

2022

Reasons for living following an acquired brain injury: A mixed thematic analysis

Parris, C.

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<http://hdl.handle.net/10026.1/20104>

University of Plymouth

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Appendices

Appendix A

Ethical approval from BABICM

(Removed to protect anonymity of BABICM research committee members)

Appendix B

Interview Schedule

1. What challenges or difficulties have you faced since your brain injury occurred?
2. What ways have you found to cope with your difficulties and challenges since your injury?
3. Some people post-injury struggle with difficult thoughts and feelings. What experiences, if any, have you had with feeling low?
4. How have you managed such thoughts and feelings since your injury?
5. What things in your life support you when you are feeling low?
6. What are your current hopes and your hopes for the future?

Appendix C

Thematic table displaying themes from Knight et al. (2020)

| Themes | <i>Loss of sense of self</i> | <i>Reliance (Self)</i> | <i>Reliance (Others)</i> | <i>TBI is a hidden disability</i> | <i>Chronic but transient suicidality</i> | <i>Protective factors</i> | <i>Hope</i> |
|------------------|---|--------------------------------------|---|-----------------------------------|---|--|---|
| Subthemes | Changes in employment Long-term effects of TBI | Distractions Risky behaviours | Support from social network Support from professionals | Poor knowledge of TBI | Triggers heighten suicidality Feeling trapped Poor self-worth | Perceived sense of others loss Positive personal attributes Spirituality | Abstract construct Finding one's sense of self |

Appendix D

Guidance document sent to case managers (interviewers)



GUIDE FOR CASE MANAGERS

Thanks for considering being involved in this research which aims to use semi-structured interviews and then thematic analysis to investigate the lived experiences of those living with ABIs and what might be acting as protective factors against any feelings of hopelessness or suicidality.

This guide includes some background information/rationale on why this research is being conducted, a step-by-step guide, a flowchart for quick reference, interview questions and guidance notes for semi-structured interviews, withdrawal instructions for participant data, and a list of required/optional demographic information. There is also an appendix with written instructions on how to record using Zoom and how to access and upload to OneDrive (for the completed recording and consent form) and copies of the consent form, information sheet and debrief sheet.

Rationale for this research

It will likely come as no surprise to those of you working in the ABI field but the statistics on suicide risk in individuals with TBI are quite startling. It is reported that individuals with TBI have been found to be 3-4 times more likely to take their own lives. Perhaps even more alarmingly these rates can remain constant for up to 25 years post-injury (Knight, Norman & Simpson, 2020).

Despite the shocking statistics, there still remains a lack of recent qualitative research around suicidality and positive coping in populations with ABIs especially using a UK demographic. Qualitative research by Brenner et al. (2009) on a US veteran demographic found *social support, hope and religion/spirituality* to act as protective factors. Hopefully gaining a better understanding of what might act as protective factors will help to inform interventions and support strategies and reduce feelings of suicidality in those living with ABIs.

Since this research has very important implications, we are very keen to get the richest most accurate/relevant data possible from the participants about their reasons for living post-injury and want to really capture their lived experience as they are the actual experts. To achieve this, we feel that case managers who already have established relationships and rapport with the clients will be best placed to conduct the interviews.

The aim is for this research to be published beyond the dissertation and to eventually be published in an academic journal. Once hopefully published It will be contributing to a very under-researched area that has important implications for individuals living with ABI, their families and any professionals involved in their care.

Your assistance in conducting this research is very much appreciated and this study would not be possible without your help.



Step by step guide

1. The first step is to identify an appropriate client to interview (must be one year plus post ABI, between 18-65 years old, psychologically stable and cognitively able for interview, and ideally someone who has experienced feelings of suicidality at some stage post ABI but not with current ideation)
2. Then gain their verbal consent/expression of interest and provide them with a copy of the **information sheet** by post or via email and arrange a suitable date/time and location for the interview (which is *likely to last 30-60 mins and needs to be in a private and quiet space.*)
3. Please now email me at catalana.parris@students.plymouth.ac.uk to let me know that you are participating so that I can send you the link to access the OneDrive folder (it is a very easy process but there are detailed instructions and a demonstration video available for how to access and upload to OneDrive in case anyone is unsure)
4. On the day of the interview first please try your best to put the participant at ease by making normal conversation, re-establishing rapport, and checking in with them. Please thank them for taking part and remind them there are no right or wrong answers that we just want to know about their experiences.
5. The next step is to give them the **information sheet** again and allow them some time to go through it offering them the opportunity to ask any questions (*they can keep the information sheet*). Remind them their contributions will be anonymous. The recordings will be kept in a password protected file until transcribed at which point any identifying details will be removed and then the recording will be destroyed.
6. If they are satisfied, and have asked any questions they may have and are still willing to participate then please give them the **consent form** to sign and give back to you (*I will need a copy of the consent form for the research*)
7. Then check if they are ready to begin and please **start recording on zoom** (*first check that volume and microphone are on etc.*) (*Please see Appendix A for separate instructions for how to record via Zoom, there is also a short demonstration video available if preferred*). Please note that it is not necessary to be visible on the call – we only require the audio recordings.
8. Then please conduct the interview using the **question sheet** (interview schedule) but using prompting questions where helpful to elicit more information, asking any follow-up questions that feel relevant and rephrasing or clarifying anything that the participant is unsure of.

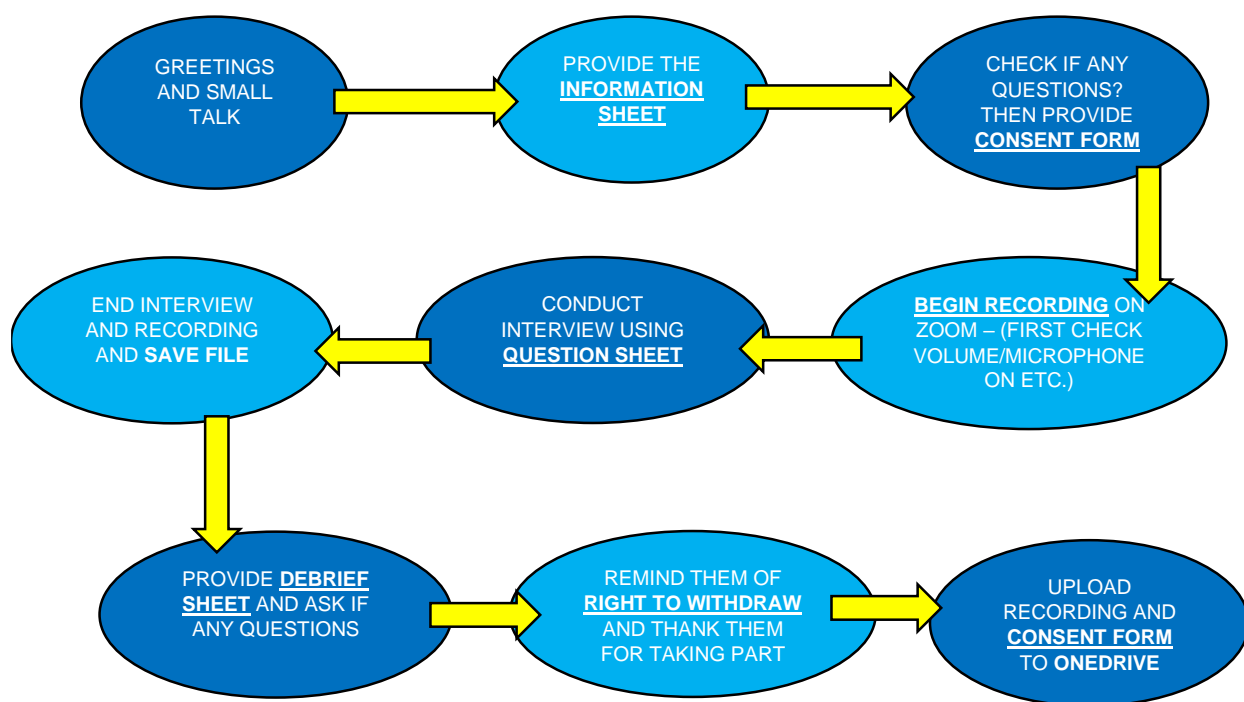
9. Once the interview is over please end and then **save** the recording
10. Provide the participant the **debrief form** and allow them to ask any questions they might have.
11. Thank them for taking part and remind them of their right to withdraw their data at any point up until 60 days after the interview has taken place (*please contact Dr Alyson Norman alyson.norman@plymouth.ac.uk to do so*)
12. Please now **upload recording and consent form to OneDrive** (*please see Appendix B for separate instructions for how to do this, there is also a short demonstration video available if preferred*)

If you have any questions or concerns, please feel free to get in touch with me. Please also remember to email me so that I can send the invite link to upload to the OneDrive folder.

catalana.parris@students.plymouth.ac.uk



Flowchart for day of interview





Interview schedule and semi-structured interview guidance

Interview Schedule

1. What challenges or difficulties have you faced since your brain injury occurred?
2. What ways have you found to cope with your difficulties and challenges since your injury?
3. Some people post-injury struggle with difficult thoughts and feelings. What experiences, if any, have you had with feeling low?
4. How have you managed such thoughts and feelings since your injury?
5. What things in your life support you when you are feeling low?
6. What are your current hopes and your hopes for the future?

Guidance notes

Although it is important to cover the content of the above questions the benefit of a semi-structured interview is that it allows some flexibility to see where the conversation leads. This includes asking additional relevant questions, rephrasing where needed and expansion or elaboration aided by probing questions.

Semi-structured interviews have a fairly open framework which allows for focused, conversational, two-way communication. They are a conversation where the interviewer knows what they want to cover and has a set of questions and a foundation of knowledge to help guide the exchange.

Some questions are created/thought of during the interview, allowing both the interviewer and the person being interviewed the flexibility to discuss issues or probe for details. This semi structured format allows for much richer and more detailed responses to be captured.

Please also remember to monitor the participant for any signs of distress and if needed the interview can be stopped and completed in multiple sessions if they need a break or if it becomes too much at any time.



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Instructions for withdraw of participant data

The participant has the right to withdraw from this study at any point up until 60 days post interview. Furthermore, any data that is collected will only be used with their permission. If they wish to withdraw their data from this study please feel free to contact the principal investigator Alyson Norman: alyson.norman@plymouth.ac.uk

There is a time limit of 60 days for data withdrawal as due to the steps involved in the analysis of the data it would not be practical to try to separate participant data from the main analysis after this point.



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Demographic information

Thanks very much for your assistance with this research. There is some vital demographic information that is required and there is some additional demographic information that would be very helpful for the research but is not all needed if unknown or too difficult to obtain.

Vital demographic information:

- Age
- Gender
- Type of ABI
- How ABI was sustained
- Date ABI acquired

Additional demographic information (please include what you can):

- Nationality/country of birth
- Relationship status
- Any children/dependents
- Religion
- Level of education obtained

Please can demographic information be uploaded on a document to the OneDrive folder or emailed to me at catalana.parris@students.plymouth.ac.uk

Appendix A

Recording interviews via zoom

Thanks for your assistance with this research and please see below instructions on how to record using Zoom. You can record via Zoom even when not on an active call with someone else so these instructions work for if you are doing the interviews face to face (in which case just open up your laptop and position near to you both and follow the instructions below) or if conducting the interviews remotely via Zoom (in which case skip step 1, as you will already be on the call with them but otherwise the instructions remain the same).

1. When on Zoom homepage → Select **“Host meeting”** (on top right of screen) → You can choose either **“With video on”** or **“With video off”** (but I only need audio for the research so video is not necessary)
2. Once inside the meeting at the bottom of the call screen there is a toolbar and midway along the toolbar there is a gray circular button ● that says **“record”** → Click on the **“record”** button and select **“Record on this computer”** (Once recording at the top left hand side of the screen you should see a small flashing red circle next to the words *“recording”*) – There are buttons on the toolbar at the bottom of the screen to both **“pause”** and **“stop”** the recording.
3. Once the interview is complete click on the **“stop recording”** button which is a small black square ■ (you should see a small message flash up on the top right hand side of the screen saying *“The recorded file will be converted to MP4 when the meeting ends”*)
4. Once you have stopped recording → Click on **“end”** a small red button on the bottom right hand of screen then select **“end meeting for all”** → A box will then flash up saying **“convert meeting recording”** and it will take a few moments for it to automatically convert the file into MP4 format
5. Once converted it will save the file to your computer, and the folder that it has saved the file in should now pop up. On my computer it was saved to a folder called **“Zoom”** in **“My documents”** and it automatically named it using the date/time and the name *“Catalana Parris’ Zoom Meeting”* (it is possible that if you have different settings that it may save the file to another folder but it should hopefully be self-explanatory/easy to locate)
6. Once saved to your computer please then upload the file to the folder on Microsoft OneDrive (please see separate instructions for how to upload to OneDrive)



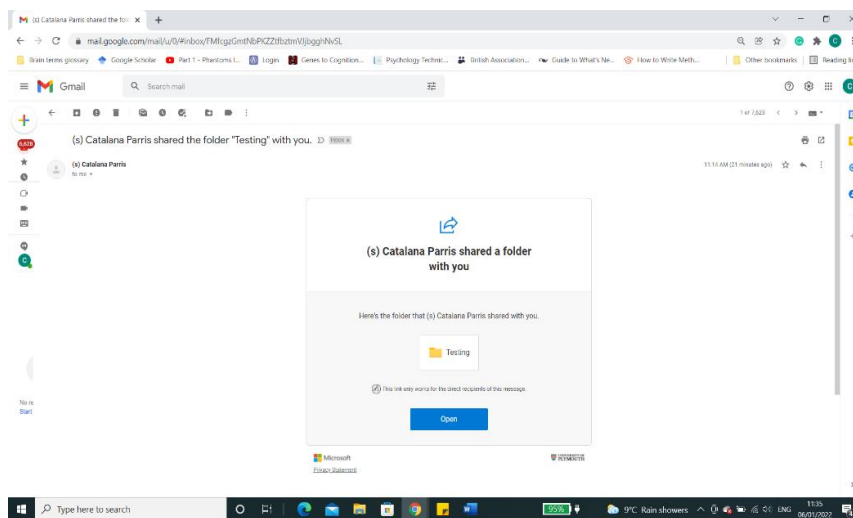
Link to demonstration video <https://youtu.be/7Bfu6uUjKFg>

Appendix B

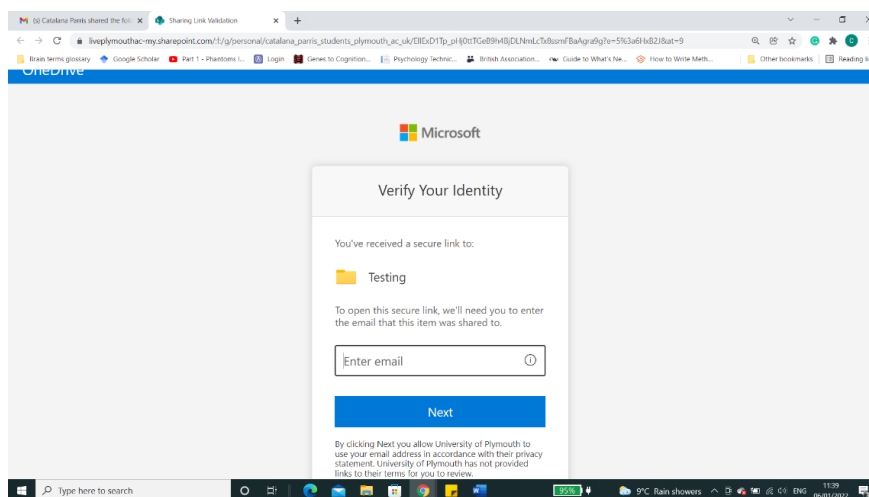
Instructions for uploading to OneDrive shared folder

The easiest method for sharing the interview recording files with me is for the various case managers to have access to a shared folder which they can easily drop their completed interview recording in. (The file size will be too large to be emailed) - You do not need to have a Microsoft email address to access OneDrive folders as they can be accessed by anyone who has received the invitation link.

1. You will receive an invitation link in your email inbox (*Please check your spam/junk folders as it sometimes ends up there*) – Please click on the folder in the image above it is called “**Testing**” - **Please see image below**

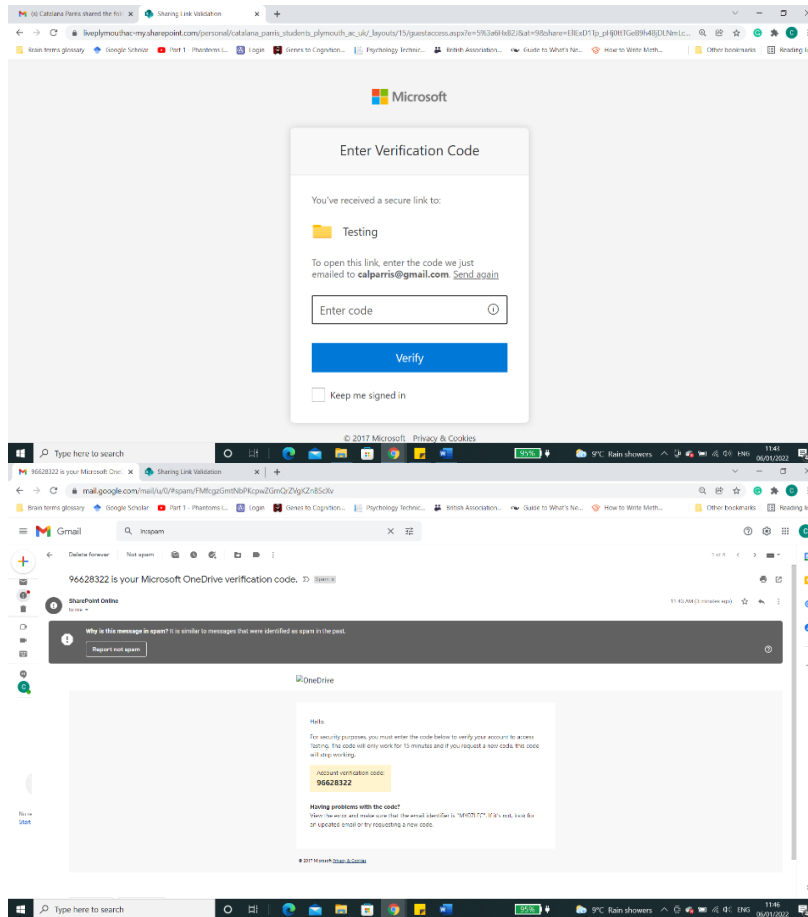


2. It will then open up a pop-up box asking you to verify your email. Enter the email address that the invite link was sent to – **Please see image below.**

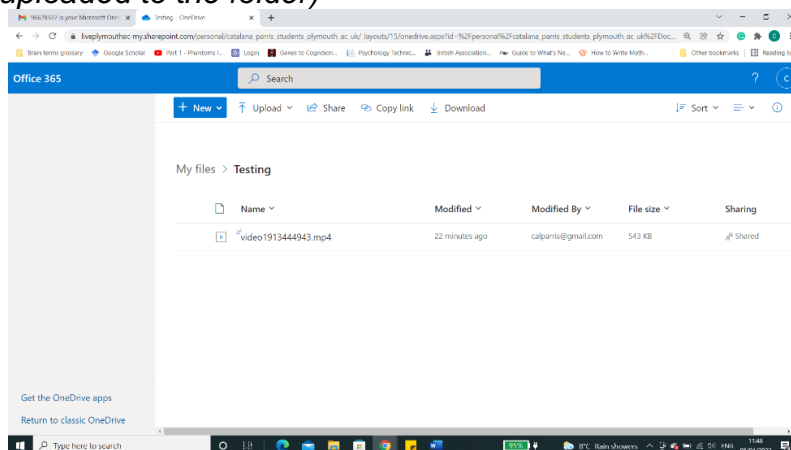


3. It will then open up another pop-up box asking you to enter the verification code that was sent to you email address (*please check junk/spam again*) – you can copy and paste the code from the email straight into the pop-up box -

Please see images below

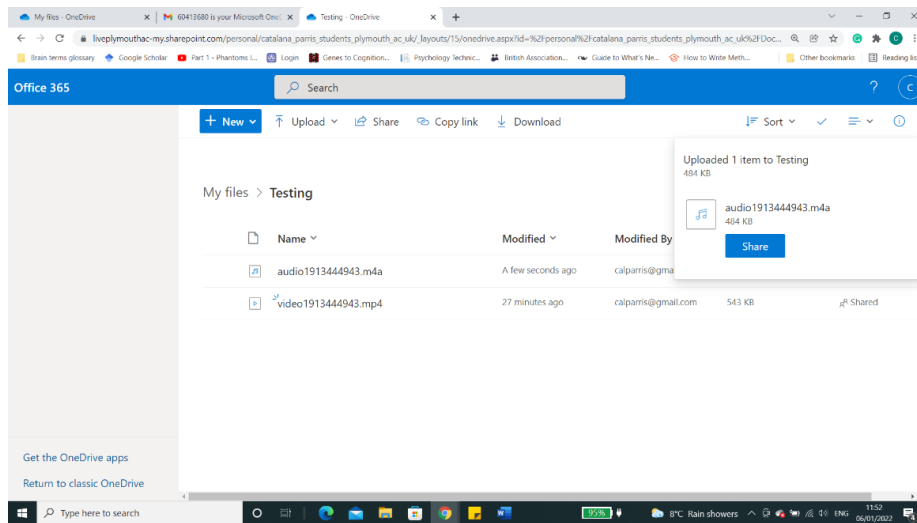


4. You will then be taken to the shared folder where you can upload any files – **Please see image below** (you will see the MP4 file that has already been uploaded to the folder)



5. To upload a file please click on the button called **“upload”** which is on the toolbar at the top of the screen → Then please select **“files”** and choose the MP4 recording from your computer
6. Once uploaded you will see a pop-up box in the top-right of the screen that says **“uploaded 1 item to Testing”** (or whatever the folder name is) and there will be a button saying **“share”** please ignore this pop-up as it is not relevant

as long as you can see the file that you have uploaded in the folder – **Please see image below**



7. As long as you can see the file that you uploaded to the folder then the upload is now complete and you can log out.



Link to demonstration video <https://youtu.be/D8a24GtdCAA>

If you have any questions or concerns please feel free to get in touch with me - catalana.parris@students.plymouth.ac.uk

Appendix C



Participant Consent Form

Title of Research – Reasons for Living Following an Acquired Brain Injury

Name of Principal Investigator

Dr Alyson Norman

Other Researchers

Catalana Parris

Mark Holloway

Sue Jackson

Grahame Simpson

I confirm that:

- I have read and understood the information sheet for this study
- I have been given the opportunity to ask questions regarding the study and I am satisfied with the responses
- I understand that my participation is voluntary and that I am free to withdraw at any time with no negative consequences
- I understand that my data will be destroyed if requested
- I understand that my anonymity is guaranteed for this study
- I agree to my responses being recorded with the knowledge that all answers will be confidential and stored safely with no direct link back to me
- I agree to my anonymised data being used in future possible publications
- I agree to take part in this study under these conditions YES/NO

PLEASE CIRCLE ABOVE AND SIGN AND DATE YOUR CONSENT

Participant signature: _____

Participant name (printed): _____

Date: _____

Appendix D



Information sheet for participants

Name of Principal Investigator:

Dr Alyson Norman

Other researchers:

Catalana Parris, Mark Holloway, Sue Jackson, Grahame Simpson

Title of Research:

Reasons for Living After an Acquired Brain Injury (ABI)

What is the study about?

This research aims to investigate the lived experiences and protective factors in adjusting to life post-injury for individuals following an acquired brain injury.

As a participant what will be expected of me?

Interview study:

You will be asked if you wish to take part in a short interview where you will be asked questions about your reasons for living post brain injury. This will be conducted by your case manager and is likely to last between 30-60 minutes. If you need the interview to be conducted over more than one session then this is fine. You are also able to have a family member or someone else to support you during the interview if required.

What will be involved in the study?

You will first be asked to read this information sheet. You will then have the opportunity to ask any questions you have about the study. If you are then happy to continue, you will be asked to sign a consent form. After the consent form is signed, you will take part in the interview.

During the interview if there are any questions that you would not like to answer please say so and the interviewer will move on. If you feel any distress during the interview, please feel free to take a break and you may withdraw from the study at any point without repercussions. The interview will be recorded and with your permission will be saved to be analysed at a later date. All the information will be anonymized within 60 days of the interview session/s taking place.

After the interview is completed, you will be given a de-brief sheet outlining further details of the study. It is important to restate that you can withdraw from the study at any point without repercussions.

What are the risks and benefits of taking part in this study?

There are no physical risks from this study. However, some of the topics covered in the interview may be sensitive to you and have the potential to cause distress. You may take a break, or even withdraw from the study, if you feel the topics are causing you undue distress.

The benefits of participating in this research are that you will be contributing to an important area of research that has had little investigation. Namely, what are the things that promote wellbeing and support people in adjusting to life post-ABI. This has the potential to provide a better evidence base to assist those with brain injuries.

Confidentiality and anonymity.

All data collected will be anonymised, with only your unique participant number linking you to your data (your name and details will not be linked to your participant number). Data will be stored in a password protected computer or an encrypted USB. The data will be kept for ten years, in accordance with University of Plymouth policy.

Will my participation in this study effect my relationship with University of Plymouth?

In no way will your participation or withdrawal from this study affect your relationship with University of Plymouth or the British Association of Brain Injury Case Managers (BABICM).

Can I withdraw from the study?

You have the right to withdraw from this study at any point up until 60 days post interview. Furthermore, any data that is collected will only be used with your permission. If you wish to withdraw your data from this study please feel free to contact the principal investigator Alyson Norman: alyson.norman@plymouth.ac.uk

Who can I contact for further information?

For any further questions on this study please feel free to contact the principal investigator Alyson Norman: alyson.norman@plymouth.ac.uk

If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance: alyson.norman@plymouth.ac.uk or 01752 584844. If you feel the problem has not been resolved please contact the admin team to the Faculty of Health Ethics Committee: Maurice Bottomley and Becky Anderson FOHEthics@plymouth.ac.uk

Appendix E



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Research debrief form for participants

Name of Principal Investigator:

Dr Alyson Norman

Other researchers:

Catalana Parris, Mark Holloway, Sue Jackson and Grahame Simpson

Title of Research:

Reasons for Living After an Acquired Brain Injury (ABI)

What was the aim of the study?

Thank you for taking part in this study. The aim of this research is to increase our understanding of the lived experiences of individuals post ABI and identify reasons for living (protective factors) following injury. It also aims to discover whether any of these factors are predictive of positive or negative psychological outcomes. That is, do any of these factors tell us who is most at risk of negative psychological outcomes, for example depression, after brain injury. If so, this could potentially allow for more targeted and early support.

If you feel any distress from this study and feel like you need support please feel free to contact your case manager or case worker for individual support.

If you would like any further details regarding the study, feel free to contact the principal investigator Dr Alyson Norman at: alyson.norman@plymouth.ac.uk

Lastly, I would like to remind you of your right to withdraw from this study at any point up until 60 days post interview, this includes any data received from you during the course of this study. Once again thank you for your participation.

If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance: alyson.norman@plymouth.ac.uk or 01752 584844. If you feel the problem has not been resolved please contact the admin team to the Faculty of Health Ethics Committee: Maurice Bottomley and Becky Anderson FOHEthics@plymouth.ac.uk

Appendix E

Information sheet



PLYMOUTH UNIVERSITY - FACULTY OF HEALTH

INFORMATION SHEET FOR PARTICIPANTS

Name of Principal Investigator:

Dr Alyson Norman

Other researchers:

Catalana Parris, Mark Holloway, Sue Jackson, Grahame Simpson

Title of Research:

Reasons for Living After an Acquired Brain Injury (ABI)

What is the study about?

This research aims to investigate the lived experiences and protective factors in adjusting to life post-injury for individuals following an acquired brain injury.

As a participant what will be expected of me?

Interview study:

You will be asked if you wish to take part in a short interview where you will be asked questions about your reasons for living post brain injury. This will be conducted by your case manager and is likely to last between 30-60 minutes. If you need the interview to be conducted over more than one session then this is fine. You are also able to have a family member or someone else to support you during the interview if required.

What will be involved in the study?

You will first be asked to read this information sheet. You will then have the opportunity to ask any questions you have about the study. If you are then happy to continue, you will be asked to sign a consent form. After the consent form is signed, you will take part in the interview.

During the interview if there are any questions that you would not like to answer please say so and the interviewer will move on. If you feel any distress during the interview, please feel free to take a break and you may withdraw from the study at any point without repercussions. The interview will be recorded and with your permission will be saved to be analysed at a later date. All the information will be anonymized within 60 days of the interview session/s taking place.

After the interview is completed, you will be given a de-brief sheet outlining further details of the study. It is important to restate that you can withdraw from the study at any point without repercussions.

What are the risks and benefits of taking part in this study?

There are no physical risks from this study. However, some of the topics covered in the interview may be sensitive to you and have the potential to cause distress. You may take a break, or even withdraw from the study, if you feel the topics are causing you undue distress.

The benefits of participating in this research are that you will be contributing to an important area of research that has had little investigation. Namely, what are the things that promote wellbeing and support people in adjusting to life post-ABI. This has the potential to provide a better evidence base to assist those with brain injuries.

Confidentiality and anonymity.

All data collected will be anonymised, with only your unique participant number linking you to your data (your name and details will not be linked to your participant number). Data will be stored in a password protected computer or an encrypted USB. The data will be kept for ten years, in accordance with University of Plymouth policy.

Will my participation in this study effect my relationship with University of Plymouth?

In no way will your participation or withdrawal from this study affect your relationship with University of Plymouth or the British Association of Brain Injury Case Managers (BABICM).

Can I withdraw from the study?

You have the right to withdraw from this study at any point up until 60 days post interview. Furthermore, any data that is collected will only be used with your permission. If you wish to withdraw your data from this study please feel free to contact the principal investigator Alyson Norman: alyson.norman@plymouth.ac.uk

Who can I contact for further information?

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If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance: alyson.norman@plymouth.ac.uk or 01752 584844. If you feel the problem has not been resolved please contact the admin team to the Faculty of Health Ethics Committee: Maurice Bottomley and Becky Anderson FOHEthics@plymouth.ac.uk

Appendix F

Consent form



UNIVERSITY OF
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PARTICIPANT CONSENT FORM

Title of Research – Reasons for Living Following an Acquired Brain Injury

Name of Principal Investigator

Dr Alyson Norman

Other Researchers

Catalana Parris

Mark Holloway

Sue Jackson

Grahame Simpson

I confirm that:

- I have read and understood the information sheet for this study
 - I have been given the opportunity to ask questions regarding the study and I am satisfied with the responses
 - I understand that my participation is voluntary and that I am free to withdraw at any time with no negative consequences
 - I understand that my data will be destroyed if requested
 - I understand that my anonymity is guaranteed for this study
 - I agree to my responses being recorded with the knowledge that all answers will be confidential and stored safely with no direct link back to me
 - I agree to my anonymised data being used in future possible publications
- I agree to take part in this study under these conditions YES/NO

PLEASE CIRCLE ABOVE AND SIGN AND DATE YOUR CONSENT

Participant signature: _____

Participant name (printed): _____

Date: _____

Appendix G

Debrief sheet



PLYMOUTH UNIVERSITY - FACULTY OF HEALTH

RESEARCH DEBRIEF FORM FOR PARTICIPANTS

Name of Principal Investigator:

Dr Alyson Norman

Other researchers:

Catalana Parris, Mark Holloway, Sue Jackson and Grahame Simpson

Title of Research:

Reasons for Living After an Acquired Brain Injury (ABI)

What was the aim of the study?

Thank you for taking part in this study. The aim of this research is to increase our understanding of the lived experiences of individuals post ABI and identify reasons for living (protective factors) following injury. It also aims to discover whether any of these factors are predictive of positive or negative psychological outcomes. That is, do any of these factors tell us who is most at risk of negative psychological outcomes, for example depression, after brain injury. If so, this could potentially allow for more targeted and early support

If you feel any distress from this study and feel like you need support please feel free to contact your case manager or case worker for individual support.

If you would like any further details regarding the study, feel free to contact the principal investigator Dr Alyson Norman at: alyson.norman@plymouth.ac.uk

Lastly, I would like to remind you of your right to withdraw from this study at any point up until 60 days post interview, this includes any data received from you during the course of this study. Once again thank you for your participation.

If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance: alyson.norman@plymouth.ac.uk or 01752 584844. If you feel the problem has not been resolved please contact the admin team to the Faculty of Health Ethics Committee: Maurice Bottomley and Becky Anderson FOHEthics@plymouth.ac.uk

Appendix H

Transcripts (removed for protection of participants)

Appendix I

Case manager perspectives (removed for protection of participants)

Appendix J

Reflexive statement

I am developing as a researcher but I am drawn to and feel that this study aligns with a contextualist epistemology and an ontological position between critical realism and relativism. It is important to note and disclose that I have personal and familial experience of ABI, suicide, substance misuse, and various mental health conditions. Most notably having lost my father to suicide (he had in fact experienced several head injuries throughout his life but I had not made that association until reflecting on this throughout the research process) and having had a significant head injury myself when younger resulting in a fractured skull, an extended period of unconsciousness and admission to the intensive care unit. Therefore, I will undeniably (and unavoidably) be approaching this research with my own assumptions, opinions, biases, and expectations. However, I view my lived experience and familiarity with some of these matters as a strength, as well as acknowledging the potential for preconceived ideas and biases affecting how I interpret and analyse the research. However, no research is ever truly without bias, and I have done a reflexive thematic analysis, kept a reflective journal/log during the research process and made sure to continually refer back to the literature and research question to protect the integrity and validity of the analysis and research.