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

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<u>Abstract</u>

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.

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72

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

96   involved in research [28]. Wray, Markovich & Manderson [29] note that conducting emotion-

97   laden research (e.g. with people experiencing disability, terminal illness, or death and dying)

98   involves researchers being immersed spatially, emotionally and indeed repeatedly in people's

99   stories through data collection, transcription and data analysis. This involvement may impact

100   on researcher wellbeing, as researchers are required to manage their own emotions as well as

101   those of participants.

102

103   Working with people who have experienced a brain injury and associated complex

104   difficulties may therefore have the potential to place an emotional burden for researchers in

105   this field, in addition to risks to personal safety. A recent paper reflecting on the personal case

106   stories of two researchers working in ABI [30] revealed that specific skills were needed by

107   researchers interviewing participants after ABI, due to the difficulties participants

108   experienced in their ability to recall information, concentrate on the interview questions, and

109   articulate their experiences and feelings. Interviewers need to be vigilant for signs of distress

110   and fatigue and ensure participants understood what they were being asked, in addition to

111   managing the challenges of 'conducting an interview' and expectations of the project. These

112   findings highlight that there are a number of unique challenges that researchers are likely to

113   encounter when working with people who have experienced an ABI and their families.

114   Consequently it is important to understand the wider experience of the researcher working in

115   this field.

116

117   It is also noted that previous research has focused predominantly on the negative aspects of

118   the researcher role. There is a need to explore the positive aspects that have been found to

119   help balance out any negative aspects of the role [25] as well the commonalities and

120   differences between using different research designs. As job satisfaction and wellbeing have

121 been widely linked to job performance [31], it is important to be able to understand the

122 broader experience of the researcher in order to provide the appropriate supports to optimize

123 the researcher's well being and resulting quality of the data collected across research teams.

124 This study aimed to investigate the challenges and positive experiences of conducting

125 qualitative and quantitative research with people who have experienced an acquired brain

126 injury and their families.

127

128 **Methods**

129 A qualitative descriptive study [32] was conducted to identify the positive and challenging

130 aspects of the researcher role when gathering data from people with ABI within the research

131 context. The study also aimed to identify the strategies they had developed or would

132 recommend to help them manage the challenges more effectively in the future. Ethical

133 approval was obtained from the Auckland University of Technology Ethics Committee

134 (AUTEC) Ref 12/75.

135

136 **Participants**

137 We refer to the participants of our study as 'researchers' throughout this paper. We highlight

138 this point to avoid any confusion, when we use the term 'participants' to refer to people with

139 ABI and their families that the researcher worked with. Researchers were eligible for

140 inclusion if they had within the prior 24 months collected data (quantitative or qualitative)

141 with people who had experienced an acquired brain injury (including stroke and traumatic

142 brain injury) and/or their families. Recruitment took place in a large tertiary institution

143 undertaking multiple projects in acquired and traumatic brain injury. Information sheets were

144 sent to those who were eligible to participate by a self-nominated member of each research

145 team known to be carrying out the relevant research. Those who were interested in taking part

146   ere able to contact a member of the research team who was not involved in the line

147   management of any research staff. Permission from managers for the data collection to occur

148   during work time was obtained before recruitment. This process was established to protect

149   researcher confidentiality and to prevent any perceived coercion or uncomfortable feeling in

150   talking about their experience. This also meant research team managers were unaware of who

151   was taking part. The methods of this study were developed in consultation with staff across

152   research teams to ensure that they were comfortable with the processes involved to protect

153   their privacy. Researchers were asked to provide written consent before commencing the

154   interview (in the case of telephone interviews, consent forms were posted back before the

155   interview was conducted).

156

157   A total of 19 researchers who worked across 4 different research teams took part in the study.

158   All researchers who expressed interest in the study were interviewed.

159

160   **Data collection**

161   Researchers were able to take part in a focus group or individual interview based on personal

162   preference. Semi-structured interviews were conducted following the same interview guide

163   (see table 1) for both focus groups and individual interviews. The interview guide included

164   topics such as: initial expectations of the role, positives, challenges, strategies developed, and

165   changes one would suggest. The interview was administered flexibly to ensure issues of

166   importance to the researchers were discussed.

167

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.

168

169   Three focus groups were conducted, each facilitated by two interviewers (GS and AG or KM)

170   with a maximum of six researchers per group. Focus groups included a range of between 3

171   and 5 researchers. Eight individual interviews were also conducted by an experienced

172   interviewer (GS) either in person or over the phone (if the researcher had moved away from

173   the immediate study area). The interviewers were selected for any one focus group or

174   interview based on them being external to the research teams involved in the study to enable

175   the researchers to talk openly about their experiences. The focus groups and individual

176   interviews were held away from the researchers' work place to help protect anonymity.

177

178   The qualitative descriptive approach was chosen for this study as this approach provides a

179   rich description of an experience or an event using language similar to that used by

180   informants. Further, when analyzing qualitative descriptive data there are no theoretical

181   strings attached, therefore results stay close to the data and the informants' point of view

182   [33].

183

184   **Data analysis**

185   The focus groups and individual interviews were audio-recorded and transcribed verbatim.

186   All identifying details (such as study names, job titles and references to gender) were

187   removed from the written transcripts by the interviewers before analysis. The written

188   transcripts were individually coded by two researchers to ensure rigor (AG and AT). Codes

189   were grouped into themes through discussion and final data themes were refined with insight

190   from other team members. The constant comparative method [34] was used to identify

191   patterns, highlight key points and to refine the findings. As described by Taylor & Bogdan

192   [35] the constant comparative methods allows researchers to simultaneously code and

193   analyze data in order to develop themes. The continual comparison of specific findings in the

194   data allows themes and their boundaries to be refined, enabling researchers to explore the

195   relationship between themes and integrate them into a coherent explanatory model. Finally,

196   salient quotes were identified to illustrate the identified themes. Quotes are reported by

197   researcher number only, without demographic identifiers (such as age or gender) to preserve

198   the anonymity of researchers.

199

200   **Expert Reference Group**

201   The findings were presented to a group of nine senior investigators and study managers from

202   across the participating research teams, to facilitate the identification of practical strategies

203   that could be implemented to support researchers based on their experiences. The aim of the

204   meeting was to give attendees the opportunity to discuss findings, and identify practical

205   suggestions that could be implemented that provide better support for researchers.

206

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

230 and qualitative researchers described feeling privileged to hear people's stories and to be able

231 to help people seek support where needed.

232

233   P008. On one occasion where an elderly man felt really quite depressed and his

234   daughter was in the room, he was very honest in answering the questions around

235   depression. It was a bit of a tricky situation because his daughter, I saw his daughter

236   tearing up and I thought 'oh gosh', but then it was quite good because his daughter …

237   let me out afterwards and she was like 'gosh I really wasn't aware the he was feeling

238   that low', so she straight away took him to the GP.

239

240 It was apparent that having a clear understanding of the purpose of the research, knowing

241 how they were performing and how it may help people was critical to the job satisfaction of

242 the researcher and was felt to reflect how they conducted their work.

243

244   P017. I thought people would have been, most people would have been recovered,

245   especially the ones with really light trauma, I'm a [clinician] so that was just my

246   expectations and… that was a real eye opener for me… because you can see how

247   much symptoms people are experiencing, so I think for me it was more motivation to

248   do everything correctly.

249

250

251

252 **Human Connection**

253 All researchers talked about the importance to them of establishing rapport and building a

254 supportive relationship with people with TBI and their families during the research process.

255

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.

261

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.

266

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?

270

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.

275

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.

278

279 Researchers also noted challenges around collecting data with certain cultures when people

280 were being polite or cautious about saying the right thing.

281

282   P012. There's also that cultural thing. I've really struggled personally with some of

283   my Samoan families because [they say] everything is fine. And you can see

284   everything is far from fine often. But it's about saying the right thing and about doing

285   the right thing and there are difficulties with that.

286

287 **Knowing and understanding the role**

288 As noted above, researchers had varying degrees of experience in research and in working

289 with people with ABI. Perceptions about training and understanding the researcher role

290 therefore varied considerably. Researchers who had worked before with people with ABI

291 explained that their prior experience gave them confidence in working with this population.

292

293   P009. I guess because of having worked with people with stroke I felt quite well

294   informed of you know, various things that they might be going through

295

296 However, researchers new to the area of brain injury talked about finding the role more

297 challenging initially.

298

299   P018. When you're confronted with somebody who's actually suffering from a brain

300   injury, the reality of doing of it, I wasn't prepared for that. The fatigue, the confusion,

301   the time, the lack of understanding, how much you can explain to people when you're

302   delivering a questionnaire.

303

304   There were diverse experiences of training that researchers had received. A number of

305   researchers noted the merits of training programs and how the skills they learnt facilitated

306   them in their role. Others noted that training did not meet their expectations or could be

307   improved, such as having more time to discuss research processes. However, the initial

308   training on some occasions was also perceived to be intensive, or too theoretical. It was

309   consistently reported across researchers that having time to practice and become familiar with

310   study procedures and assessments was crucial to them feeling prepared and able to fulfill the

311   role. It also became clear that although the research teams may have piloted questionnaires –

312   the researchers still found new difficulties when using questionnaires in the field:

313

314   P008. We initially had to go over all these questionnaires ourselves like with the team,

315   we had to read through them and try to find any mistakes or any things that might be

316   wrong within the questionnaires. I think we really started to find out what was wrong

317   while doing, while starting it with the participants, and so I guess for another time it

318   might be an idea to bring some…well not participants yet but some people in who

319   have had a stroke for example or other type of brain injury, ask them to be practice

320   clients and practice with them …I think it will be quicker and easier to find the

321   mistakes or the tricky parts of the questionnaires.

322

323   The importance of well-established procedures and protocols at the start of the study were

324   considered important. However, researchers also described the benefit from on-going training

325   to refresh and improve skills, to learn from others experiences and to address specific issues

326   that arose throughout the research process as well as the importance of receiving feedback

327   from managers. The opportunity to observe more experienced colleagues was perceived to be

328   highly beneficial:

329

      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]…

354   They've consented to being in the study but when you go there you have to ask them

355   questions that they don't understand and then you start worrying that where, you

356   know where is the informed consent and at what level? And so I don't think I

357   probably [was] as equipped as I maybe could have been too with dealing with those

358   kinds of issues and again, when you have questions to ask and they can't answer

359   them… Their data is irrelevant.

360

361   **The Research Process**

362   Researchers discussed a number of challenges in fulfilling the researcher role in terms of

363   following research procedures and protocols, and how they went about managing these. One

364   tension that emerged from the researchers was the need for established protocols and

365   procedures at the start of the study to help them to make decisions such as when to refer a

366   patient for further support or not during an assessment. Specified actions to take when certain

367   measurements or assessments suggested a significant problem or risk helped remove the

368   sense of responsibility and uncertainty that researchers felt when needing to make difficult

369   decisions. However, these were at times also felt to be too rigid due to their lack of coverage

370   of some individual circumstances or contextual factors (such as overly interpreting children's

371   comments e.g. when child described talking with imaginary friends according to guideline

372   this would be grouped under 'I see or hear things others can't'). In contrast, for researchers

373   who had been more involved in developing protocols and questionnaires as the study

374   progressed, there appeared a sense of having had a voice and greater flexibility, although they

375   expressed feeling vulnerable and unsure initially in the role. They also talked of difficulty in

376   keeping up with the changes particularly in large teams and/or where researchers were

377   working off-site and were not able to attend all team discussions.

378

379   P012. I mean as much as I'm saying why do things keep changing and carts before

380   horses, they are changing because we are saying this isn't ideal and someone is then

381   reacting to it.

382

383 Researchers discussed having to manage complex situations during interviews or assessments

384 in the home with at times a number of other people present during the interview process.

385 Whether they were parents, children or extended whānau of the person with ABI, they at

386 times posed challenges for researchers in gathering accurate information.

387

388   P016. "There were a couple of times I had, it would be a mother or partner [in the

389   room] … they would be doing all the talking for the person with the TBI. So you

390   would have to just sit and listen, so you would have some difficulties around there, or

391   it would be a lot of their story and not really the person with the head injury – their

392   story. You'd be asking the participant with the head injury you know about their

393   difficulties in their life and they'd start talking and the other person would jump in

394   [and say] "Oh no – no that's not it at all". That certainly was a challenge.

395

396 A number of problems arose when researchers had to get in contact with participants. They

397 discussed the frustration of trying to make appointments with some people with ABI, and not

398 knowing if that was because they didn't want to participate or because it just wasn't

399 convenient. This caused a tension in acknowledging the importance of giving them the

400 opportunity to participate and share their story.

401

402   P001. The worst part was being stood up and having to constantly try and chase

403   people that you knew didn't want to do it but they wouldn't say they didn't want to do

404   it so you had to keep on and make appointments and they wouldn't be there or ringing

405   them and they were never home.

406

407   **State of the Researcher**

408   Researchers described a number of factors that they perceived to impact on their performance

409   as a researcher. Firstly, it was challenging for researchers to put aside their own family or

410   personal issues that may be weighing on their minds, or to focus if they were feeling unwell

411   during an interview. Secondly, gathering information from people with ABI was seen as

412   being emotionally demanding and it was therefore difficult to always switch off after an

413   interview. As a result of this, researchers highlighted the importance of having a support team

414   network available at all hours so participants could off load and share thoughts and feelings if

415   they had had a difficult interview.

416

417   P007. Sometimes just hearing how other people handled their cases. You are asking

418   yourself that because it happened to you and then 'oh is that what you did? Ok I'll do

419   that next time'. So communication within staff is definitely really good and just

420   sharing new experiences with each other.

421

422   The need to be able to discuss and reflect on processes within a team highlighted the

423   importance of feeling connected. Researchers who worked part time or on a study on their

424   own appeared to find coping with the research process more challenging. Researchers new to

425   a research area or particular methodology also expressed needing time to learn and to reflect

426   on their practice to increase confidence.

427

428   Feeling safe when working in the community was a further issue of importance to

429   researchers. Having well-established procedures set up before starting a study was key to

430   increasing confidence particularly when working out in the community. A number of

431   researchers noted environmental situations where they felt uncomfortable or that unexpected

432   people present at the interview could make them feel vulnerable.

433

434   P018. You have some kind of assumptions that the person's safe. But you don't

435   always know about what else is happening around the area

436

437   Whilst each theme is distinct, each theme was interconnected with other themes as illustrated

438   in figure 1, the multidirectional arrows show the relationships between the themes are

439   interactive as learning during the research process that continually develops over time within

440   the researcher role. For example, 'Knowing and understanding the role' had an impact on

441   experiences and 'The research process'. Researchers with prior experience felt more

442   comfortable in the role and therefore would have desired flexibility in protocols, whereas

443   those new to the research role expressed a desired and value for having set protocols to

444   follow. Thus variations in knowing and understanding the researcher role influence how they

445   dealt with professional issues that occurred during the research process.
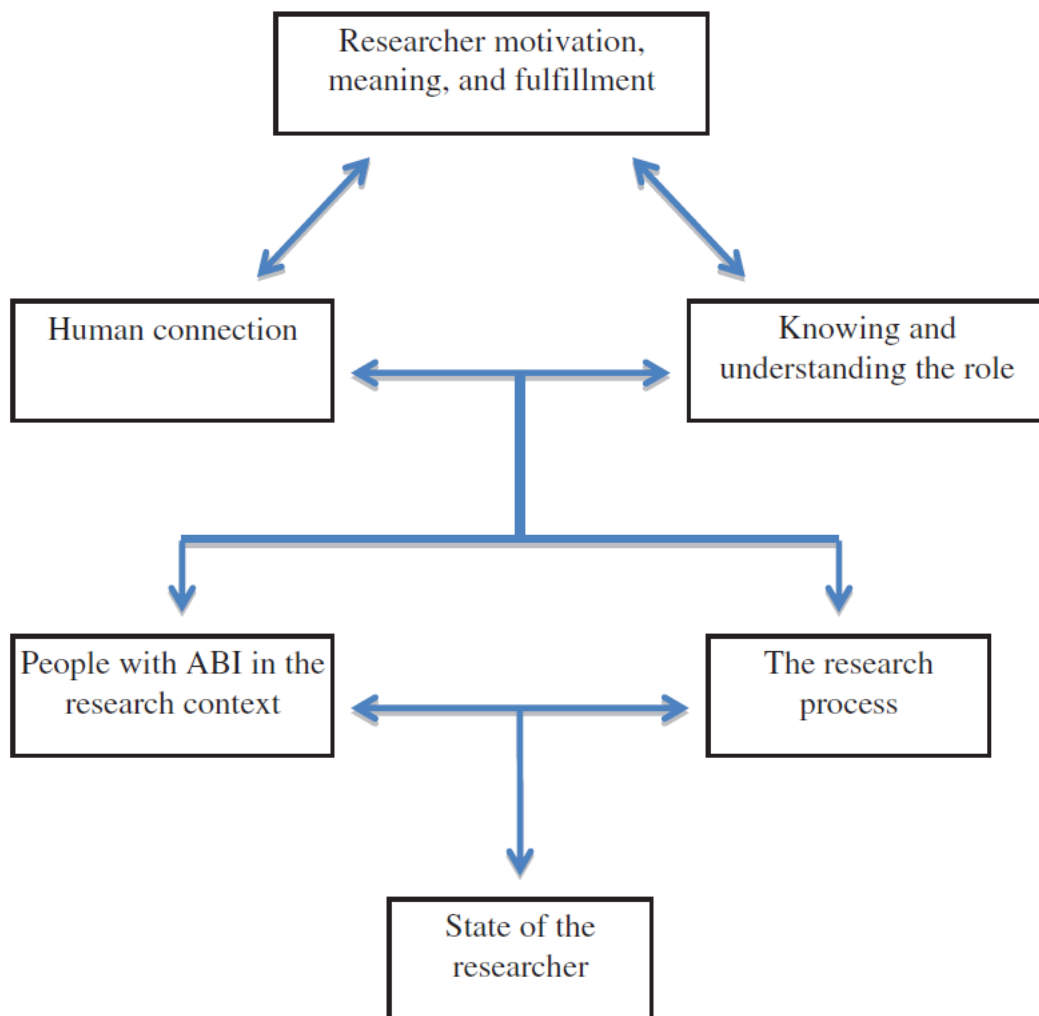
446

Figure 1. Overview of identified themes.

447

448   Recommendations directly identified by the researchers and by attendees of the expert

449   reference group are outlined in table 2.

450

451

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. ● 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. ● 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. ● 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.	● 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. ● Build time into training schedule to practice conducting assessments and to enable new researchers to observe other more experienced staff conducting interviews. ● 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. ● 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. ● 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. ● Supervisory mechanisms may help to facilitate researchers to discuss any issues arising in their role and open up communication pathways. ● 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. ● Connecting with other researchers was found to be an important support mechanism and formalizing links with other researchers across teams could facilitate this connection.	● Facilitate clear team communication processes and set up concrete pathways of communication to enable feedback both ways – between researchers, and study managers. ● 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. ● Develop a feedback loop and/or group discussion sessions for researchers to de-brief and allow information to be shared and issues raised. ● 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. ● 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. ● 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. ● Researchers highlighted that there were tensions between protocols and procedures that were either too broad or too restrictive. ● 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.	● 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. ● 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. ● 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. ● 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.

453

454 **<u>Discussion</u>**

455

456 Research considering researchers experiences of being involved in the research process is

457 limited, particularly in the field of brain injury. This study extends previous research by

458 considering wider aspects of researchers experience and identifying strategies that can be

459 developed to support researchers working with people with ABI. Researchers described a

460 number of positive aspects of the researcher role such as the rewarding experience of

461 developing a relationship with people with ABI, feeling they are giving back to the

462 community through helping people make changes and monitoring their recovery. However,

463 they also described a number of tensions they encountered in their role, particularly in

464 balancing the needs of the study against needing to be responsiveness to the needs of people

465 with ABI. This research has helped to highlight some areas that study designers should

466 consider when developing research protocols with suggestions to support researchers more

467 effectively within their role.

468

469 Studies that have considered researchers experiences have focused on single aspects of the

470 research experience such as emotional burden or safety. The findings of this study support

471 previous research, highlighting that researchers perceive a need for support mechanisms in

472 place to enable them to have the skills and feel safe when working with people with ABI.

473 Mechanisms identified to minimize risk and support include assessing risk, education on how

474 to respond when they feel unsafe and de-briefing following interviews to deal with emotional

475 burden/issues [25, 29, 36, 37]. However, this study revealed that researchers experienced a

476 far wider range of issues when working in their role than has been previously acknowledged

477   in the literature, many of which could be proactively managed to ensure researchers are

478   adequately supported in their roles.

479

480   The importance of understanding the role and the purpose of the researcher were key to

481   researcher satisfaction. Prior experience influenced perceptions of the role and researcher

482   motivation appeared to increase over the time people had been working as a researcher. This

483   may reflect that new researchers often felt unsure and overwhelmed by the role, and found it

484   difficult to balance what they believed was required of them in the role, whilst trying to be

485   responsive to the people with ABI and their families. It became evident in this study that

486   researchers new to the role, perceived a need for time to observe others, become familiar with

487   study processes, and to understand the needs of people and situations they may encounter to

488   equip them to manage when they were conducting solo interviews/assessments and to

489   understand their role. Many researchers discussed how these skills were developed over time

490   in the field. Training at times was felt to be too distant from the context, and there was a

491   desire for role plays/training examples of how to handle more complex situations that may

492   arise with this population. Time to observe more experienced colleagues conducting

493   interviews was felt to be the most valuable training strategy by many researchers and even as

494   a consistency check for more experienced interviewers.

495

496   Developing an effective relationship with people with ABI was described by all researchers

497   as a rewarding and fulfilling part of their researcher role, and it became clear that the human

498   connection with participants was critical to comprehensive and valid data collection.

499   Researchers described that the importance of establishing rapport was not reflected in study

500   protocols and frequently caused them a tension in their role between knowing they needed to

501   spend time with the participants before and after the interview but then feeling rushed when

502 collecting data to ensure the interview was completed within allocated timeframes. There is a

503 wealth of evidence suggesting that human connection is critical to treatment adherence and

504 effectiveness of health care, quality of care and patient satisfaction [38-42] and the

505 importance of the human connection in research needs to be acknowledged and time allowed

506 for researchers to develop this.

507

508 Whilst many of the findings may not be unique to ABI (and could be applied to other health

509 conditions) it became apparent that working within the context of ABI made these themes far

510 more significant and pronounced for researchers. The need to be flexible in administering

511 interviews to people with complex needs including an awareness of information processing

512 and concentration difficulties, the presence of fatigue as well as physical impairments made

513 conducting research with this population far more challenging and placed a greater emotional

514 burden and sense of responsibility on researchers. Previous literature concerning emotional

515 burden highlights that researchers working with vulnerable patient groups are exposed to

516 stories and revelations that can carry significant emotional burden [36, 37, 43, 44]. In this

517 study researchers similarly described that conducting interviews/assessments with people

518 with ABI could leave them feeling drained. Thus, researchers described developing their own

519 support systems (such as peer/colleague debriefing) to share their experiences, resulting

520 emotions and to follow up on any issues causing researchers anxiety. However, it appears

521 there is need to formalize these processes, particularly for researchers who may be working

522 alone on a project. There is a need for support mechanisms to be in place to support

523 researchers working in this role, this finding highlights that these issues should also be

524 considered for researchers working in other areas of health care and rehabilitation.

525

526 The context of the research appeared to influence the researcher experience with researchers

527 working in larger teams having access to greater support mechanisms than researchers

528 working more in isolation. As support and debriefing opportunities are seen as a necessity in

529 this role, this highlights the need to connect researchers across teams for training and peer

530 support where possible. Whilst the context of the team set up influenced the researcher

531 experience it appeared the nature of the study design was less influential. The majority of

532 previous literature concerning researcher experiences focuses on qualitative researchers,

533 describing challenges and risks that arise when engaged in the research process especially

534 when conducting research on sensitive topics. There is however, limited research concerning

535 quantitative researchers' experiences of the research process. While the methods by which

536 quantitative researchers gather information differs from qualitative researchers, they are still

537 required to build rapport with participants and gather personal information about their lives.

538 This study found that researchers working in both qualitative and quantitative studies

539 recounted similar experiences in terms of emotional involvement with people with ABI and

540 both valued support and debriefing either informally, from peers or from managers.

541

542 Whilst this study was only completed across four research teams within one institution it was

543 evident that even within this context alone, researchers described a number of positive

544 aspects, challenges and identified different strategies to manage difficulties that arose when

545 working with people with ABI. However, all researcher perspectives may not have been

546 captured in this study, given that the unique characteristics of the researcher and the context

547 within which they were working influenced their experience and strategies employed.

548 Additionally, it may be the case that whilst the interviewers were external to the research

549 teams and actions were taken to protect researcher anonymity, some researchers may still

550   have felt uncomfortable talking about some aspects of their role and experience which may

551   not be reflected in the findings.

552

553   It became evident through the strategic planning meeting that different teams had

554   implemented different mechanisms to support their researchers. Whilst this may reflect the

555   different needs of the teams and studies involved, this study has assisted in pooling strategies

556   from across teams to facilitate knowledge sharing and future planning to assist in supporting

557   researchers most effectively. By utilizing these strategies we can help to increase job

558   satisfaction as well as the quality of data collection in research within the field of ABI. The

559   findings highlight that whilst there were no strategies found to be most effective by

560   researchers, what was important was that strategies matched the unique circumstances of the

561   researchers, the study and the wider context as shown in figure 1. There is limited literature

562   that directly identifies and discusses researchers' experiences of being involved in the

563   research process. This study provides a greater understanding of the experience of researchers

564   working within brain injury, and findings from this research could have implications for

565   researchers working in other health-related fields. Future studies could consider whether

566   these recommendations improve researcher experience.

572 **<u>Declaration of Interest</u>**

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

574 injury

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