

1) Researcher motivation, meaning and fulfillment
2) Human connection
3) Knowing and understanding the role
4) Complexity of ABI in the research context
5) The research process
6) State of the researcher

Each theme encompassed both challenging and positive aspects of the researcher role.

Researcher motivation, meaning and fulfillment

Researchers discussed how their research role contributed both to their personal growth and career development. Researchers expressed the importance of feeling their role had meaning, with many noting they found motivation and fulfillment in helping people, seeing them progress and through receiving positive feedback from people with ABI. Both quantitative and qualitative researchers described feeling privileged to hear people’s stories and to be able to help people seek support where needed.

> P008. On one occasion where an elderly man felt really quite depressed and his daughter was in the room, he was very honest in answering the questions around depression. It was a bit of a tricky situation because his daughter, I saw his daughter tearing up and I thought ‘oh gosh’, but then it was quite good because his daughter … let me out afterwards and she was like ‘gosh I really wasn’t aware the he was feeling that low’, so she straight away took him to the GP.

It was apparent that having a clear understanding of the purpose of the research, knowing how they were performing and how it may help people was critical to the job satisfaction of the researcher and was felt to reflect how they conducted their work.

> P017. I thought people would have been, most people would have been recovered, especially the ones with really light trauma, I’m a [clinician] so that was just my expectations and… that was a real eye opener for me… because you can see how much symptoms people are experiencing, so I think for me it was more motivation to do everything correctly.

Human Connection

All researchers talked about the importance to them of establishing rapport and building a supportive relationship with people with TBI and their families during the research process.

> P018. [I] didn't actually expect that I'm actually building a relationship with that person and that I, as a person, in a way I'm creating the data but I'm actually creating the situation for the data to be collected. And so the more I learnt about that, the more I felt comfortable, and feel comfortable now, you know with collecting that data within that whole, you know it's only part of what I'm doing in the interview.

An investment in the relationship with participants in research studies appeared to also result in researchers feeling a lack of closure and concern for participants. This occurred when a team member needed to conduct the final follow up or if the researcher was unable to make contact with a participant.

> P007. You know you meet someone and you consent them, they tell you a little bit of their life story and then you just don't know what happened to them so you're like oh ok … should you worry?

While conducting the research, researchers noted the challenge of allowing enough time to establish connection with participants and give enough time to collect good quality data whilst managing their caseload and avoiding leaving too long in between interviews to prevent wasting time.

> P018. There's always the time tension. You have this time between creating the relationship and collecting the data and saying the goodbyes that you need to manage.

Researchers also noted challenges around collecting data with certain cultures when people were being polite or cautious about saying the right thing.

> P012. There's also that cultural thing. I've really struggled personally with some of my Samoan families because [they say] everything is fine. And you can see everything is far from fine often. But it's about saying the right thing and about doing the right thing and there are difficulties with that.

Knowing and understanding the role

As noted above, researchers had varying degrees of experience in research and in working with people with ABI. Perceptions about training and understanding the researcher role therefore varied considerably. Researchers who had worked before with people with ABI explained that their prior experience gave them confidence in working with this population.

> P009. I guess because of having worked with people with stroke I felt quite well informed of you know, various things that they might be going through

However, researchers new to the area of brain injury talked about finding the role more challenging initially.

> P018. When you're confronted with somebody who's actually suffering from a brain injury, the reality of doing of it, I wasn't prepared for that. The fatigue, the confusion, the time, the lack of understanding, how much you can explain to people when you're delivering a questionnaire.

There were diverse experiences of training that researchers had received. A number of researchers noted the merits of training programs and how the skills they learnt facilitated them in their role. Others noted that training did not meet their expectations or could be improved, such as having more time to discuss research processes. However, the initial training on some occasions was also perceived to be intensive, or too theoretical. It was consistently reported across researchers that having time to practice and become familiar with study procedures and assessments was crucial to them feeling prepared and able to fulfill the role. It also became clear that although the research teams may have piloted questionnaires – the researchers still found new difficulties when using questionnaires in the field:

> P008. We initially had to go over all these questionnaires ourselves like with the team, we had to read through them and try to find any mistakes or any things that might be wrong within the questionnaires. I think we really started to find out what was wrong while doing, while starting it with the participants, and so I guess for another time it might be an idea to bring some…well not participants yet but some people in who have had a stroke for example or other type of brain injury, ask them to be practice clients and practice with them …I think it will be quicker and easier to find the mistakes or the tricky parts of the questionnaires.

The importance of well-established procedures and protocols at the start of the study were considered important. However, researchers also described the benefit from on-going training to refresh and improve skills, to learn from others experiences and to address specific issues that arose throughout the research process as well as the importance of receiving feedback from managers. The opportunity to observe more experienced colleagues was perceived to be highly beneficial:

> P017. A couple of colleagues who did the interviews for a long time, I observed them and then they, you know we talked about it and then I started doing it on my own with someone observing me. So that was really guided all through.

Complexity of ABI in the research context

Researchers expressed having a number of concerns when working with people with ABI within research context. A number of researchers discussed worries about overburdening people with ABI, when participants' lives were often already busy and complex. Additionally, researchers talked about having to develop a number of strategies to take the needs of people into account when conducting research interviews including how they talk about the study and phrase the questions, prioritizing assessment requirements, whilst being aware of how the brain injury may be affecting the person with ABI and their ability to take part in the study.

> P016. I had to watch out for outward signs of fatigue and not necessarily rely on peoples' own self report 'cos sometimes people would feel quite excited about having this opportunity to talk about their head injury and participate in some of the activities that we did, but they wouldn't really be so aware of their fatigue.

Researchers also discussed worries around informed consent, the impact of comorbidity and how the managing everyday life after brain injury affected the validity of data.

> P018. Sometimes the worry is around informed consent. In that when you're working with people with head injury and they've consented to be in part of the [study]…

> They've consented to being in the study but when you go there you have to ask them questions that they don't understand and then you start worrying that where, you know where is the informed consent and at what level? And so I don't think I probably [was] as equipped as I maybe could have been too with dealing with those kinds of issues and again, when you have questions to ask and they can't answer them… Their data is irrelevant.

The Research Process

Researchers discussed a number of challenges in fulfilling the researcher role in terms of following research procedures and protocols, and how they went about managing these. One tension that emerged from the researchers was the need for established protocols and procedures at the start of the study to help them to make decisions such as when to refer a patient for further support or not during an assessment. Specified actions to take when certain measurements or assessments suggested a significant problem or risk helped remove the sense of responsibility and uncertainty that researchers felt when needing to make difficult decisions. However, these were at times also felt to be too rigid due to their lack of coverage of some individual circumstances or contextual factors (such as overly interpreting children's comments e.g. when child described talking with imaginary friends according to guideline this would be grouped under 'I see or hear things others can't'). In contrast, for researchers who had been more involved in developing protocols and questionnaires as the study progressed, there appeared a sense of having had a voice and greater flexibility, although they expressed feeling vulnerable and unsure initially in the role. They also talked of difficulty in keeping up with the changes particularly in large teams and/or where researchers were working off-site and were not able to attend all team discussions.

> P012. I mean as much as I’m saying why do things keep changing and carts before horses, they are changing because we are saying this isn’t ideal and someone is then reacting to it.

Researchers discussed having to manage complex situations during interviews or assessments in the home with at times a number of other people present during the interview process. Whether they were parents, children or extended whānau of the person with ABI, they at times posed challenges for researchers in gathering accurate information.

> P016. “There were a couple of times I had, it would be a mother or partner [in the room] … they would be doing all the talking for the person with the TBI. So you would have to just sit and listen, so you would have some difficulties around there, or it would be a lot of their story and not really the person with the head injury – their story. You’d be asking the participant with the head injury you know about their difficulties in their life and they’d start talking and the other person would jump in [and say] “Oh no – no that’s not it at all”. That certainly was a challenge.

A number of problems arose when researchers had to get in contact with participants. They discussed the frustration of trying to make appointments with some people with ABI, and not knowing if that was because they didn’t want to participate or because it just wasn’t convenient. This caused a tension in acknowledging the importance of giving them the opportunity to participate and share their story.

> P001. The worst part was being stood up and having to constantly try and chase people that you knew didn’t want to do it but they wouldn’t say they didn’t want to do

> it so you had to keep on and make appointments and they wouldn’t be there or ringing them and they were never home.

State of the Researcher

Researchers described a number of factors that they perceived to impact on their performance as a researcher. Firstly, it was challenging for researchers to put aside their own family or personal issues that may be weighing on their minds, or to focus if they were feeling unwell during an interview. Secondly, gathering information from people with ABI was seen as being emotionally demanding and it was therefore difficult to always switch off after an interview. As a result of this, researchers highlighted the importance of having a support team network available at all hours so participants could off load and share thoughts and feelings if they had had a difficult interview.

> P007. Sometimes just hearing how other people handled their cases. You are asking yourself that because it happened to you and then ‘oh is that what you did? Ok I’ll do that next time’. So communication within staff is definitely really good and just sharing new experiences with each other.

The need to be able to discuss and reflect on processes within a team highlighted the importance of feeling connected. Researchers who worked part time or on a study on their own appeared to find coping with the research process more challenging. Researchers new to a research area or particular methodology also expressed needing time to learn and to reflect on their practice to increase confidence.

Feeling safe when working in the community was a further issue of importance to researchers. Having well-established procedures set up before starting a study was key to increasing confidence particularly when working out in the community. A number of researchers noted environmental situations where they felt uncomfortable or that unexpected people present at the interview could make them feel vulnerable.

> P018. You have some kind of assumptions that the person's safe. But you don't always know about what else is happening around the area

Whilst each theme is distinct, each theme was interconnected with other themes as illustrated in figure 1, the multidirectional arrows show the relationships between the themes are interactive as learning during the research process that continually develops over time within the researcher role. For example, 'Knowing and understanding the role' had an impact on experiences and 'The research process'. Researchers with prior experience felt more comfortable in the role and therefore would have desired flexibility in protocols, whereas those new to the research role expressed a desired and value for having set protocols to follow. Thus variations in knowing and understanding the researcher role influence how they dealt with professional issues that occurred during the research process.

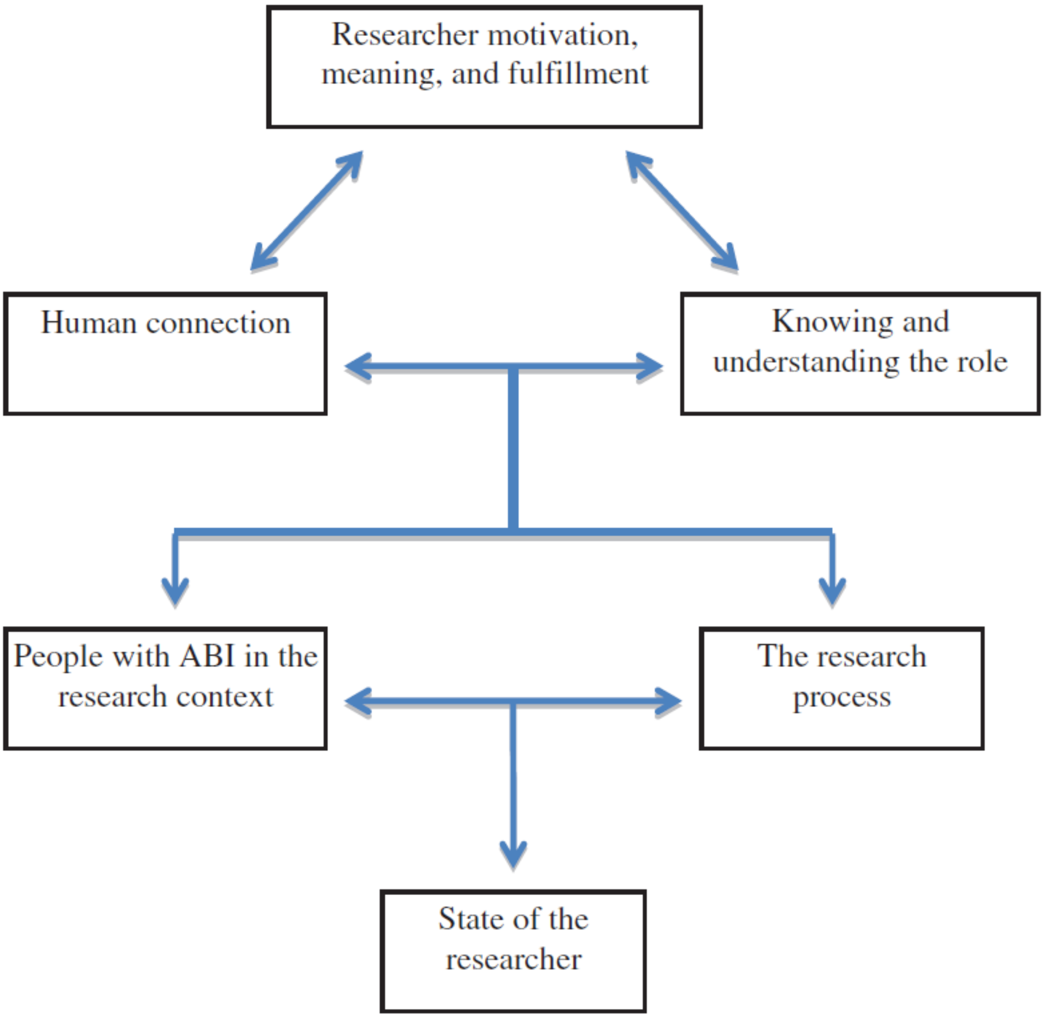

Figure 1. Overview of identified themes.

Recommendations directly identified by the researchers and by attendees of the expert reference group are outlined in table 2.

Table II. Recommendations to support researchers working with people following acquired brain injury.

Rationale	Recommendations
Training:	
• Researchers described only being able to take in a certain amount of information at the beginning of a study and finding training more useful when they could discuss situations they had encountered.	• Training needs to address all facets of the role (e.g. how to obtain informed consent, responding to emotional distress/abuse, how to manage emotions, working with different cultures and how to effectively end a research relationship) and be on-going throughout course of study. • Videoing training sessions may enable all researchers to benefit from the training even if they are unable to attend.
• Researchers' levels of confidence and competence were linked to familiarity with assessment structure and material. Observation was noted as the most useful way to learn valuable researcher skills.	• Build time into training schedule to practice conducting assessments and to enable new researchers to observe other more experienced staff conducting interviews.
• Researchers stated that they felt a reference guide would be useful to record issues and clarifications as they are raised to help communicate to all involved and as a reminder to ensure consistency.	• Collate a reference guide document with key questions/comments, e.g. to clarify what a question is getting at or to provide clarifications on what to do if a question isn't relevant or to address impact of comorbidities on responses.
• Understanding the importance of research enables researchers to communicate this to participants to assist with recruitment and to reiterate why they are working in such a challenging role.	• Talk through and discuss the protocol with researchers to ensure researchers clearly understand the purpose of the research and why it is important.
Communication:	
• Researchers highlighted that they needed clear pathways outlining who they should talk to, particularly where several people were involved in a study.	• Facilitate clear team communication processes and set up concrete pathways of communication to enable feedback both ways – between researchers, and study managers.
• Researchers expressed a sense of vulnerability in talking to their managers about aspects of their role, particularly as they were often working on short-term contracts.	• Promote a 'safe' culture with a continual open narrative between all involved in the study so researchers feel they can ask questions. It may be helpful for managers to observe some researcher assessments/interviews to facilitate communication and provide constructive feedback.
• Supervisory mechanisms may help to facilitate researchers to discuss any issues arising in their role and open up communication pathways.	• Develop a feedback loop and/or group discussion sessions for researchers to de-brief and allow information to be shared and issues raised.
• Given researchers are often working in difference locations, it was felt to be important to connect as a whole team at points throughout the study to facilitate a collective vision and team cohesiveness.	• Having one manager or key person such as a peer mentor to discuss issues with and dedicated time to reflect on how things are going and to de-brief with.
• Connecting with other researchers was found to be an important support mechanism and formalizing links with other researchers across teams could facilitate this connection.	• Need to ensure all researchers (including interventionists and outcome assessors) understand the point of the research. Important to keep emphasizing this throughout the study. • Development of meetings/forum where researchers from different research teams can share difficulties and strategies with each other.
Good research practice:	
• Researchers need to understand what else is going on in participants' lives so they are able to respond appropriately, e.g. take a break or re-arrange assessment time. This is critical in ensuring the quality of data collection and facilitating participant retention.	• Time needs to be explicitly built into planned assessment time for building rapport, checking in with participants through interviews/assessments and effectively closing an assessment.
• The importance of randomizing questionnaire administration may be less feasible for this population and emphasis should be placed more on ensuring the quality of data collected and to prevent over-burdening participants and avoid less valid data collection when participants are bored/fatigued.	• Allow for multiple assessment sessions, order assessment administration so that primary (most important) outcome measures are at beginning of assessment in case there is a need to finish the assessment early. When developing studies consideration should be given to including only essential outcome measures.
• Researchers highlighted that there were tensions between protocols and procedures that were either too broad or too restrictive.	• Clear guidelines need to be available for researchers to clarify what issues researchers can respond to directly in the field without managerial consent and those they need to discuss.
• Well-established protocols and procedures enhanced the researcher experience. It was evident that researchers felt there was often a gap between protocols and operational procedures and additional procedure documents were needed. Further information on these areas will allow researchers to feel more competent in their roles.	• More detailed guidelines needed in areas such as: – How to ask questions for people who have difficulty with comprehending what is being asked; – Finding the balance between hassling people whilst giving them the opportunity to participate; – How to account for the demand of working in different context, e.g. hospital vs community setting; and – What to do if there are violations to protocol, e.g. data missing, assessment missed.

Discussion

Research considering researchers experiences of being involved in the research process is limited, particularly in the field of brain injury. This study extends previous research by considering wider aspects of researchers experience and identifying strategies that can be developed to support researchers working with people with ABI. Researchers described a number of positive aspects of the researcher role such as the rewarding experience of developing a relationship with people with ABI, feeling they are giving back to the community through helping people make changes and monitoring their recovery. However, they also described a number of tensions they encountered in their role, particularly in balancing the needs of the study against needing to be responsiveness to the needs of people with ABI. This research has helped to highlight some areas that study designers should consider when developing research protocols with suggestions to support researchers more effectively within their role.

Studies that have considered researchers experiences have focused on single aspects of the research experience such as emotional burden or safety. The findings of this study support previous research, highlighting that researchers perceive a need for support mechanisms in place to enable them to have the skills and feel safe when working with people with ABI. Mechanisms identified to minimize risk and support include assessing risk, education on how to respond when they feel unsafe and de-briefing following interviews to deal with emotional burden/issues [25, 29, 36, 37]. However, this study revealed that researchers experienced a far wider range of issues when working in their role than has been previously acknowledged in the literature, many of which could be proactively managed to ensure researchers are adequately supported in their roles.

The importance of understanding the role and the purpose of the researcher were key to researcher satisfaction. Prior experience influenced perceptions of the role and researcher motivation appeared to increase over the time people had been working as a researcher. This may reflect that new researchers often felt unsure and overwhelmed by the role, and found it difficult to balance what they believed was required of them in the role, whilst trying to be responsive to the people with ABI and their families. It became evident in this study that researchers new to the role, perceived a need for time to observe others, become familiar with study processes, and to understand the needs of people and situations they may encounter to equip them to manage when they were conducting solo interviews/assessments and to understand their role. Many researchers discussed how these skills were developed over time in the field. Training at times was felt to be too distant from the context, and there was a desire for role plays/training examples of how to handle more complex situations that may arise with this population. Time to observe more experienced colleagues conducting interviews was felt to be the most valuable training strategy by many researchers and even as a consistency check for more experienced interviewers.

Developing an effective relationship with people with ABI was described by all researchers as a rewarding and fulfilling part of their researcher role, and it became clear that the human connection with participants was critical to comprehensive and valid data collection. Researchers described that the importance of establishing rapport was not reflected in study protocols and frequently caused them a tension in their role between knowing they needed to spend time with the participants before and after the interview but then feeling rushed when collecting data to ensure the interview was completed within allocated timeframes. There is a wealth of evidence suggesting that human connection is critical to treatment adherence and effectiveness of health care, quality of care and patient satisfaction [38-42] and the importance of the human connection in research needs to be acknowledged and time allowed for researchers to develop this.

Whilst many of the findings may not be unique to ABI (and could be applied to other health conditions) it became apparent that working within the context of ABI made these themes far more significant and pronounced for researchers. The need to be flexible in administering interviews to people with complex needs including an awareness of information processing and concentration difficulties, the presence of fatigue as well as physical impairments made conducting research with this population far more challenging and placed a greater emotional burden and sense of responsibility on researchers. Previous literature concerning emotional burden highlights that researchers working with vulnerable patient groups are exposed to stories and revelations that can carry significant emotional burden [36, 37, 43, 44]. In this study researchers similarly described that conducting interviews/assessments with people with ABI could leave them feeling drained. Thus, researchers described developing their own support systems (such as peer/colleague debriefing) to share their experiences, resulting emotions and to follow up on any issues causing researchers anxiety. However, it appears there is need to formalize these processes, particularly for researchers who may be working alone on a project. There is a need for support mechanisms to be in place to support researchers working in this role, this finding highlights that these issues should also be considered for researchers working in other areas of health care and rehabilitation.

The context of the research appeared to influence the researcher experience with researchers working in larger teams having access to greater support mechanisms than researchers working more in isolation. As support and debriefing opportunities are seen as a necessity in this role, this highlights the need to connect researchers across teams for training and peer support where possible. Whilst the context of the team set up influenced the researcher experience it appeared the nature of the study design was less influential. The majority of previous literature concerning researcher experiences focuses on qualitative researchers, describing challenges and risks that arise when engaged in the research process especially when conducting research on sensitive topics. There is however, limited research concerning quantitative researchers' experiences of the research process. While the methods by which quantitative researchers gather information differs from qualitative researchers, they are still required to build rapport with participants and gather personal information about their lives. This study found that researchers working in both qualitative and quantitative studies recounted similar experiences in terms of emotional involvement with people with ABI and both valued support and debriefing either informally, from peers or from managers.

Whilst this study was only completed across four research teams within one institution it was evident that even within this context alone, researchers described a number of positive aspects, challenges and identified different strategies to manage difficulties that arose when working with people with ABI. However, all researcher perspectives may not have been captured in this study, given that the unique characteristics of the researcher and the context within which they were working influenced their experience and strategies employed. Additionally, it may be the case that whilst the interviewers were external to the research teams and actions were taken to protect researcher anonymity, some researchers may still have felt uncomfortable talking about some aspects of their role and experience which may not be reflected in the findings.

It became evident through the strategic planning meeting that different teams had implemented different mechanisms to support their researchers. Whilst this may reflect the different needs of the teams and studies involved, this study has assisted in pooling strategies from across teams to facilitate knowledge sharing and future planning to assist in supporting researchers most effectively. By utilizing these strategies we can help to increase job satisfaction as well as the quality of data collection in research within the field of ABI. The findings highlight that whilst there were no strategies found to be most effective by researchers, what was important was that strategies matched the unique circumstances of the researchers, the study and the wider context as shown in figure 1. There is limited literature that directly identifies and discusses researchers' experiences of being involved in the research process. This study provides a greater understanding of the experience of researchers working within brain injury, and findings from this research could have implications for researchers working in other health-related fields. Future studies could consider whether these recommendations improve researcher experience.

Acknowledgments

This study was funded by a development grant from the Person Centred Research Centre, Auckland University of Technology. We would also like to acknowledge the involvement and expertise of Gill Stokes in conducting the interviews with researchers in this study.

Declaration of Interest

All co-authors are researchers working with people who have experienced an acquired brain injury

References

1. World Health Organization. Neurological disorders: Public health challenges. World Health Organization; 2006.

2. National Institute of Neurological Disorders and Stroke. Traumatic brain injury: Hope through research. 2002.

3. Stables R. The silent epidemic of ABI. Health Matters 2010, Summer;6(2):110.

4. Centers for Disease Control and Prevention. Injury Prevention & Control: Traumatic Brain Injury [Internet]; c2014 [cited 2014 Feb 03]. Available from: http://www.cdc.gov/TraumaticBrainInjury/index.html.

5. Feigin VL, Barker-Collo S, Parag V, Senior H, Lawes CM, Ratnasabapathy Y, Glen E, ASTRO study group. Auckland stroke outcomes study. part 1: Gender, stroke types, ethnicity, and functional outcomes 5 years poststroke. Neurology 2010 Nov 2;75(18):1597-607.

6. Dennis M, O'Rourke S, Lewis S, Sharpe M, Warlow C. Emotional outcomes after stroke: Factors associated with poor outcome. J Neurol Neurosurg Psychiatry 2000 Jan;68(1):47-52.

7. David A, Pelosi A, McDonald E, Stephens D, Ledger D, Rathbone R, Mann A. Tired, weak, or in need of rest: Fatigue among general practice attenders. BMJ 1990 Nov 24;301(6762):1199-202.

8. Hillier SL, Sharpe MH, Metzer J. Outcomes 5 years post traumatic brain injury (with further reference to neurophysical impairment and disability). Brain Injury 1997;11(9):661-75.

9. Middelboe T, Andersen HS, Birket-Smith M, Friis M. Minor head injury: Impact on general health after 1 year. A prospective follow-up study. Acta Neurol Scand 1992;85(1):5-9.

10. Oddy M, Coughlan T, Tyerman A, Jenkins D. Social adjustment after closed head injury: A further follow-up seven years after injury. J Neurol Neurosurg Psychiatry 1985 Jun;48(6):564-8.

11. Ouellet M, Morin CM. Fatigue following traumatic brain injury: Frequency, characteristics, and associated factors. Rehabilitation Psychology 2006;51(2):140.

12. van Zomeren AH, van den Burg W. Residual complaints of patients two years after severe head injury. J Neurol Neurosurg Psychiatry 1985 Jan;48(1):21-8.

13. Wrightson P, Gronwall D. Time off work and symptoms after minor head injury. Injury 1981;12(6):445-54.

14. Nochi M. “Loss of self” in the narratives of people with traumatic brain injuries: A qualitative analysis. Soc Sci Med 1998;46(7):869-78.

15. Lincoln NB, Brinkmann N, Cunningham S, Dejaeger E, De Weerdt W, Jenni W, Mahdzir A, Putman K, Schupp W, Schuback B, et al. Anxiety and depression after stroke: A 5 year follow-up. Disabil Rehabil 2013;35(2):140-5.

16. Jorge RE, Starkstein SE. Pathophysiologic aspects of major depression following traumatic brain injury. J Head Trauma Rehabil 2005 Nov-Dec;20(6):475-87.

17. Hyder AA, Wunderlich CA, Puvanachandra P, Gururaj G, Kobusingye OC. The impact of traumatic brain injuries: A global perspective. NeuroRehabilitation 2007;22(5):341-53.

18. National Institute on Aging, World Health Organisation. Global health and aging. 2011.

19. Rosewilliam S, Roskell CA, Pandyan AD. A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. Clin Rehabil 2011 Jun;25(6):501-14.

20. Levack WM, Kayes NM, Fadyl JK. Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. Disability & Rehabilitation 2010;32(12):986-99.

21. Deprince AP, Chu A. Perceived benefits in trauma research: Examining methodological and individual difference factors in responses to research participation. J Empir Res Hum Res Ethics 2008 Mar;3(1):35-47.

22. Scott DA, Valery PC, Boyle FM, Bain CJ. Does research into sensitive areas do harm? experiences of research participation after a child's diagnosis with ewing's sarcoma. Med J Aust 2002;177(9):507-11.

23. Kerrison S, Laws S, Cane M, Thompson A. The patient's experience of being a human subject. J R Soc Med 2008 Aug;101(8):416-22.

24. Theadom A, Fadyl J, Hollands T, Foster A, McPherson KM. Exploring participant experiences of research after traumatic brain injury. Brain Injury 2014(0):1-8.

25. Derrett S, Colhoun S. Being a quantitative interviewer: Qualitatively exploring interviewers' experiences in a longitudinal cohort study. BMC Medical Research Methodology 2011;11(1):165.

26. Paterson BL, Gregory D, Thorne S. A protocol for researcher safety. Qual Health Res 1999 Mar;9(2):259-69.

27. Parker N, O'Reilly M. “We are alone in the house”: A case study addressing researcher safety and risk. Qualitative Research in Psychology 2013;10(4):341-54.

28. Hubbard G, Backett-Milburn K, Kemmer D. Working with emotion: Issues for the researcher in fieldwork and teamwork. International Journal of Social Research Methodology 2001;4(2):119-37.

29. Wray N, Markovic M, Manderson L. "Researcher saturation": The impact of data triangulation and intensive-research practices on the researcher and qualitative research process. Qual Health Res 2007 Dec;17(10):1392-402.

30. Paterson B, Scott-Findlay S. Critical issues in interviewing people with traumatic brain injury. Qual Health Res 2002 Mar;12(3):399-409.

31. Judge TA, Thoresen CJ, Bono JE, Patton GK. The job satisfaction–job performance relationship: A qualitative and quantitative review. Psychol Bull 2001;127(3):376.

32. Sandelowski M. Focus on research methods-whatever happened to qualitative description? Research in Nursing and Health 2000;23(4):334-40.

33. Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description–the poor cousin of health research? BMC Medical Research Methodology 2009;9(1):52.

34. Glaser BG, Strauss AL. The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine: Transaction; 1967.

35. Taylor SJ, Bogdan R. Introduction to qualitative research methods: The search for meanings. New York: Wiley; 1984.

36. Dickson-Swift V, James EL, Kippen S, Liamputtong P. Researching sensitive topics: Qualitative research as emotion work. Qualitative Research 2009;9(1):61-79.

37. Warr DJ. Stories in the flesh and voices in the head: Reflections on the context and impact of research with disadvantaged populations. Qual Health Res 2004 Apr;14(4):578-87.

38. Schönberger M, Humle F, Zeeman P, Teasdale TW. Working alliance and patient compliance in brain injury rehabilitation and their relation to psychosocial outcome. Neuropsychological Rehabilitation 2006;16(3):298-314.

39. Schönberger M, Humle F, Teasdale TW. Subjective outcome of brain injury rehabilitation in relation to the therapeutic working alliance, client compliance and awareness. Brain Injury 2006;20(12):1271-82.

40. Hall AM, Ferreira PH, Maher CG, Latimer J, Ferreira ML. The influence of the therapist-patient relationship on treatment outcome in physical rehabilitation: A systematic review. Phys Ther 2010 Aug;90(8):1099-110.

41. Sherer M, Evans CC, Leverenz J, Stouter J, Irby Jr JW, Eun Lee J, Yablon SA. Therapeutic alliance in post-acute brain injury rehabilitation: Predictors of strength of alliance and impact of alliance on outcome. Brain Injury 2007;21(7):663-72.

42. Kayes NM, McPherson KM. Human technologies in rehabilitation:'Who'and'how'we are with our clients. Disabil Rehabil 2012;34(22):1907-11.

43. Bloor M, Fincham B, Sampson H. Qualiti (NCRM) commissioned inquiry into the risk to well-being of researchers in qualitative research. 2008.

44. Woodby LL, Williams BR, Wittich AR, Burgio KL. Expanding the notion of researcher distress: The cumulative effects of coding. Qual Health Res 2011 Jun;21(6):830-8.