Research Project Portfolio

University of Nottingham
Division of Psychiatry and Applied Psychology
School of Psychology

Doctorate in Clinical Psychology

2024

Adapting a self-help acceptance and commitment therapy (ACT) intervention for adults with a spinal cord injury (SCI)

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Submitted in part fulfilment of the requirements for the Doctorate in Clinical Psychology

Word Count: 21,303

Acknowledgements

I would like to say thanks to all the participants who kindly took part in my study and were passionate about what we are trying to create. This gave me motivation to keep going at difficult times and all your thoughts and opinions were greatly appreciated!

I would secondly like to thank both Dr Danielle De Boos and Dr Mark Gresswell, my research supervisors. They have provided lots of support both emotional and research related throughout this project and at times some much needed comic relief!

I would also like to say thank you to my work colleagues in my qualified job who have been very understanding and offered plenty of encouragement as I have finished this project.

I would like to thank my family, friends and husband, Alex who have kept me going with lots of encouragement and support. I couldn't have done it without you!

Finally, thanks to my fellow trainees who have been the perfect group of people to share three years of the doctorate with and have always been there for support and guidance when asked.

A heartfelt thankyou to you all!

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Portfolio Abstract

The psychological impact of SCI is well known and there is a growing body of evidence supporting the effectiveness of Acceptance and Commitment Therapy (ACT) for people with a spinal cord injury (SCI). However, the acceptability of the ACT approach for those with a SCI and its underlying processes has rarely been considered. Furthermore, well known barriers to accessing mental health support for those with SCI such as, inadequate transportation, financial resources and stigma are significant. Therefore, self-help is suggested as a potentially useful intervention for providing support to this population as it has shown some efficacy in other populations. This study utilised a qualitative design to explore acceptability of an ACT self-help manual via 14 semi-structured interviews with those with a SCI, family members and professionals working with SCI. Furthermore, it aimed to explore and understand the lived experiences of those with a SCI and their relevance to the ACT model. The data gathered was analysed using Reflexive Thematic Analysis. Three main themes were identified: (1) ACT Concepts, with three sub-themes identified (i) Is acceptance important or achievable, (ii) Cognitive Defusion, too airy fairy, (iii) Values important to rehabilitation; (2) Self-help, with three sub-themes identified, (i) Self-help after adjustment, (ii) Self-help too labour intensive, (iii) Language is the key to engagement; (3) Lived Experiences, with three sub-themes identified (i) life is a battle, (ii) deal with it or hide away, (iii) different to the person I was before. The main themes were discussed in the context of the wider literature and suggestions for adaptations to the self-help manual, including simplification, personalisation, amending language use and considering a hybrid approach including both self-directed and professional led modules were considered to improve acceptability of the manual. Generally, participants deemed ACT to be an acceptable and relevant approach based on their experiences after SCI. This study provides information on the acceptability of ACT processes for those with SCI and has supported the development of a self-help manual specifically designed for those with a SCI.

Statement of Contribution

All parts of this thesis were completed primarily by me, this included project design, applying for ethical approval, recruiting participants which was completed via reaching out to charitable organisations, professionals known to me or members of the University SUCAP panel, designing project materials, arranging and conducting semi-structured interviews, arranging transcription of interviews, data analysis and write up. I did have support via regular project supervision sessions with Dr Danielle De Boos and Dr Mark Gresswell (Research supervisors and Course codirectors). During these research meetings we discussed any challenges I was having during the process of the study and received support and guidance. I also asked for support during the initial coding process, and we went through an initial interview transcript together to ensure I was completing the process correctly. I also received guidance during the write up phase and gathered feedback on my journal paper and sections of the extended paper.

Abstract

The psychological impact of SCI is well known and there is a growing body of evidence supporting the effectiveness of Acceptance and Commitment Therapy (ACT) for people with a spinal cord injury (SCI). However, the acceptability of the ACT approach for those with a SCI and its underlying processes has rarely been considered. Self-help support could be a potentially useful intervention for providing support to this population as it has shown some efficacy in other populations. This study utilised a qualitative design to explore acceptability of an ACT self-help manual via 14 semi-structured interviews with those with a SCI, family members and professionals working with SCI. The data gathered was analysed using Reflexive Thematic

Analysis (Braun & Clark., 2019). Two main themes were identified: (1) ACT Concepts, with three sub-themes identified (i) Is acceptance important or achievable, (ii) Cognitive Defusion, too airy fairy, (iii) Values important to rehabilitation; (2) Self-help, with three sub-themes identified, (i) Self-help after adjustment, (ii) Self-help too labour intensive, (iii) Language is the key to engagement. This study provides information on the acceptability of ACT processes for those with SCI and has supported the development of SCI specific self-help manual.

Keywords: Acceptance and Commitment Therapy, Spinal Cord Injury, Self-Help, Acceptability, Qualitative.

Conflict of interest statement: The author has no conflicts of interest to declare.

Funding information: This research was funded as part of a Doctorate in Clinical Psychology by the University of Nottingham. The University of Nottingham had no involvement in the development, implementation, or writing of this study.

Introduction

Spinal Cord Injury

Spinal Cord Injury (SCI) is a life-changing neurological condition resulting from damage to the spinal cord or nerves at the end of the spinal canal. The damage results in a disruption of sensory and motor signals that are conducted via the spinal cord, resulting in a loss of limb function (National Institute for Health and Care Excellence [NICE], 2016)[1]. SCI is estimated to impact 50,000 people in the UK, with 2,500 individuals sustaining injuries every year (Aspire, n.d.). Rehabilitation after SCI is complex with focus often placed on improving physical health[2].

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[1] See section 1.2 of the extended paper for more information on SCI.

[2] See section 1.3 of extended paper for more information on rehabilitation.

Psychological impact of SCI

The emotional impact of SCI is significant and struggles with social and self-stigma, changes to relationships and financial pressures can result in social disconnection, reduced self-efficacy and low mood (Craig et al., 2009; Dunn, 2010; Engblom-Deglmann & Hamilton, 2020; Monden et al., 2020; Weber et al., 2021; Woolrich et al., 2006).

Low mood has links to poorer physical health outcomes and suicidal ideation is three times higher than the general population. (Craig et al., 2009; Fann et al., 2011; Spinal Injury Association; SIA, 2021). Many report their emotional needs are not met post-SCI due to inadequate and inaccessible support services (Noreau at al., 2014; SIA, 2021)[3]. These inadequacies have prompted recommendations for targeted support for mental health post-SCI (SIA, 2021).

Investigators have attempted to determine what factors increase positive outcomes post-SCI and acceptance was particularly important (Elfstrom et al., 2002). Acceptance is correlated with personal growth and significantly predicts psychological quality of life (QoL) and reduced psychological distress (Aaby et al., 2020; Elfstrom et al., 2002). Consequently, with acceptance suggested as an important construct for improved outcomes post-SCI the development of an acceptance-based intervention is important.

Acceptance and Commitment Therapy

Acceptance and Commitment Therapy (ACT; Hayes et al., 1999) is a “third wave” cognitive behavioural therapy that aims to increase psychological flexibility, defined as our ability to contact the present moment, then decide to change or persist in behaviour that serves our values, rather than reacting to immediate thoughts and feelings (Hayes et al., 2006). ACT aims to increase psychological flexibility via six core processes shown in figure one.

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[3] See section 1.4 of extended paper for more information on the psychological impact of SCI.

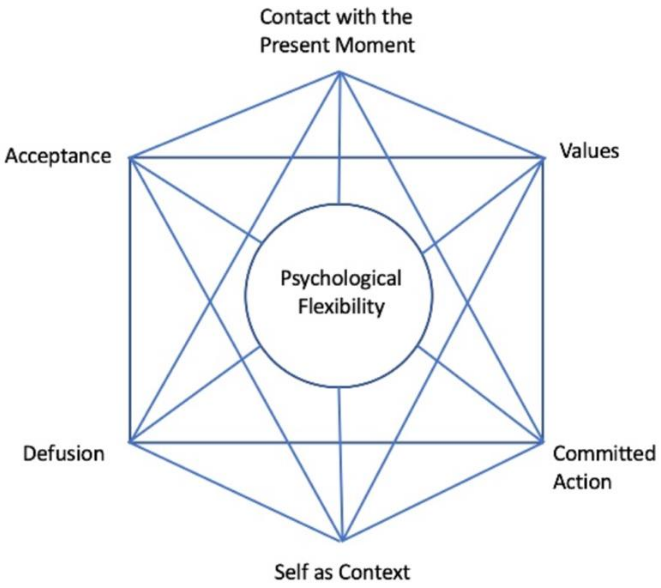

Figure one: ACT Hexaflex (Hayes et al., 2006).

Ultimately, ACT suggests each process overlaps and intertwines in the pursuit of increasing psychological flexibility (Hayes et al., 2006)[4][5].

ACT can improve mental health in populations with long-term chronic conditions (Graham et al., 2016). However, challenges faced after SCI are thought to be different from chronic conditions due to their rapid onset and common plateau after a period of functional improvement alongside complex social and psychological factors (Budd et al., 2022; Hall et al., 1999). Furthermore, barriers to accessing therapy for those with SCI, such as, inadequate transportation, financial resources and stigma are significant (Fann et al., 2011; Torabian et al., 2019) indicating the need for a tailored approach.

Initial studies investigating therapist-delivered ACT for those with a SCI indicate promising results in improving psychological flexibility, emotional regulation and mental health (Khanjani et al., 2021; Torabian et al., 2016). However, these studies had small sample sizes and do not provide commentary on participant drop out data therefore gaining information on how acceptable participants found the interventions is unclear. The self-selecting sample within these studies may also represent a population different from the typical. The primary researcher initially aimed to investigate efficacy of an existing ACT self-help manual (Shepherd et al.,

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[4] See section 1.6 of extended paper for more information on psychological flexibility.

[5] See section 1.7 of extended paper for more information on ACT.

2022) for individuals with SCI but struggled with recruitment. Anecdotal information suggested the existing ACT manual was too confronting indicating to the primary researcher that acceptability of ACT interventions for those with SCI is poorly understood[6].

Self-help[7] has been found to be effective in other populations (French et al., 2017; Shepherd et al., 2022) however the ACT manual used in the latter study[8] is a generalised manual and not SCI specific. The SIA (2021) recommend psychological support should be informed by first-hand knowledge of SCI. Given the described complexities, recommendations from the SIA (2021) and importance of acceptance on positive outcomes post-SCI, further investigation into the acceptability of ACT and adaptation of an acceptance-based self-help intervention specific to SCI is an important step to reducing barriers and improving outcomes (Elfstrom et al., 2002; Kennedy & Jones, 2017)[9].

Study Aims

The study aimed to answer the following questions:

- Is ACT an acceptable therapeutic approach to meet the psychological needs of individuals with a SCI, when delivered using self-help?
- Do the carers and family of people with a SCI perceive ACT to be acceptable and meet their psychological needs when delivered using self-help?
- Is the "ACTing towards better living" manual acceptable to individuals with a SCI, their family or carers and professionals working alongside those with a SCI?
- What adaptations are required to increase acceptability of the "ACTing towards better living" manual for those with a SCI.

Methods

Design

Initially, this study aimed to use an interventional single case study design to determine the efficacy of an existing ACT self-help manual (Shepherd et al., 2019) in a population of individuals with a SCI. However, due to difficulties with recruitment this study was amended to utilise a qualitative design[10]. Reflexive Thematic Analysis (RTA; Braun & Clark, 2021) was

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[6] See section 1.10 of extended paper for information on acceptability.
[7] See section 1.9 of extended paper for information on self-help.
[8] See section 2.4 of extended paper for further information on study materials.
[9] See section 1.8 of extended paper for information on ACT and SCI.
[10] Further information on this decision is discussed in section 1.8 of the extended paper.

chosen as it allowed for both inductive and deductive coding. Both inductive and deductive frameworks were important as this research aimed to explore participants experiences of using an ACT informed self-help manual and therefore focused inductively on the participants experiences of SCI and how these fit with this type of intervention and more deductively on their opinions of the ACT concepts and format of using a self-help manual. RTA (Braun & Clark, 2021) posits analysis of qualitative data is subjective and occurs between the researcher, data and wider context (Cowie & Braun, 2022). Analysis was informed by Critical; Realism (CR; Bhaskar, 1975)[11]. Ethical approval was granted by the Leeds East Research Ethics Committee, IRAS project ID: 306658 (22/YH/0079; Appendix B)[12] .

Recruitment

Recruitment cultivated participants from three groups, individuals with a SCI, their family and carers and professionals working with SCI[13]. A purposive sampling method was used via a poster (Appendix C) displayed on a Facebook SCI support group, Back-up's twitter page and in the SIA's monthly newsletter, 'The Voice', to attract individuals with a SCI and their family or carers. The poster described the study and how to contact the research team[14]. Organisations supporting those with a SCI were contacted by the primary researcher and given the poster asking staff to take part.

Inclusion criteria

Participants were required to fulfil these criteria:

- Have a SCI.
- Be a carer or family member of someone with a SCI.
- Be a professional with experience of working with those with a SCI.
- Aged 18 or over.

Exclusion criteria

Participants were excluded if they were unable to take part in an interview, for example due to difficulties communicating[15].

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[11] See section 2.1 of extended paper for more information on ontology and epistemology.
[12] See section 2.8 of extended paper for more information on ethical considerations.
[13] See section 1.9 of extended paper for further information on rationale for these participants.
[14] See section 2.3 of extended paper for more information on participant recruitment.
[15] See section 2.2 of the extended paper for rational of inclusion/exclusion criteria.

Participants

14 semi-structured interviews were completed, this number was contingent upon the quality of the data rather than data saturation which is not believed to be an appropriate method for determining sample size in RTA (Braun & Clark, 2021). The primary researcher determined the data received at participant 14 did not generate new ideas related to the aims of this study. This research recruited participants from three groups however, the carers or family members and professionals did not have opposing views and confirmed ideas generated by those with SCI therefore further recruitment from these groups was not required. Table one details the demographics of participants.

Table 1

Participant Demographic Information[16].

Categories		Number	%
		N= 14	
Participant Category	Individual with SCI	11	79%
	Carer	1	7%
	Professional	2	14%
Gender			
	Male	8	57%

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[16] See section 2.3 of extended paper for further participant demographic information.

	Female	6	43%
Age			
	18-28	1	7%
	29-39	2	14%
	40-50	4	29%
	51-61	1	7%
	62-72	6	43%

Reflexivity and Positionality

A key aspect of quality reflexive qualitative research is understanding the positionality of the researcher undertaking the research (Braun & Clark, 2021). The primary researcher has worked within neurological settings and alongside individuals with brain injuries and spinal cord injuries for six years prior to undertaking this research. Working with individuals with SCI in several roles, from healthcare assistant to assistant psychologist, allowed the researcher to understand some of the challenges and what life can be like. Understanding the psychological impact of SCI is relatively understudied and this was shocking to the primary researcher. Some participants described limited psychological support after injury and the manual offered has only recently included any mental health or psychological support so developing this manual was something deemed to be incredibly important. To ensure the primary researchers experience was acknowledged during the coding process effort was taken not to take preconceived ideas but instead construct meaning from the data. The primary researchers also discussed this with research supervisors during regular supervision. Furthermore, the primary researcher went into each interview with participants openly so as not to ask leading questions instead focusing on keeping the interviews open ended.

Study Materials

The “ACTing towards better living” manual was used for this research (Shepherd et al., 2022). Adaptations were made to this manual before participants reviewed it, including amending wording to reference SCI and including boxes for participant comments to serve as aide memoires during their interview[17].

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[17] See section 2.4 of the extended paper for more information on study materials.

Procedure

Participants were a self-selecting sample that contacted the primary researcher and provided informed consent (Appendix E for information sheet, Appendix F for consent form). Four participants were contacted by the primary researcher via email following contact by a person known to both the primary researcher and the participant[18]. Following consent, an appointment to complete a semi-structured interview either using Microsoft (MS) Teams (N=10) or telephone (N=4) was arranged. Participants were sent a copy of the manual to read prior to the interview. Upon completion of their interview (Appendix G) participants were sent a £10 shopping voucher[19].

Analysis

The participants' written transcripts were analysed by the primary researcher using RTA (Braun & Clarke, 2019)[20]. Concurrent inductive and deductive coding was completed during data analysis. A deductive framework was constructed prior to coding (Appendix H) based on the "Theoretical Framework for Acceptability" (TFA; Sekhon et al., 2017) that allowed identification of codes related to suggested concepts of acceptability[21]. The primary researcher initially read participant transcripts gaining familiarity with the data. Initial coding involved reading each transcript and coding data related to the research questions or deductive frameworks. The primary and secondary researchers discussed initial coding to ensure the codes were effective and discussed emerging themes and reflections. Once initial coding was completed the primary researcher clustered codes into initial themes and conducted checks to ensure themes were reflected in the data (Braun & Clark, 2019). Initial themes were revised and overlapping themes collapsed creating sub-themes where necessary. This ensured theme and subtheme definition and selection were not guided by interview questions, but through methodical coding and analysis of data. A thematic map was created[22] and reorganisation continued until the primary researcher believed themes were reflective of the data and answered the research questions.

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[19] See section 2.7 of extended paper for more information the study procedure.

[20] See section 2.6 of extended paper for more information on RTA.

[21] See section 1.10 of extended paper for more information on TFA.

[22] See section 2.6 of extended paper, figure one for thematic map.

Results

Participants have been given pseudonyms and codes used to indicate groups; LE – lived experience of SCI, F – a family member of someone with a SCI, or P – a professional. Quotations were edited to omit hesitations or repetition using (…) but only when this does not alter the meaning[23].

Themes

Two main themes were identified with six sub themes[24].

Theme one: ACT Concepts

This theme comprises discussion about perceived acceptability of aspects of the ACT model (Hayes et al., 2006) as portrayed in the manual.

Subtheme 1a: 'Is acceptance important or achievable?'.

Acceptance was a concept widely discussed by participants and conjured differing viewpoints. Donald described his experiences post-SCI and said at one timepoint taking his own life or acceptance were the only options, 'you've got two choices, find yourself somewhere with a gun or get on with it, that was part of the process' (LE). Donald suggests acceptance is a necessary part of moving forward with your life after SCI and this was also described by Greg, 'a degree of acceptance is necessary, you can't get too bitter about it' (LE). Acceptance was also considered to be one of the building blocks of rehabilitation after injury and some of the acceptance exercises included in the manual were 'really, really good exercises to get people to start accepting' (Mark, LE). Mark also described the manual as the beginning of developing acceptance, 'so I think that's the starting point of acceptance' (LE). Acceptance was evidently an important concept and how it was described in the manual was acceptable and even effective in developing acceptance.

A conflicting view of acceptance was constructed with some participants suggesting focusing too much on this concept within the manual could be damaging to people after SCI who might become resigned to their situation.

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[23] The results section is formatted based on guidance from the Neuropsychological Rehabilitation Journal and APA guidance on quotes https://apastyle.apa.org/style-grammar-guidelines/citations/quoting-participants.
[24] See section three of the extended paper for the extended results.

‘I think saying to somebody you’ve got to accept this and live like this day by day; I don’t think that’s going to be the best thing…I don’t think they’re going to accept it. I think they’re going to fight against it’ (Nicole, LE).

‘Yeah. And just accepting it and sitting back. I mean you just do nothing, I think there is balance to the situation as well, I think if you go too far and then you could make people feel you know… become rather resigned to that situation rather than having any fight to continue, you know’ (Greg, LE).

Participants suggested there is an element of fighting against the reality of life after SCI that could be helpful or motivating because the alternative would be giving up. Potentially, these beliefs could be a barrier to engagement with the acceptance concept and exercises discussed in the manual. Paul described something similar when discussing his experiences after SCI.

‘Everything had changed, not just the injury, but my business would have to close because obviously I couldn't do my job anymore. We have to move house because the house wasn’t suitable for somebody who's now probably in a wheelchair. Pretty much everything has changed. That's a huge thing to deal with you kind of have to deal with it to a degree. You can't really sort of set that anxiety free and say OK this has happened but I need to move on with my life you know you need, you do need to have to go through that grief process’ (Paul, LE).

Paul indicated the gravity of changes to his life after injury would be difficult to accept and a period of grieving is necessary before acceptance can be considered. Potentially, the sudden and catastrophic nature of these changes to every part of life after injury for some people can make developing acceptance particularly challenging. Others agreed with this view and suggested acceptance could be unattainable for some, ‘…although there is still no such thing as I've said earlier as full and complete acceptance even now at 42 years’ (Donald, LE), ‘There's a few things in there, but it's the business of accepting the situation and that sort of thing. I'm not sure I've ever accepted it’ (Greg, LE),

‘For five years on. He can play again, but he's not good enough to be at their level. But he's got other things that he's doing. This is part of the… charity team now. Yeah. So, they're all different, but they're not all capable, I would have said of accepting’ (Callum,LE).

These quotes suggest there is balance required between developing acceptance and becoming defeated by your circumstances. People described individual differences regarding their experiences of acceptance after injury with some suggesting that it would be too difficult. This could impact acceptability of the manual however, acceptance within ACT is not an endpoint but something to work towards therefore ensuring this is effectively communicated is important to this population.

Other factors for improving acceptability of the manual were discussed such as the importance of timing. Nicole and Mark gave their opinions:

‘No, I don't think they'll be able to get round acceptance…that very early stage, no. Absolutely not’ (Nicole, LE), ‘You know, there are some people that it takes years, yeah, to accept what's happened. I've got a lady at the moment, she's eight years post injury and she's only just. I need to face what I've what's happened to me, yeah’ (Mark, LE).

Nicole and Mark suggest that it is more difficult to begin accepting earlier on but for some the process could take years to feel ready. However, there is no consensus with suggestions from professionals and those with lived experience between one and six years after injury,

‘reach a year before changes or even just before a year, yeah, before the acceptance. And you know the values of still continuing to enjoy life. And changes will be much, will be more clear to them’ (Rachel, P), ‘I don't know. I think there's a use for it, but maybe 6 plus years down the line’ (Nicole, LE).

This illustrates the variability of time required for people to begin accepting after SCI and this differed between those with lived experience and professionals. Implications for offering the manual after an initial adjustment period post-rehabilitation may improve acceptability.

These quotes illustrate a person’s acceptance is personal and variable however, offering support when people have undergone their initial rehabilitation, left the spinal centre and are settled back at home might be the most opportune time to foster acceptance. Greg agreed that a period of adjustment to both physical and mental changes is required, ‘People would need a period of adjustment before they're even in a position to start accepting. Physically and mentally, yes’ (Greg, LE).

Recommendations for the manual related to the tone of the acceptance section were also constructed with Greg and Donald.

‘OK. It has to be said in the way look. This has got to happen in order for you to feel a little bit more fulfilled and so on and so on at some point in your journey as a wheelchair user. Spinal patient, yeah, listen to it if you can. But don't dismiss it out of hand. Yeah, yeah, that, that sort of tone’ (Donald, LE), ‘Don't bother fighting it, because you know there's nothing you can do about it, right? And you don't want that. You know, you, at that stage you really want to be saying, you know, I'm gonna make the most of this’ (Greg, LE).

This suggests the message of acceptance as communicated in the manual should aim to inspire hope with an indication of necessity even if it feels unachievable. Potentially, describing acceptance as an aspiration achieved by action is important to consider when amending the acceptance section of the manual.

In conclusion, acceptance is an important and necessary concept in rehabilitation with evidence to suggest how it is described in the manual is acceptable and prompts development. Despite this, others suggested acceptance could be difficult to develop or even damaging due to the nature of sudden changes post-SCI. Evidently, how acceptance is initially introduced is important due to pre-existing beliefs. Recommendations for a hopeful tone and considering timing were offered.

Subtheme 1b: ‘Cognitive Defusion, too airy fairy?’.

Cognitive Defusion as described in the “ACTing towards better living” manual was discussed by Lee and Callum, they suggested this strategy could be challenging for individuals’ post- SCI due to experiencing ‘big worries’ that are often all consuming.

‘I've got a ramp to get in the house. How do I get upstairs? poor fella. The people spinal cord injured late in life similar sort of age. His problem was he lived in a terraced house and they couldn't do anything for him to get him upstairs we had to sell his house you know all at the same time as dealing with spinal cord injuries. So going to him and saying you know put your put your problems on the leaf send them down the is beyond me’ (Callum, LE), “If I had a dentist appointment, I'd tell myself, don't even think about it till an hour before the appointment. Yeah, but when it's something like the bowels, bladder pressure, sores, spasms. Pain management, falling out your chair, being able to move those things can't be put on the back burner’ (Lee, LE).

Callum and Lee suggest the impact of distressing thoughts is too large for cognitive defusion and indicate the exercises described in the manual would not be helpful. Mark agreed and believed offering these strategies could result in disengagement, ‘But you've got a lot of stuff that's going on… for some people it's gonna be unreasonable to try… That could result in people not engaging’ (Mark, LE). The thoughts Callum and Lee are describing require action and the manual describes ‘cognitive fusion’ as “treating all our thoughts literally” but suggests “cognitive fusion isn’t always a problem, sometimes it is helpful to have opinions about events and act accordingly” (Hayes et al., 2006). Bringing emphasis to the idea that cognitive fusion can be useful with thoughts that require action and planning, within the manual may alleviate these concerns.

Evidently, challenges with negative thoughts are present after SCI with Donald and Mike describing a ‘battle’ and experiences of being on ‘autopilot’.

‘But again, that battle with our thoughts is a continuous one. And you know the circle…you'll get less and less of a circle and you move on’ (Donald, LE), “I'm in a Tesla sometimes, not that I can afford one, but you know, the Tesla autodrive thing, yeah, it was like my body wants to do the…autopilot and I can't do it because physically I just literally can't do it. So I think definitely when it comes to stepping back from your thoughts…understanding where your thoughts come from’ (Mike, LE).

Cognitive defusion techniques may be useful to this population when battling challenging thoughts is continuous and taking time to understand our thoughts and providing a strategy to help manage the ‘battle’ in the manual could be useful. The type of cognitive defusion strategies offered needs to be considered as Mark and Callum indicated some of the exercises were too abstract.

‘The concept of putting your troubles on the leaf and keep sending them down is just beyond me. You know? It's yeah, so. Looking at your cup of tea and working out. Wow, it's got whoa, it's gone. You know all that? It's too hairy fairy for me, that’ (Callum, LE), ‘Engrained, probably atypical male Yorkshireman. From a working-class family, you know. That sort of detaching yourself from your thoughts can be quite difficult. Yeah, it's almost, it's not the norm’ (Mark, LE).

These quotes suggest that the activities discussed in the manual such as, ‘leaves on a stream’ (Appendix J) could be difficult to engage with. Suggestions that the “cognitive defusion” practices could have cultural connections and males from working-class backgrounds may find these activities particularly challenging because of their abstract nature. Acknowledging these opinions and validating this may be useful in increasing engagement. Including a section in the “ACTing towards better living” manual on cognitive defusion is necessary based on the described experiences of participants but focusing on less abstract strategies might increase acceptability. Mark suggested incorporating a check-in with a professional might improve this section of the manual, ‘Every couple of weeks, um, this is probably where every couple of weeks it. A check-in would come in useful, yeah. That's that was one of the areas that I've struggled a little bit’ (Mark, LE). Providing the manual as part of a guided process requires consideration and offering the manual via professionals already involved with participants to provide support could increase engagement with cognitive defusion.

In conclusion, cognitive defusion and the way it is described in the manual could be challenging for some people to engage with. Despite this, cognitive defusion also seemed relevant given the descriptions of an all-consuming battle with thoughts post-SCI. Suggestions that some of the cognitive defusion exercises were abstract and unfamiliar particularly to working-class males, which is known to be a high percentage of those with SCI, could result in disengagement from this section of the manual. Less abstract cognitive defusion activities (Appendix K), and validation that some thoughts require action may increase acceptance of cognitive defusion ideas.

Subtheme 1c: 'Values important to rehabilitation''.

Values are described within ACT as principles that guide the way we would like to live and unlike goals cannot be accomplished. Mike suggested 'Living a meaningful life, stepping forwards, making different choices, learning what matters, what new values and concepts… I think that's really important' (LE). Donald agreed and suggested focusing on what you can still do after injury is also important,

> 'I'd planned to climb Mount Everest or I'd planned, you know…those sort of hopes and aspirations. OK, well, you perhaps. No, you can't do that. But what are you able to do? Figuratively or physically? Yeah. And again, understanding the levels of disability. What? What can a c5 like me do? What can a T1 and so on[25]' (LE)

This indicates the section focused on values within the manual has ideas relevant and acceptable to those with a SCI that are particularly important to focus on. The "learning what matters" section within week five of the manual describes the difference between values and goals and suggests values are an internal compass and goals are steppingstones along the way. Donald discussed his previous goals that became unattainable after SCI and the impact the injury has had on what he can now achieve. He identified that focusing on new goals in the context of values could provide a meaningful framework that deters from focusing on now unachievable goals. It was surmised that focusing on values could be vital as they remain stable despite any changes to a person's physical ability post-SCI.

One metaphor described in the manual which enables people to clarify their values is the 'Magic Wand' (Appendix L) metaphor. The magic wand metaphor encourages participants to imagine their painful thoughts and feelings have disappeared and to imagine what their lives would be like. This conjured strong opinions for Donald who stated,

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[25] See section 1.2 of extended paper for further information on types of SCI.

‘I didn't think that that would work. I don't think…people could imagine. I mean, if I could even begin to think about, imagine what I know what I'd wish for. But it isn't going to happen. Yeah, really something that's totally not fanciful…It's not a useful tool to have. I think them as you want, you know. Well, you know, you gonna tap me and up? Stand up out of my chair. Well, yeah, you said. Yeah, don't use those phrases because…You know if they’re angry and bitter, that’s not going to help at all’. (Donald, LE).

Donald indicates this could be distressing for people to imagine post-SCI, especially for those who are angry or in denial which could result in disengagement with the manual. Removing of this technique in favour of other values clarifying techniques may improve the manual for those with a SCI. Mark suggested moving values earlier in the self-help manual and combining this with therapeutic goals could increase the positive impact of these techniques,

‘So, if the mental side is missing, then the therapy side is probably going to be missing and the person's not going to get to where they want to be and that goal setting that’s in these”, “Put those later ones earlier…And start to get the goal setting earlier’ (LE).

By introducing values earlier in the manual and practically to inform rehabilitation goal setting the applicability and acceptability could be increased.

In conclusion, participants suggested clarifying values was important post-SCI and this could improve a person’s mindset and willingness to engage with rehabilitation. Focusing on values to guide goals could ensure the focus is on what people can do post-SCI versus cannot, which many reported was a common worry. Furthermore, it was inferred that values were particularly useful because they are not related to physical ability. Considering a person’s physical ability is likely to change post-SCI, re-aligning individuals with their values is relevant and could be moved to an earlier section to increase engagement.

Theme two: Self-help

This theme discusses the format of self-help and considers the challenges of this approach for those with a SCI.

Subtheme 2a: ‘Self-help after adjustment’

The timing of receiving the ACT manual was discussed and considerations around when it might be best received were suggested. Nicole and Greg suggested receiving the manual after a period of adjustment and physical mobilisation might be most beneficial.

‘But I just, I think it's useful, but not for your early stages… For people who once they're out of hospital and they're settled” (Nicole, LE), “Probably after. Couple of months” (Greg, LE), “they're probably immobilised for a lot less these days, but until you actually get going, I would think you'd find it hard to. Take this stuff in” (Greg, LE).

These quotes describe that readers may engage more with the manual once they have settled back at home and are familiar with the changes to their life. Paul indicated having this time would enable processing and increase ability to engage with the manual, ‘Mine was seven years ago now, so yeah…So, I have the headspace to engage with it’ (LE). Paul discussed ‘headspace’ as a factor suggesting in the early stages post-injury emotional distress is high making engagement with psychological work challenging. Similar views were expressed by Nicole who discussed an initial trauma inhibiting someone’s ability to engage, ‘So personally, I just don't think that you can do it when you're in the throes of trauma’ (LE).

In conclusion, offering this self-help manual to individuals after a period of adjustment and rehabilitation might be more acceptable increasing engagement, it was suggested that the initial trauma response post-SCI may hinder engagement. However, given access to self-help manuals cannot be policed this could be challenging. A statement at the beginning of the manual to this effect may be useful.

Subtheme 2b: ‘Self-help too labour intensive’

Participants commented on the volume of text in the manual and the impact this could have on engagement. Donald, Lee and Mark each suggested the manual was, ‘too wordy’ (Donald, LE, Lee, LE) and ‘there is too much there’ (Mark, LE). These participants indicated the impact of this amount of text meant the manual became ‘very, very heavy going’ (Mark, LE) and ‘labour intensive’ (Donald, LE). Based on these findings considerations around reducing the amount of text to increase engagement are important. Jenny and Greg suggested why this amount of text might be particularly challenging after SCI stating, “Sorry I didn't get through it all and some of them I just thought they were too long to read and I have a problem with reading anyway because I've got my backbone is sort of falling apart and so I can't bend over reading pretty easily” (Greg, LE), ‘So that somebody doesn't look at it and all they can see is, oh God, there's just 20 pages of text… the vast majority of people, particularly in this situation, will just be overwhelmed by it” (Jenny, LE).

Suggestions that difficulties engaging with the manual could be related to both physical and cognitive factors were constructed. Reading was challenging due to physical limitations post-SCI for Greg and given the common occurrence of pain and other physical sequalae post-SCI these difficulties are likely to be common. Cognitive factors were also identified with suggestions the amount of text would be overwhelming and could impact engagement.

Mark suggested the amount of text in the manual became a barrier to the useful parts of the manual.

‘I just think some of the blurb before you get to the useful stuff…it's a little bit too long’ (Mark, LE), ‘there's long sections and you seem to be trawling through these sections and then you get to the… useful fun stuff’ (Mark, LE). This quote indicates the theoretical explanation within the manual is too long and becomes a barrier to accessing the practical activities that were deemed to be the most useful aspects of the manual. Callum, Lee and Jenny suggested how the text could be reduced,

‘Bullet point type as opposed to you've got some really long paragraphs’ (Callum, LE), ‘when there's given examples looking, reducing it down from lots of examples, just one or two. Pertinent ones’ (Lee, LE), ‘maybe breaking it down into smaller chunks’ (Jenny, LE).

In conclusion, the volume of text within the manual became burdensome, especially post-SCI due to both physical and cognitive factors, which decreased acceptability. Reducing examples, smaller paragraphs, and using bullet points were suggested remedies for the manual.

Subtheme 2c: 'Language is the key to engagement'.

Participants commented on language within the manual and discussed both the positive and negative aspects. Four participants stated the language was easy to understand and concepts were well explained without complex terminology.

'Again, the wording itself was quite good…I thought they explained it really well. Particularly one was about the next-door neighbour, the annoying neighbour coming to the party' (Lee, LE), 'I think because they'll just get the layman terms out of it, you know what I mean?...So I think the way you set it out has been easier to understand, especially for people without medical backgrounds' (Mike, LE), 'This is a really good for me it was a really good level' (Mark, LE), 'I understood the language that was being used' (Jenny, LE).

These quotes suggest the explanations of metaphors within the manual, such as "the annoying neighbour" (Appendix M) were well explained and easy to understand and the way ACT is explained is at an understandable level without complex jargon. Participants commented on the perceived tone of the language and stated the wording humanised their experiences post-SCI and was not patronising or intrusive. There were suggestions that the language was motivating and encouraged focus.

'The way you've actually set it up and you the language you use… it's more humanised I think' (Mike, LE), 'it's not patronising, it just gets you to focus your thoughts in a specific in a particular area…I didn't find it. Um, intrusive…I just looked at it and thought, you know what this is a really. This is a really good for me it was a really good level' (Mark, LE).

These quotes suggested the language used prompted focus to engage with the activities which may increase its acceptability for those with a SCI.

Participants provided commentary on negative aspects of the language in the manual.

'The next one actually made me laugh, which was willingness, learning how to jump. And again, as a spinal cord injured person, when I read that, it made me giggle because

I've been 25 years in the chair. So, I still find things that when people say to me take a seat, I still find myself in my head going, It's alright, I brought my own' (Lee, LE), 'Go and find a nice comfy chair and find somewhere quiet to sit. Well, they're in a wheelchair…So again, that needs to be looked at and…You could say, you know, if you are a wheelchair user, you know, find somewhere quiet' (Donald, LE).

Physical language used within the manual requires adaption and while some found this amusing, others may become frustrated and disengage. Using inclusive language for wheelchair users is a simple change likely to significantly impact engagement. Finally, two participants talked about the use of negative wording that requires adaptation.

'Section 4 still the word suffering and a lot of that in in that particular one. And it was about our past…And I mean, OK, again from the 80s and crippled, you know, all those sorts of words which are now viewed as not politically correct. It didn't really bother me. It still doesn't bother me now. But some people today might think, well, I'm not suffering in a sense, suffering to me describes something in agony, in pain, which emotionally they are, but you know, they're hiding that or they're still in denial.... So a better choice of word in respect' (Donald, LE). 'You know worries or concerns or some softer, more explanatory… In my mind, I'm not psychologically struggling. I've got worries and concerns' (Callum, LE), 'Keep it simple. Lead them by their hand. Yeah, forget all the big words…use simple words rather than big ones and stick to the same terminology for this' (Callum. LE).

Both participants suggested that the word "suffering" or "psychologically struggling" could be viewed as harsh or offensive and called for a better choice of wording. Callum suggested simplifying the language by replacing "psychologically struggling" with "worries or concerns" to reduce the impact of this language and demonstrate a more empathetic approach.

In summary, there were both positive and negative comments on the use of language used. Some viewed the language as easily understandable and not patronising. However, others stated the use of physical and negative language was inappropriate and could trigger distress requiring adaptation to increase the manuals acceptability.

Discussion

This study aimed to explore whether the "ACTing towards better living" manual was acceptable to those with SCI. Adaptations to increase acceptability of this manual were suggested by participants because certain aspects of the "ACTing towards better living" manual were challenging to accept and the manual requires key adaptation.

Study findings indicated acceptance was deemed an important concept for those with SCI but difficult to attain, with timing identified as a key factor to achieve this. Reactions to acceptance were positive and negative, which was found in research investigating ACT for chronic pain and irritable bowel syndrome (IBD) (Casey et al., 2020; Wilkin et al., 2023). Participants with chronic pain and IBD liked acceptance but considered it abstract but something to aim towards, whereas others likened it to giving up, similar to the findings of this study (Donahue & Levin., 2024); Wilkin et al., 2023). Acceptance likened to 'giving up' can be common amongst participants and could indicate a conflict between the understanding of acceptance between authors and participants which may be a barrier for interventions aiming to develop acceptance. Suggestions the language used is crucial and rebranding acceptance as willingness within the manual may reduce some of the negative reactions to the concept of acceptance in ACT for this population (Kanter et al., 2006).

Timing was identified as key to development of acceptance, in particular time since the event causing their SCI. Considering timing seems SCI specific as it acknowledges there is a time before and after SCI. Monitoring timing of introducing ACT interventions for those with SCI in future research may be useful in determining whether acceptance is looked at favourably or if this influences efficacy. The qualitative findings of this research suggested developing acceptance too early in this population could be damaging. This raises a challenging point for the rationale of using self-help materials for SCI as there would be no way to determine when participants were accessing the manual. A hybrid approach involving check-ins with a professional to monitor progress and engagement could be critical. The input of a professional could mitigate timing challenges by assessing readiness. Including a message within the manual expressing the importance of monitoring their own progress and engagement, with recommendations to make adaptations (e.g., returning to acceptance sections of the manual later and focusing on other aspects of the manual) is important.

The relationship between time since injury and level of acceptance was suggested by participants and indicated those who have had a recent injury might be less likely to accept their new reality and some of the ideas suggested in the “ACTing towards better living” manual. There is limited research suggesting the optimal time for introducing acceptance post-SCI, which is likely related to many factors and personal. However, some research suggests when considering positive outcomes fostering acceptance within the first year post-SCI is correlated to increased QOL, but this was not so closely correlated when this time moved up to two years (Aaby et al., 2022). Introducing the manual within the first two years is likely to be most helpful if aiming for improved QOL. This may be related to the suggestions around valued living and if acceptance is fostered earlier, experiential avoidance is reduced, and you are more likely to be living within values sooner positively impacting QOL. However, this does not suggest the manual will be unhelpful to those with more time since injury and was suggested to increase engagement and acceptance by participants in this study.

Research suggests ‘accepting your new reality’ may not be enough if not linked to ‘value-change’, particularly when considering the impact of acceptance on positive outcomes over time (Aaby et al., 2022). The section of the manual based around values was particularly acceptable to those with a SCI and the results of this study found this may be related to the reduced impact of physical ability on values as opposed to goals. The understanding of values work for those with a SCI is limited, with one study investigating individual ACT processes (Waldron-Perrine et al., 2022). Research suggests clarifying intrinsic values and committing to action based on this can modify an individual’s perception of their disability in a positive way (Khanjani et al., 2021). Modifications were suggested by participants, such as, removing the magic wand question (MWQ) which was believed to be damaging to those with a SCI. Research on MWQ in SCI is limited but research from CAMHS has been found to be positive (Wells & McCaig, 2016), however, it is likely these results are not generalisable due to significant differences between these populations. Using a different exercise to clarify values and intertwining this throughout other sections could improve the manual. Furthermore, multicollinearity found between values work and committed action provides a rationale for condensing the ACT model within the manual (Waldron-Perrine et al., 2022). The ACT triflex model (Harris, 2009) compresses the six core processes of ACT in to three dyadic processes, open up (acceptance and defusion), be present (contact with the present moment and self as context) and do what matters (values and committed action).

This study's findings indicated battling with thoughts was a common experience post-SCI and fusion to negative thoughts can increase distress. Participants found manual sections relating to cognitive defusion conjured negative reactions. Previous research found when fusion to thoughts decreases via psychological flexibility post-SCI, people become less prone to the negative effects of common stigma's (Khanjani et al., 2021). Evidently, reducing cognitive fusion has a positive impact on distress but likelihood of engagement with interventions is poorly understood (Khanjani et al., 2021). Participants found some of the suggested cognitive defusion strategies in the manual "airy fairy" and did not take in to account the severity of their situations which could result in disengagement. One adaptation for the manual is distinguishing between thoughts requiring action which is likely to be validating. Furthermore, potentially defusion is a complementary process. Research into those with SCI found defusion was not uniquely linked to quality of life and suggested significant multicollinearity between defusion and acceptance (Waldron-Perrine et al., 2022). Using the ACT triflex (Harris, 2009), could combine less acceptable concepts such as defusion with other concepts increasing acceptability.

Participants discussed the burdensome nature of the "ACTing towards better living" manual in its current state. The amount of text became a barrier as many participants stated they struggled to read the full manual. The burden potentially impacted participants ability to provide commentary on the manual and suggested it was "too long and wordy". Participants stated several reasons for difficulties engaging with this amount of information after SCI. Guided self-help manuals rely on written text rather than verbal information as in one-to-one therapy. Considering whether guided self-help is appropriate for this population is necessary, and reducing the reliance on written text by using video or pictures could be a solution. Furthermore, as previously suggested condensing the model and using the ACT Triflex (Harris, 2009), could reduce and simplify the manual. Combining a simplified manual with the previously mentioned hybrid approach to monitor progress is likely to improve acceptability and is seen as best-practice when using self-help material (Shafran et al., 2024).

Finally, language within the manual requires adaptation due to complexity and ambiguity. Using terms such as “let’s go for a walk” to someone who is a wheelchair user is not offensive, however the use of physical terms within this manual was deemed inappropriate by participants (Muehe, 2003). Using metaphors for those with physical disabilities has been found to contribute to development and maintenance of mental health difficulties (Holmes et al., 2007). Considering techniques within this manual could increase acceptability by avoiding unnecessary metaphors. Participants suggested the complexity of some language could be disengaging therefore when adapting the manual simplifying and avoiding physical language is important.

Strengths and Limitations

Many studies investigating ACT focus on efficacy (Huang et al., 2021; Khanjanie et al., 2021; Dorenkamp et al., 2023). This study focuses on acceptability using semi-structured interviews to understand what we can learn to tailor a guided self-help intervention for SCI. The findings provide a clearer idea about aspects of ACT that are acceptable to those with a SCI and those likely to result in disengagement.

This research could be improved by amending the methodological design. The ‘ACTing towards better living’ manual was difficult for participants to engage with as they described the manual generally and did not focus on particular aspects. More focused discussion by offering the manual to participants in sections and focusing on each in multiple semi-structured interviews might have increased our ability to adapt specific sections. Discussing the manual as a whole in one interview meant the discussion was general. Conducting multiple interviews was not done initially due to not wanting to burden participants with multiple interviews.

Participants were recruited from three separate groups, those with lived experience, carers and professionals working with those with SCI. The groups recruited were unbalanced meaning conclusions from each separate group could not be constructed. However, it was deemed the largest group comprising those with lived experience were dominant within this research and the other participants voices did not diverge from the dominant perspectives indicating convergence across the three groups.

Conclusion

The findings suggested key areas of relevance to this population; focusing on values, acceptance and committed action. It is recommended the manual be adapted to mirror the ACT Triflex Model (Harris, 2009) more closely to simplify and reduce the burden of text. By combining less desirable aspects with more acceptable concepts acceptability of this manual could be improved. A hybrid approach combining check ins with a guide alongside self-directed models could be the most useful way to approach self-help for a population of those with SCI due to the complexities following this type of injury. Further research should focus on making the adaptations to the manual and piloting in a population of individuals with a SCI[26].

Word count: 7907, excluding tables, figures and appendix information.

References

Aaby, A., Ravn, S. L., Kasch, H., & Andersen, T. E. (2020). The associations of acceptance with quality of life and mental health following spinal cord injury: a systematic review. *Spinal cord, 58*(2), 130–148. https://doi.org/10.1038/s41393-019-0379-9

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[26] See section 4.1 and 4.2 of extended paper for further information on clinical contributions and future research.

Aaby, A., Ravn, S. L., Kasch, H., & Andersen, T. E. (2022). Using the Multidimensional Model of Acceptance to Investigate How Different Facets of Acceptance are Related to Quality of Life Following Spinal Cord Injury. *Journal of rehabilitation medicine*, *54*. https://doi.org/10.2340/jrm.v54.1055

Aspire (n.d.). *Every two hours someone is paralysed by a Spinal Cord Injury in the UK.* https://www.aspire.org.uk/news/every-two-hours#:~:text=Previous%20estimates%20stated%20that%20there,considerable%20increase%20across%20both%20figures.

Bhaskar, R., (1975) Forms of realism, *Philosophica* 15. doi: https://doi.org/10.21825/philosophica.82713

Braun, V., & Clark, V., (2021). *Thematic Analysis A Practical Guide.* Sage Publishing.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative research in sport, exercise and health*, *13*(2), 201-216.

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis?. *Qualitative research in psychology*, *18*(3), 328-352.

Budd, M. A., Gater, D. R., Jr, & Channell, I. (2022). Psychosocial Consequences of Spinal Cord Injury: A Narrative Review. *Journal of personalised medicine*, *12*(7), 1178. https://doi.org/10.3390/jpm12071178

Casey, M. B., Cotter, N., Kelly, C., Mc Elchar, L., Dunne, C., Neary, R., Lowry, D., Hearty, C., & Doody, C. (2020). Exercise and acceptance and commitment therapy for chronic pain: a case series with one-year follow-up. *Musculoskeletal Care*, *18*(1), 64-73. https://doi.org/10.1002/msc.1444

Cowie, L., & Braun, V. (2021). Between social and biomedical explanation: queer and gender diverse young people's explanations of psychological distress. *Psychology & Sexuality*, *13*(5), 1179–1190. https://doi.org/10.1080/19419899.2021.1933147

Craig, A., Tran, Y., & Middleton, J. (2009). Psychological morbidity and spinal cord injury: a systematic review. *Spinal cord*, *47*(2), 108–114. https://doi.org/10.1038/sc.2008.115

Donahue, M. L., & Levin, M. E. (2024). Pilot evaluation of a prototype online acceptance and commitment therapy program for adults living with a chronic health condition. *International Journal of Mental Health*, *53*(4), 1–23. https://doi.org/10.1080/00207411.2024.2321432

Dorenkamp, M. A., Waldron-Perrine, B., & Hanks, R. (2023). Influence of Acceptance and Commitment Therapy Core Processes on Anxiety and Stress in Persons With Spinal Cord Injury: A Cross-sectional Study. *Archives of physical medicine and rehabilitation*, *104*(4), 612–618. https://doi.org/10.1016/j.apmr.2022.11.004

Dunn, D. S. (2010). The social psychology of disability. In R. G. Frank, M. Rosenthal, & B. Caplan (Eds.), *Handbook of rehabilitation psychology* (2nd ed., pp. 379–390). American Psychological Association. https://doi.org/10.1037/15972-026

Elfström, M. L., Rydén, A., Kreuter, M., Persson, L. O., & Sullivan, M. (2002). Linkages between coping and psychological outcome in the spinal cord lesioned: development of SCL-related measures. *Spinal cord*, *40*(1), 23–29. https://doi.org/10.1038/sj.sc.3101238

Engblom-Deglmann, M. L., & Hamilton, J. (2020). The impact of spinal cord injury on the couple relationship: A grounded theory exploration of the adjustment process. *Journal of Couple & Relationship Therapy*, *19*(3), 250–275. https://doi.org/10.1080/15332691.2020.1746459

Fann, J. R., Bombardier, C. H., Richards, J. S., Tate, D. G., Wilson, C. S., & Temkin, N., (2011). Depression after spinal cord injury: comorbidities, mental health service use, and adequacy of treatment. *Archives of physical medicine and rehabilitation*, *92*(3), 352–360. https://doi.org/10.1016/j.apmr.2010.05.016

French, K., Golijani-Moghaddam, N., & Schröder, T. (2017). What is the evidence for the efficacy of self-help acceptance and commitment therapy? A systematic review and meta-analysis. *Journal of Contextual Behavioral Science*, *6*(4), 360-374.

Graham, C. D., Gouick, J., Krahé, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical psychology review*, *46*, 46–58. https://doi.org/10.1016/j.cpr.2016.04.009

Guest, G., Bunce, A., & Johnson, L., (2006). How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field methods, 18*(1), 59-82. DOI: 10.1177/1525822x05279903

Hall, K. M., Cohen, M. E., Wright, J., Call, M., & Werner, P. (1999). Characteristics of the Functional Independence Measure in traumatic spinal cord injury. *Archives of physical medicine and rehabilitation*, *80*(11), 1471–1476. https://doi.org/10.1016/s0003-9993(99)90260-5

Harris, R. (2009). *ACT Made Simple: An Easy-To-Read Primer on Acceptance and Commitment Therapy*. New Harbinger.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: model, processes and outcomes. *Behaviour research and therapy*, *44*(1), 1–25. https://doi.org/10.1016/j.brat.2005.06.006

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change.* Guilford Press.

Holmes, E. A., Arntz, A., & Smucker, M. R. (2007). Imagery rescripting in cognitive behaviour therapy: images, treatment techniques and outcomes. *Journal of behavior therapy and experimental psychiatry*, *38*(4), 297–305. https://doi.org/10.1016/j.jbtep.2007.10.007

Huang, G., Lin, B. L., Hu, J. H., Qiu, F. H., Zhang, W. Y., Zhang, Z. L., ... & Li, J. B. (2021). Effect of acceptance and commitment therapy on rehabilitation patients with spinal cord injury. *Contemporary Clinical Trials Communications*, *24*. 100778. https://doi.org/10.1016/j.conctc.2021.100778

Kanter, J. W., Baruch, D. E., & Gaynor, S. T. (2006). Acceptance and commitment therapy and behavioral activation for the treatment of depression: description and comparison. *The Behavior analyst*, *29*(2), 161–185. https://doi.org/10.1007/BF03392129

Kennedy, P., & Garmon-Jones, L. (2017). Self-harm and suicide before and after spinal cord injury: a systematic review. *Spinal cord*, *55*(1), 2–7. https://doi.org/10.1038/sc.2016.135

Khanjani M., S., Kazemi, J., Younesi, J., Dadkhah, A., Biglarian A., & Barmi, B., E., (2021). The Effect of Acceptance and Commitment Therapy on Psychological Flexibility and Emotional Regulation in Patients with Spinal Cord Injuries: A Randomized Controlled Trial. *Iranian Journal of Psychiatry and Behavioral Sciences, 15*(2). https://doi.org/10.5812/ijpbs.105378.

Monden, K. R., Philippus, A., Draganich, C., MacIntyre, B., & Charlifue, S. (2020). A qualitative exploration of perceived injustice among individuals living with spinal cord injury. *Rehabilitation Psychology*, *65*(1), 54–62. https://doi.org/10.1037/rep0000301

Muehe, M., (2003). *Spinal Cord Injury Zone: Understanding the importance of language*. https://spinalcordinjuryzone.com/info/7493/understanding-the-importance-of-language

National Institute for Health and Care Excellence. (2016). *Spinal Injury: Assessment and Initial Management* [NICE Guideline no. 41]. https://www.nice.org.uk/guidance/ng41

Noreau, L., Noonan, V. K., Cobb, J., Leblond, J., & Dumont, F. S. (2014). Spinal Cord Injury Community Survey: Understanding the Needs of Canadians with SCI. *Topics in spinal cord injury rehabilitation*, *20*(4), 265–276. https://doi.org/10.1310/sci2004-265

Sekhon, M., Cartwright, M. & Francis, J.J. (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Services Research*, *88*. https://doi.org/10.1186/s12913-017-2031-8

Shafran, R., Egan, S. J., de Valle, M., Davey, E., Carlbring, P., Creswell, C., & Wade, T. D. (2024). A guide for self-help guides: best practice implementation. *Cognitive Behaviour Therapy*, *53*(5), 561–575. https://doi.org/10.1080/16506073.2024.2369637

Shepherd, K., Golijani-Moghaddam, N., & Dawson, D. L. (2022). ACTing towards better living during COVID-19: The effects of Acceptance and Commitment therapy for individuals affected by COVID-19. *Journal of contextual behavioral science, 23*, 98–108. https://doi.org/10.1016/j.jcbs.2021.12.003.

Spinal Injuries Association. (2021). *What Matters: A report on what really matters to spinal cord injured people in the UK today.* https://spinal.co.uk/wp-content/uploads/2021/10/SIA_What_Matters_Report_v4.pdf

Torabian, S., Vahid, H. S., & Meschi, F. (2019). The Effectiveness of Acceptance and Commitment Therapy on Anxiety, Depression, and Stress in Patients with Spinal Cord Injuries. International Clinical Neuroscience Journal, *6*(2), 46-52. doi:10.15171/icnj.2019.10

Waldron-Perrine, B., Kisser, J., Robinett, E., Hanks, R. A., & Kratz, A. (2022). Association between Acceptance and Commitment Therapy (ACT) processes and depressive symptoms and pain interference in persons with spinal cord injury (SCI). *Rehabilitation psychology, 67*(4), 602.

Weber, L., Voldsgaard, N. H., Holm, N. J., Schou, L. H., Biering-Sørensen, F., & Møller, T. (2021). Exploring the contextual transition from spinal cord injury rehabilitation to the home environment: a qualitative study. *Spinal cord*, *59*(3), 336–346. https://doi.org/10.1038/s41393-020-00608-y

Wells, K., & McCaig, M. (2016). The magic wand question and recovery-focused practice in child and adolescent mental health services. *Journal of Child and Adolescent Psychiatric Nursing, 29*(4), 164–170. https://doi.org/10.1111/jcap.12159

Wilkin, K., Evans, S., Van Niekerk, L., Romano, D., Fuller-Tyszkiewicz, M., Knowles, S., Chesterman, S., Raven, L., & Mikocka-Walus, A. (2024). Moving Towards Acceptance and Values: A Qualitative Study of ACTforIBD Compared to IBD Psychoeducation. *Journal of clinical psychology in medical settings*, *31*(2), 245–257. https://doi.org/10.1007/s10880-023-09999-5

Woolrich, R. A., Kennedy, P., & Tasiemski, T. (2006). A preliminary psychometric evaluation of the Hospital Anxiety and Depression Scale (HADS) in 963 people living with a spinal cord injury. *Psychology, Health & Medicine, 11*(1), 80–90. https://doi.org/10.1080/13548500500294211

Extended Paper

This extended paper is written to provide supplementary information to complement the journal paper. The aim of this document is to provide further information on concepts or ideas that could not be included in the main journal paper. Consideration of wider themes within the results and discussion section that were not deemed by the primary author to be a key part of the journal paper are also included.

1. Extended Introduction

The extended introduction section provides further information regarding the background literature relevant to this study. This section will provide a rationale for the chosen publication journal, a more detailed explanation of the types of Spinal Cord Injury (SCI) and demographic information, an explanation of the physical symptoms that often accompany a SCI alongside discussion regarding what rehabilitation after SCI can involve. Finally, there is further explanation of Acceptance and Commitment Therapy (ACT), its uses within a population of individuals with SCI, and the development of the self-help materials. By providing further expansion on the key points of the introduction section from the journal paper a clearer context for the journal paper is offered.

1.1. Rationale for Target Journal

The journal paper was prepared for submission in the Neuropsychological Rehabilitation Journal[27]. This journal was selected as they publish human experimental or clinical research related to rehabilitation and recovery of function. They have previously published papers related to rehabilitation after SCI and psychosocial wellbeing and it was felt to be an appropriate journal for publication of this paper. Furthermore, the focus of many of the published papers within this journal is to inform clinical practice which aligns closely with the purpose of the journal paper.

1.2. Spinal Cord Injury

The spinal cord can become injured at any point and the site of the injury interrupts nerve signals travelling up and down, resulting in differing abilities based on the location of the injury (National Institute of Neurological Disorders and Stroke [NIH], 2023). The cervical spine, also called C1-C7, is the part of the spine located in the neck. This part of the spine and surrounding nerves control the back of the head, the neck, shoulders, arms, hands and diaphragm (NIH, 2023). The thoracic spine, also called T1-T12, lies within the upper to mid back and controls the chest muscles, muscles of the back and many organ systems (NIH, 2023). The lumbar spine referred to as L1 – L5, is in the lower back, abdomen and buttocks and send signals to some parts of the genitals and leg (NIH, 2023). Finally, the Sacral spine, known as S1-S5 is in the low back and controls signals to the thighs, lower parts of the leg, feet, genitals and anus (NIH, 2023). The location of the injury impacts the use and control of each of the associated areas and disrupts the transmission of nerves impacting sensation and function below the point of injury. Injuries that occur higher up the spinal cord can impact more of the function within the body, quadriplegia or

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[27] Author guidelines available: https://www.tandfonline.com/action/journalInformation?show=aimsScope&journalCode=pnrh20

tetraplegia are terms used to describe paralysis in most of the body, legs and arms (NIH, 2023). The term paraplegia is used to describe an injury lower down in the spinal cord that affects the function of the lower body and legs (NIH, 2023).

SCI can be traumatic or non-traumatic in nature. Traumatic SCI (T-SCI) occurs when external forces impact the spinal cord, such as in a road traffic accident, causing injury. Non-traumatic SCI (NT-SCI) occurs following acute or chronic disease, such as tumors (Ahuja et al., 2017). SCI is categorised based on the permanence of the damage; complete injury means damage is permanent, and nerve transmission is completely disrupted below the point of injury, often resulting in paraplegia or tetraplegia (Shepherd Centre, n.d.). Incomplete injury is partial damage, meaning some nerve messages still reach the brain and partial sensation below the injury site is retained (NIH, 2023). Incomplete injuries result in varying levels of disability dependent on the location and severity of the injury (Shepherd Centre, n.d.). Young men were most reported to have SCI's however, a rising number of older people, both male and female are commonly suffering from SCI's following periods of illness (McCaughey et al., 2016). Despite this occurrence, young and middle-aged men and older women still tend to be at highest risk of SCI, with road traffic collisions, falls, violent attacks, sporting injuries and domestic accidents being the most common causes within the UK (National Institute for Health and Care Excellence [NICE], 2016). The cost of SCI to the UK government is high, estimated to average £1.12 million across an individual's post-SCI lifespan comprising healthcare costs, loss of employment and the cost of providing care (McDaid et al., 2019).

1.3. Secondary Complications and Rehabilitation after SCI

Secondary complications after SCI are common and complex requiring ongoing rehabilitation and treatment. Secondary complications can be related to breathing difficulties, blood clots, autonomic dysreflexia (AD), pressure sores, chronic pain and bladder and bowel dysfunction (NIH, 2023). These complications can impede functional progress and impact rehabilitation trajectory and quality of life post-SCI (Ataoglu et al., 2013; Costa et al., 2001; Richards et al., 2004). Many individuals with a SCI require temporary or permanent support with breathing (NIH, 2023). Most commonly, breathing difficulties occur in injuries between the C1-C4 area of the spine due to the nerve connections to the diaphragm and lungs (NIH, 2023). A person's ability to breathe post-SCI can result in respiratory infections, such as pneumonia, which is the leading cause of death post-SCI (NIH, 2023).

Changes to circulation from decreased movement in the legs post-SCI can result in further complications including arrythmias and blood clots requiring close monitoring and anti-coagulant medications (NIH, 2023). Pressure sores also commonly occur when areas of the skin break down due to continuous pressure and reduced blood flow, those with paraplegia or tetraplegia require frequent changes in position to prevent sores (NIH, 2023). Autonomic dysreflexia (AD) is a life-threatening reflex, that involves symptoms such as, flushing, sweating, headache, anxiety and a sudden increase in blood pressure that can be life-threatening and often occurs most commonly in those with an injury to the neck or upper back. Neurogenic pain can occur post-SCI in parts of the body that have lost all sensation and can present as an intense burning or stinging sensation which can be constant or fluctuating (NIH, 2023). Chronic pain treatments involve long-term use of medications, acupuncture and surgery; however, no treatment has been found to be fully effective for long-term neurogenic pain management (NIH, 2023). Bladder and bowel dysfunction is common due to the disruption of nerve messages to lower parts of the body and many individuals require catheterisation increasing the risk for infections (NIH, 2023). Sexual function can also be significantly impacted after SCI and treatment options are varied, but often require the input of a urologist (NIH, 2023).

Rehabilitation post-SCI involves stabilising physical health complications in order to begin mobilisation via aids, such as a wheelchair (Sezer et al., 2015; Wyndaele & Wyndaele, 2006). Specialist rehabilitation centre can offer this type of support however, there are only eleven spinal centres within the UK designed to provide the complex rehabilitation required post-SCI. Rehabilitation combines physical therapy with skills building activities and counselling to improve an individual’s independence and quality of life and is carried out by a multi-disciplinary team including, psychologists, occupational therapists, nurses, doctors and physiotherapists (NIH, 2023).

1.4. Psychological Impact of SCI

The emotional impact of SCI can be significant and poor mental health is common, with up to 91% of individuals struggling with anxiety and depression post-SCI (Craig et al., 2009; Woolrich et al., 2006). A complex intertwining of biopsychosocial factors, such as chronic pain, impact of stigma and social disconnection, often related to changes in relationship roles, can impact mental health post-SCI and a person’s ability to manage life stressors (Dunn, 2010; Engblom-Deglmann & Hamilton, 2020; Jeyathevan et al., 2019; Monden et al., 2020; Tough et al., 2022; Weber et al., 2021). Accessing employment post-SCI can be challenging for several reasons, such as transportation difficulties, physical inaccessibility and workplace discrimination (Inge et al., 2018; Wilbanks & Ivankova, 2015). Disruptions in employment can result in financial strain related to lost income for both the individual and their carers further exacerbating psychological stress (Budd et al., 2022).

The impact of poorer mental health on functional outcomes is well known, with untreated low mood linked to longer hospital stays, increased pain, increases in pressure ulcers and poorer quality of life (Craig et al., 2009; Fann et al., 2011). The Spinal Injuries Association (SIA) (2021) found that suicidal ideation was three times more likely in those with SCI than the general population and up to 28% of those with SCI have thoughts of suicide. Furthermore, suicide accounted for between 5.8 and 11% of deaths after SCI (Kennedy & Garmon-Jones, 2017). Many individuals reported their emotional needs are not met post-SCI, with only one third accessing the appropriate mental health support and 68% stating support services do not meet their needs (Noreau et al., 2014; SIA, 2021).

Counselling and emotional support is purported to be a priority within rehabilitation services however, the reality of availability can vary. Accessing specialist support for emotional health post-SCI can be challenging with a recent report from the Spinal Injuries Association (SIA, 2021) finding 68% of those that accessed standard mental health services withdrew from treatment early without experiencing gains or resolving their mental health difficulties and some found services worsened their issues. Furthermore, up to 63% of individuals state they were discharged to the community with non-specialist community rehabilitation that did not meet their needs (SIA, 2021).

1.5. Relational Frame Theory

Relational Frame Theory (RFT) posits that our communication is heavily reliant on our ability to identify and create relational links between stimuli and this skill is the basis of all human language (Hayes et al., 2001). RFT also describes how psychological distress can be maintained through normal language processes (Blackledge, 2003). Relational networks are created during language development and allow us to connect words and meaning and widen language repertoires through relational frames (Hayes et al., 2001). A relational frame refers to a pattern of relational responding that we learn through reinforcement by our verbal and social communities (Gross & Fox, 2009). An example given is that of a child seeing many types of birds and is told each type is a bird, the child can then identify a bird they have never seen before because they have developed the relational frame that animals with beaks and wings are birds (Hayes et al., 2001).

There are three types of relational frames that explain how relationships can be formed, mutual entailment, combinatorial entailment and transformation of functions. Mutual entailment is the process whereby an individual might notice that A relates to B in a certain way and therefore can determine the relationship between B and A (Gross & Fox, 2009). Combinatorial entailment is the process of noticing that if A has a relationship to B and B has a relationship to C then A must have a relationship to C, such as displaying an apple next to a watermelon because the apple is smaller and then placing a cherry next to the apple because it is smaller, you would then learn the watermelon is larger than the cherry without comparing the two fruits directly (Gross & Fox, 2009). Finally, transformation of functions is the process whereby certain stimuli can acquire behavioural functions based on their involvement in verbal relations with other events (Gross & Fox, 2009). Research in to RFT posits that relational responding serves important functions, such as problem solving, but can be detrimental when applied to our private experiences (Hayes et al., 2001).

1.6. Psychological Inflexibility, Experiential Avoidance and Cognitive Fusion

Suggestions that there are underlying components to many different mental health difficulties has been indicated by recent research. Comorbidity is high in many mental health difficulties indicating the potential presence of a common pathological process, furthermore, when treatments focusing on one symptom inadvertently improve symptoms of an unintended difficulty more evidence for this hypothesis is gathered (Borkovec et al., 1995; Kessler et al., 2005; Tsao, 2002). Based on these findings many have created transdiagnostic models to treat mental health difficulties, such as ACT.

The suggested transdiagnostic process underlying mental health difficulties according to the ACT model is psychological inflexibility (Levin et al., 2012). Psychological inflexibility is a term used to describe patterns of behaviour that are influenced by our thoughts, emotions and other internal experiences with the aim of actively avoiding internal experiences at the expense of more meaningful behaviours (Levin et al., 2014). Cognitive fusion and experiential avoidance are processes believed to foster psychological inflexibility (Levin et al., 2014 et al., 2017).

Cognitive Fusion

Cognitive fusion is a process whereby people equate their thoughts with reality and are unaware of the process of thinking, they miss the distinction between the content of their thoughts and themselves as the thinker (Levin et al., 2014 et al., 2017; Xiong et al., 2021). Individuals that are cognitively fused tend to believe the literal meaning of their thoughts rather than viewing them as transient internal states (Greco et al., 2008). According to RFT, cognitive fusion perpetuates mental health difficulties when an individual is unhelpfully guided by the content of thoughts rather than their direct environmental experiences (Levin et al., 2014 et al., 2017). The relationship between cognitive fusion and presence of mental health difficulties has not been heavily researched, however some research has indicated the presence of a link to anxiety, depression, health anxiety, body dissatisfaction and eating disorders (Fergus, 2015; Gillanders et al., 2014; Trindade & Ferreria, 2014). This research suggests cognitive fusion could have some transdiagnostic importance in understanding the underlying mechanisms of mental health difficulties and provide a target for intervention.

Experiential Avoidance

Experiential avoidance is defined as an unwillingness to remain in contact with aversive experiences including, painful thoughts, emotions, memories, images and bodily sensations (Hayes et al., 2006). People also attempt to alter the content of internal experiences even when this causes behavioural or emotional harm (Levin et al., 2014 et al., 2017). Research suggests that attempting to avoid, control or inhibit unpleasant thoughts or feelings can be effective in managing distress in the short-term, for example, avoiding anxiety provoking situations is likely to be reinforced by the immediate alleviation of aversive thoughts and feelings (Levin et al., 2014). However, in the long-term continuing to use this strategy rigidly and inflexibly actually increases the frequency of distress (John & Gross, 2004). Other identified avoidant actions are, thought suppression, distraction, expressive suppression, avoidance coping, wishful thinking and cognitive reappraisal (Cutuli, 2014; Li et al., 2017; Magee et al., 2012; Penley et al., 2002). Experiential avoidance of unwanted thoughts and feelings at the expense of engaging in valued actions is considered critical to the development and maintenance of mental health difficulties, such as anxiety and depression (Hayes et al., 1996). This explanation suggests many mental health disorders may develop initially as avoidant and psychologically inflexible strategies to adjustment that eventually become more rigid and severe over time (Levin et al., 2014).

A direct relationship has been identified between psychological inflexibility and mental health difficulties, such as anxiety, depressions, substance use, eating disorders and psychosis (Goldstone et al., 2011; Hayes et al., 2006; Levin et al., 2012; Rawal et al., 2010; Venta et al., 2012). However, much of this research has focused on self-reported symptoms rather than clinical interview which may influence the validity of this research. Furthermore, the link is correlational rather than causal indicating other factors could have also influenced these findings (Levin et al., 2014).

1.7. Acceptance and Commitment Therapy

As discussed, Hayes et al. (2006) suggests psychological inflexibility is a maladaptive coping strategy that comprises both cognitive fusion and experiential avoidance and is a key process in the development and maintenance of mental health difficulties. The ACT model suggests developing psychological flexibility may alleviate mental health difficulties, although this is not the core aim (Hayes et al., 2006). ACT attempts to increase psychological flexibility by using the concepts of acceptance and mindfulness to develop more flexible patterns of responding to psychological struggles (Levin et al., 2014). Reducing the impact of thoughts and self-conceptualisations on behaviour moves the person towards contact with actual experiences and increases values-based behaviours (Levin et al., 2014).

The six core processes within the ACT model are suggested as positive psychological skills and are believed to be interconnected and often overlap (Levin et al., 2014).
The six ACT processes can be categorised into acceptance and mindfulness practices, such as contact with the present moment, acceptance, cognitive defusion and self as context (Prevedini et al., 2011). There are also processes related to behavioural change, values and committed action (Prevedini et al., 2011).

Acceptance

Acceptance is embracing both positive and negative aspects of human life and is the opposite of experiential avoidance. Individuals are encouraged to drop the struggle with their difficulties and instead embrace their challenging feelings, thoughts and emotions without attempts to change their frequency or form, especially when this is likely to cause psychological harm (Hayes et al., 2006). Acceptance is not suggested to be an end point but a way to increase values-based action (Hayes et al., 2006).

Cognitive defusion

Cognitive defusion is the process of learning to observe our thoughts rather than attempting to change them. Cognitive Defusion techniques are used to alter our relationship or the way we interact with our thoughts rather than trying to change their form, frequency or situational sensitivity (Hayes et al., 2006). Cognitive Defusion techniques attempt to create contexts in which the unhelpful functions of our thoughts are diminished and there are many different techniques designed for different clinical presentations (Hayes et al., 2006; Hayes & Strosahl., 2005). Such techniques could be things like, repetition of a word until only the sound remains, externalisation of a thought by giving it a size, shape colour etc., or labelling the process of thinking e.g., “I am having the thought that…”. These techniques aim to reduce the quality of the thought and often decrease believability and attachment rather than a reduction in frequency (Hayes et al., 2006).

Present Moment Awareness

Present moment awareness is the ability to be in contact with the present moment non-judgmentally rather than ruminating on the past or future. ACT suggests that being present or having non-judgmental contact with our psychological and environmental experiences as they occur increases flexibility in terms of behaviour and potentially allows more contact with values (Hayes et al., 2006). By being present we can exert more control over our behaviour by using language as a tool to notice and describe events rather than predicting and judging events (Hayes et al., 2006).

Self as Context

Self as context involves developing both the “observing self”, the part of us that does all the observing of our inner and outer world, but also developing our ability to be flexible and consider different perspectives. Self as context is a viewpoint from which we can observe our thoughts and feelings and a place that we can observe our experience without being caught up in it (Hayes et al., 2006). There is growing evidence to suggest this perspective is important in the development of empathy, sense of self and theory of mind (Mchugh et al., 2004). Self as context is deemed to be very important in ACT as it suggests we can be aware of our experiences without attachment to them meaning defusion and acceptance can be fostered (Hayes et al., 2006). Self as context is often explained using metaphors such as “the weather”, which suggests our internal experiences are like the weather and our self-as context perspective is like the blue sky always there and allows us to see our changing thoughts, and emotions (Hayes et al., 2006).

Mindfulness exercises and experiential exercises are also used in ACT to help us develop this perspective (Hayes et al., 2006).

Values

Values are freely chosen and verbally constructed; they can never be fully achieved but give us a direction to work towards in the present moment. Values are chosen and offer a framework for ongoing action that guide us towards what we feel is important to us (Hayes et al., 2006). Values in themselves can never be obtained as an object but can be expressed by our behaviour choices moment to moment (Hayes et al., 2006). Values are clarified within ACT using a variety of exercises to determine a person's values in particular areas such as, family, relationships and work life, identifying our values also helps us to see when we are making choices in life based on avoidance, social compliance or defusion (Hayes et al., 2006). The other processes within ACT such as, defusion, acceptance and being present are not the main goal but increase a person's ability to lead a values consistent life (Hayes et al., 2006).

Committed Action

The goal of ACT is to develop patterns of behaviour that are aligned with the other core processes within ACT and these behaviours are defined as committed action. In this way ACT is aligned with more traditional behavioural therapy meaning many of the methods used for behavioural change can be used when delivering ACT, such as exposure or goals setting (Hayes et al., 2006). Values are used within ACT to inform short, medium and long-term goals that can be achieved and to inform behaviour change during therapy, the behavioural change can at times result in psychological barriers that are addressed through other ACT processes such as, defusion, acceptance or contact with the present moment (Hayes et al., 2006).

Many of the core ACT processes are often overlapping and closely related and each come together to increase a person's psychological flexibility. More recently the six core processes of ACT have been condensed in to three overarching processes called the ACT triflex; open up (acceptance and defusion), be present (contact with the present moment and self as context) and do what matters (values and committed action). (Harris, 2009). This has helped to increase the applicability of these processes and has allowed measurement of psychological flexibility as a multidimensional rather than a unidimensional construct that has increasing empirical evidence (Rogge et al., 2019).

1.8. Rationale for ACT and SCI

SCI can be particularly difficult to manage as it is an irreversible long-term health condition that combines both a high level of impairment and frequent and complex comorbidities (Ona et al., 2023). SCI has been found to generate the highest needs and costs within the healthcare system despite its low incidence and this is thought to be due to the high dependency on a range of services, including paramedics, general physicians and both specialised and community care (Pacheco Barzallo, 2018; Scelza et al., 2007; World Health Organisation [WHO], 2013). When considering the risk of mortality there is significant variations depending on the geographical location and in some developing countries the lifespan post-SCI is much shorter, with death often occurring straight after injury or because of preventable health conditions (WHO, 2013). In comparison, those with SCI living in more developed countries often live more than 20 years post-injury (Ona et al., 2021; WHO, 2013). This variation indicates the significant impact healthcare can have on life span post-sci but also the need for specialised interventions that focus on improving quality of life post-SCI.

Evidence for the need to develop specialised psychological interventions for those with a SCI comes from research investigating factors that can impact longer term outcomes. Many assume ability to cope post-SCI is linked to the level and severity of injury, with beliefs that the higher the level of injury and more severe, the harder it is to cope. However, research suggests these beliefs are untrue and positive coping in the longer-term post-SCI is more heavily linked to factors such as an individual’s perceptions of the situation, their beliefs around ability to cope, social support and ability to continue engaging with meaningful activity (National Health Service [NHS]., n.d.). Clearly, developing and delivering psychological interventions that aim to focus on these factors should be a priority. This provides a rationale as to why it is important to ensure the psychological interventions developed for this population focus on these factors and are specifically developed to provide support in the context of complex biological, psychological and social difficulties. Research has often focused on therapist delivered ACT for those with SCI, which has been found to have positive effects, however the acceptability of ACT and considerations around modifications specific to this population have received little focus in the research (Schulz et al., 2022).

1.9. Rationale for including professional and family/carers in intervention development

Whilst the focus for this research was around the perspectives of those with lived experience it was also deemed necessary to include insights into the acceptability of the manual from both families and professionals. It was believed that recruiting participants from professional and family groups may provide a different perspective on acceptability of the ACT manual given they are reading the manual from a different viewpoint to those with lived experience. Furthermore, it was thought that the adapted manual may be supported by professionals in spinal injury centres within the UK, therefore considering their perspectives about what would be practical would likely be useful.

1.9. Self-Help

Self-help (SH) is as a continuum of approaches designed to help someone to help themselves, generally this work is completed individually and relies to varying extents on support from professionals or non-professionals (Harwood & L'abate., 2010). SH is commonly used in populations of individuals struggling with their mental health but can also be aimed at general development of skills for individuals without mental health difficulties (Harwood & L'abate., 2010). Self-help material is increasing in popularity and given that these materials are often an attempt by those with a particular problem to take control and reduce aversive experiences and more formal mental health support services are overstretched this growth is inevitable (Harwood & L'abate., 2010). Research investigating SH indicates the psychological benefits can be related to increasing competence, self-acceptance, self-efficacy, autonomy and a decrease in anxiety and depression (Watkins, 2007).

1.10. Acceptability and Theoretical Framework for Acceptability

Acceptability has developed into a key consideration when considering the design, evaluation and implementation of healthcare interventions (Sekhon et al., 2017). Acceptability is intertwined with effectiveness as it is necessary to achieve efficacy but acceptability alone is not sufficient to ensure efficacy (Sekhon et al., 2017). The content, context and quality of care can impact the acceptability of health care interventions, and it is suggested that adherence is likely to improve if participants deem an intervention to be acceptable (Sekhon et al., 2017). Definitions of acceptability greatly vary within the research and describe differing aspects such as, social acceptability, described as the "patients' assessment of acceptability, suitability, adequacy and effectiveness of the intervention" and treatment acceptability, described as the interventions appropriateness to address the clinical problem (Sidani et al., 2009; Staniszewska et al., 2010). It is deemed important to create interventions that are acceptable in order to increase efficacy and treatment adherence.

The Framework for Acceptability

There are differing frameworks defining acceptability in healthcare however, The Framework for Acceptability (TFA, Sekhon et al., 2017) is one model that provided a comprehensive theoretical framework that was kept in mind when interpreting responses about acceptability of the "ACTing towards better living" manual. The TFA suggests acceptability is a multi-faceted construct consisting of seven areas which reflect the extent to which people either delivering or receiving a healthcare intervention consider it to be appropriate based on their experiential or anticipated cognitive and emotional responses to the intervention (Sekhon et al., 2017). This was a key factor in the identification and use of this framework as it considered the views of both the individual delivering and the individual receiving the intervention and this study asked both professionals and those with a SCI and their families about the acceptability of the "ACTing towards better living" intervention. The seven key areas described within the TFA are shown in table two below.

Table 2

The Framework of Acceptability

Framework Item	Description
Affective Attitude	How a person feels about the intervention.
Burden	The perceived amount of effort required to participate in the intervention.
Ethicality	The extent to which the intervention is a good fit for the intended audience's value system.
Intervention Coherence	The extent to which the individual understands the intervention and how it works.
Opportunity Costs	Meaning the extent to which benefits, profits or values must be given up when engaging in the intervention.
Perceived Effectiveness	The extent to which the intervention is perceived as likely to achieve its purpose.
Self-efficacy	The participants confidence that they can perform the behaviour required to participate in the intervention.

(Sekhon et al., 2017)

1.11.Extended Aims

The extended paper also aimed to:

- Explore and understand the lived experiences of individuals with a SCI and consider their relevance to the ACT model.

.2. Extended Method

2.1. Ontology and Epistemology

Critical Realism

This research adopted a critical realist approach (Bhaskar, 1975), because critical realism is an approach that distinguishes between "real" and "observable" worlds and suggests our world is constructed from our perspectives and experiences. Our experiences and the meanings we draw from our experiences can be causal according to critical realists because meanings can impact our behaviour and therefore our perception of reality (Edgley et al., 2016). This position has been adopted for this study as the methods used acknowledge that data analysis cannot be independent of the authors perspective and aimed to explore the unobservable reality of individuals with a SCI and consider their experiences and how this impacts their view of the "ACTing towards better living" manual" (Braun & Clarke, 2013). Furthermore, CR suggests context is important and causal explanations are not about deterministic patterns but the activation of causal influences under certain conditions (Tsoukas, 1989).

Functional Contextualism

ACT itself is grounded in Functional Contextualism which aims to identify variables that both predict and influence the behaviour of individuals or groups (Zettle, 2016). Functional Contextualism comes from pragmatism and aims to identify ongoing interactions of the individual alongside the historical and actual contexts of behaviours. Furthermore, functional contextualism suggests understanding the functions of behaviours is key to understanding the behaviour and associated experiences (Biglan & Hayes, 2016). This emphasis on the function of behaviour rather than the topography (e.g., the shape or frequency) is believed to enable a change in the variables of the context that are linked to "negative" behaviours (Hayes et al., 2006).

2.2. Rationale for inclusion and exclusion criteria

Please see table three below for further information on the inclusion and exclusion criteria for this study with the associated rationale.

Table 3

Inclusion and exclusion criteria with rationale

Inclusion Criteria	**Rationale**
Have a SCI.	The study is interested in exploring the opinions of those with a SCI on the "ACTing towards better living" manual.
Be a carer or family member of an individual with a SCI.	The study is interested in exploring the opinions of carers of those with a SCI on the "ACTing towards better living" manual.
Be a professional with experience of working with individuals with SCI.	The study is interested in exploring the opinions of carers of those with a SCI on the "ACTing towards better living" manual.
Aged 18 or over.	The study was focusing on adults which are determined to be 18 or over.
Exclusion Criteria	**Rationale**
Participants were excluded if they were not able to engage in a semi-structured interview.	The study was reliant on gaining opinions of the manual based on a semi-structured interview.

2.3. Recruitment and Participant Information.

Recruitment was completed via a purposive sampling method either via posting the research advert on social media SCI support pages, tweeting by The Back-up trust to their Twitter page or advertisement in 'The Voice' publication. The Back-up Trust is a charitable organisation based within the United Kingdom that provides guidance and support for individuals with a SCI. The Back-up trust has been supporting individuals with SCI and their families for thirty years with the aim of rebuilding independence after SCI. ‘The Voice’ is a monthly newsletter created by the Spinal Injuries Association (SIA) and sent monthly to their members. This newsletter involves information for SIA members on different topics and events and research happening within the SIA.

A total of 14 participants were recruited for this research. Of all participants, three participants contacted the primary research after seeing the adverts posted on Facebook SCI support groups, five participants contacted the primary research after seeing the advert in ‘The Voice’ newsletter and two participants were contacted by the primary researcher and asked if they would like to take part because they were coordinators for the SIA and their details were passed over by people known to the primary researcher. Two participants were contacted by the primary researcher and asked to take part as they were known to work professionally alongside individuals with SCI. Two participants contacted the primary researcher after hearing about the study through their contact with the university and doctorate programmes in clinical psychology within the UK. Information on participants injuries and time since injury can be found in table four below.

Table 4

Participant injury information for participants with a SCI

		Number	%
Level of injury	T12	1	7%
	T2	1	7%
	C5/6	3	21%
	T7c	1	7%
	C3-7	1	7%
	C5	1	7%
	L3/4	1	7%
	T4	1	7%
Time since injury	1-5 years	4	29%
	6-11 years	2	14%
	12-30 years	2	14%
	30-40 years	1	7%
	40 – 50 years	2	14%

2.4. Study Materials

This study used a previously created self-help manual that was amended from the "get out of your mind and into your life" book created by Stephen Hayes. Please see information on the "ACTing towards better living" manual in table five below. The "ACTing towards better living" self-help manual was used as the base material for this research and was obtained from previous research completed by Shepherd et al. (2022). The manual was previously used in an experimental study with those with Covid-19 (Shepherd et al., 2022) and there were minimal amendments completed prior to using the manual in this research. Amendments completed involved removing any wording related to covid-19 however the content and ACT material within the manual remained the same.

Table 5

Summary of content within the "ACTing towards better living" manual

Section title	Facet of psychological flexibility/ACT hexaflex	Summary
ACTing towards better living, week 00, Introduction	N/A	Overview of all sections. Identifying therapy focus.
ACTing towards better living, week 01, Acceptance and Willingness	Acceptance	Problems and benefits of experiential avoidance and acceptance.
ACTing towards better living, week 02, Defusion stepping back from thoughts	Cognitive defusion	Difficulty with thought fusion and cognitive defusion activities (e.g., 'leaves on a stream').
ACTing towards better living, week 03, If I'm not my thoughts who am I?	Self as context	Introduction to three senses of self, 'the conceptualised self', 'self-awareness' and 'the observing self'. Summary of previous weeks.
ACTing towards better living, week 04, Mindfulness	Attention to present moment	Introduction to mindfulness and mindfulness activities (e.g., breathing techniques or activity engagement).
ACTing towards better living, week 05, Learning what matters	Values	Activities to aid in clarifying values, explanation of difference between values and goals.
ACTing towards better living, week 06, Doing what matters	Committed action	Choice point explanation. Goal setting. Barriers to values-based living.

(Shepherd et al., 2022)

2.5. Design

A qualitative design was used for this study as it was determined to be the best method to answer the research questions. The study was initially designed to be a two-phase process, the first phase involves a qualitative exploration of acceptability of the ACT manual as described in this study. The second phase would involve creating the adapted ACT manual and conducting focus groups to determine if the amended ACT manual was deemed to more acceptable based on the adaptations made. It was decided that due to time restraints the first phase would be completed in this study and the second phase would be suggested for future research. This study was primarily concerned with exploring whether the ACT Model and the "ACTing towards better living" manual in particular was acceptable for individuals with a SCI and what adaptations could be made to improve the manuals acceptability and increase its utility for the difficulties described by this population. It was assumed the responses to this question would be complex, intertwining and difficult to understand therefore a qualitative approach focused on interpreting and making meaning from responses was thought to be the most appropriate (Tenney et al., 2022). The primary researcher took an active role in the interpretation of the information gathered from those with SCI, their carers and professionals that work in settings supporting those with SCI and constructed suggested adaptations for this manual based on this data. The data gathered was analysed using a Reflexive Thematic Analysis (RTA) approach and the themes were then used to inform the adaptations to create a SCI specific ACT informed guided self-help manual. Further information on RTA is discussed below.

2.6. Reflexive Thematic Analysis

Reflexive Thematic Analysis (RTA) is an approach developed by Braun and Clarke (2019) in response to misinterpretations of their earlier papers describing thematic analysis (TA; Braun & Clarke, 2006). Braun and Clarke (2006) acknowledged their previous papers incompletely defined TA and suggested there were areas that could be left to interpretation. RTA is differentiated from other thematic approaches as it deems the research has an active role in knowledge production rather than information being extracted from the data (Braun & Clarke, 2019). In RTA, codes are believed to represent the researcher's interpretations of patterns across the dataset with the interpreted analysis conducted at the intersection of the dataset, theoretical assumptions of the analysis and the resources and skills of the researcher (Braun & Clarke, 2019). Due to this, Braun & Clarke (2019) suggest it is unlikely for a different researcher to create a similar analysis further implicating the active role of the researcher as paramount in the analysis process.

Braun and Clarke (2006; 2012; 2013; 2019), created six key phases within their analytical process that require completion when using RTA. The six phases are described linearly below however, in practice these phases are often more iterative and fluid movement back and forth between phases is common. A commentary on how the primary researcher followed each stage is also offered below.

Phase One: Familiarisation with the Data

The first phase is 'familiarisation with the dataset', this phase involves reading and re-reading the interview transcripts. The interview transcripts were read through in their entirety whilst listening to the audio of the interviews to correct any mistakes in the transcribed interviews. Once this was completed the transcriptions were again read through by the primary researcher to reach familiarisation with the data. The primary researcher made initial notes and reflections regarding parts of the data that stood out to them.

Phase Two: Generating Initial Codes

Codes are the necessary building blocks to develop themes and coding involves turning the data into succinct descriptive or interpretive labels to begin categorising information that could be useful to answer the research questions (Byrne, 2021). The primary researcher worked systematically through the data set, with each data item being considered equally and codes were created for data deemed relevant to developing themes related to the research questions (Byrne., 2021). Codes were initially created using the comments function in Microsoft Word enabling easy viewing of the code and associated text from the transcript. Iterations of coding were completed and tracked during this process. The codes were initially grouped and transferred to a Microsoft excel spreadsheet.

Phase Three: Generating Themes

Phase three begins once all chosen items within the data set are coded. In this stage, the focus changes to interpretation of meaning across the dataset (Byrne, 2021). The initial codes were reviewed and analysed by the primary researcher with a focus on how they could be grouped based on shared meaning. This process was done via Microsoft Excel however to aid fluidity and movement the primary researcher switched to printed codes to begin grouping (Appendix I). At this point an initial thematic map was created. See figure one below.

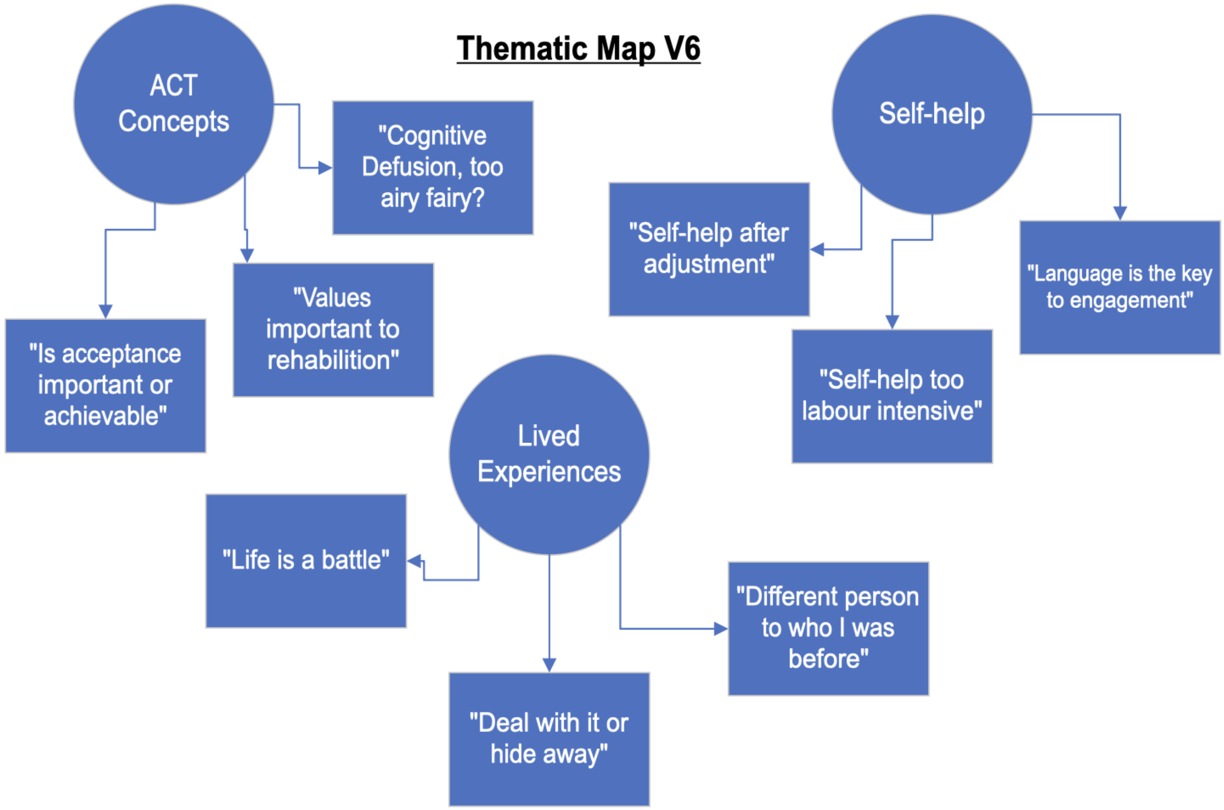


Figure 1: Final version of thematic map.

Phase Four: Reviewing Potential Themes

Phase four involved reviewing initial themes to ensure they provided meaning relevant for answering the research question and were indicative of the data set. Further checks for coherence and ensuring themes were backed up by the data by tracking back was completed. Braun and Clarke (2006) recommend completing a dual review, ensuring items and codes inform the themes and that themes are indicative of the dataset. The idea of a dual review was held in mind by the primary researcher during this phase and based on this some revisions or collapsing of themes into subthemes and further iterations of the thematic map were completed at this stage. This process was discussed amongst the wider research team who provided support to the primary researcher to ensure this process was being completed correctly.

The primary researcher constructed themes related to participants experiences post-SCI. This was relevant to understanding the context as to why developing a self-help manual like this was important and what problems existed for those with SCI. On reflection it was determined that whilst this meaning was important it was not key to answering the research question, therefore this analysis has been included in section three of this extended paper. At this point iterations of previous phases were completed to ensure themes were indicative of the data set and answered the research questions. An example of these iterations was that initially language sub-themes were separated, but then it was understood by the primary researcher that these sub-themes conveyed meaning on the same subject and became too thin when separated, so were collapsed in to one theme that describes the impact of language use on acceptability of the manual overall.

Phase Five: Defining and Naming Themes

At this stage Braun and Clarke (2006) suggest each theme should provide a coherent account of the data that cannot be told by other themes with all themes coming together to create a narrative consistent with the dataset and informative to the research question. The names of themes were also revised at this point and final theme names were constructed. Generally, theme names were extracted from the data and quotes or words that demonstrated the meaning of each theme and sub-theme were used.

Phase six: Writing-up

The final phase of the six-phase process is to write up the process and results. This was completed by the primary researcher with some guidance being offered from the wider research team during this process.

2.7. Procedure

Favourable opinion was gained for this research via the Leeds East Research Ethics Committee (REC), REC reference: 22/YH/0079 (Appendix B). One amendment to this study was completed in November 2022 and was granted which changed the focus of the study from an interventional design to a qualitative design focused on amending an existing ACT self-help intervention for a population of people with a SCI (Appendix B.i).

Once favourable opinion was achieved the research poster was displayed in several places as described in section 2.3 of this research paper. Interested participants then used information contained in the poster to email the researcher and request to take part. Participants were sent a pre-planned email message (see appendix D) and a copy of the participant information sheet along with a link to an online consent form. Four participants were contacted by the researcher via email after this research was discussed with them by someone known to both the researcher and the participant. This was the case for the two professionals involved in this research and two individuals who had lived experience of a SCI but also worked for charitable organisations in support roles. Their information was passed to the primary researcher by the charitable organisations when the primary researcher requested to advertise the research poster.

Once participants provided consent via the online form, they were contacted by email to arrange a suitable time for their remotely conducted interview. Participants were offered the options of conducting the interview by telephone or MS Teams and were sent the “ACTing towards better living” manual to review. The “ACTing towards better living” manual was amended by the primary researcher to include notes sections that participants could write their thoughts in as they reviewed the manual. It was hoped these sections of the manual would serve as aide memoires during their semi-structured interviews. A reminder email was sent the day before the interviews to ensure participants were still able to attend. Participants provided verbal consent for their interviews to be recorded when on the call whether this was via MS Teams (10) or telephone (4). Interviews typically lasted for 1 hour and took place between January and April 2023. During the interviews participants were asked several questions about the manual.

Once the semi-structured interviews were completed participants were thanked for their input and sent a £10 shopping voucher. The recordings of the semi-structured interviews were converted to MP4 files by the primary researcher and uploaded to the University of Nottingham auto transcription service which provided a written transcript of each interview. Each interview was checked against the original recording file by the primary researcher to confirm their accuracy. The recordings and transcripts were stored on a university approved cloud drive in line with university policy and as approved by the REC.

2.8. Ethical considerations

This study was conducted in accordance with the University of Nottingham (UoN) ethical framework (UoN., n.d.), British Psychological Society Code of Human Research Ethics (BPS, 2010) and received favourable opinion from the Leeds East REC (see more information in section 2.7 above).

Ethical considerations were important when designing this study as they are believed to hold particular importance in qualitative research, especially when using methods such as semi-structured interviews involving discussing emotive topics (Arifin, 2018). This was considered by the primary researcher when designing the research posters to ensure participants were aware the focus was to gather opinions on the self-help manual not provide psychological support for emotional distress. An initial email and the information sheet described the purpose and process of this research and was sent to all potential participants prior to them providing consent to ensure this was fully informed. Any people who mistakenly emailed the researcher requesting psychological support were sent an email encouraging them to contact their General Practitioner (GP) and given the information of national charities such as SIA and Back-up that offer this type of support.

Another ethical decision to be considered was conducting the semi-structured interviews by telephone or MS teams. Considerations around whether this was appropriate due to the nature of the research and concerns participants could become distressed when discussing their experiences. It was decided that the focus of the semi-structured interview questions involved exploring opinions of the existing self-help manual and this would be unlikely to cause distress. Furthermore, the primary researchers own training in managing the emotional wellbeing of others was believed to be sufficient if any distress occurred. It was therefore deemed acceptable to conduct the semi-structured interviews by video or telephone due to low risk of distress and many of the participants geographical locations meant this would be impractical for completion to be in person. Participants were also asked to arrange the telephone call or MS teams calls at a time that was suitable for them and the primary researcher was flexible to participants requests. One example involved a participant stating they would be having a two-week period of intensive rehabilitation and they requested to be contacted after this period. This was agreed by the primary researcher and the participant to ensure the research request did not add any undue stress to the participants lives. This was considered for all participants to ensure that taking part in this research felt manageable for them. It was also explained to participants that they could withdraw from the research at any point. No participants withdrew from this research or reported that it caused any emotional distress.

2. Extended Results

The extended results section below comprises a complementary theme related to participants lived experiences post SCI. It was important to understand the context participants were approaching the self-help manual from but on reflection it was decided this theme did not provide enough direct recommendations about acceptability of the manual for it to be included in the journal paper. Participants pseudonyms are used throughout this results section. Codes were used to decipher which category participants fell in to e.g., LE – someone who has lived experience of having a SCI, P – professional working with those with a SCI and F – family of someone who has a SCI.

Theme three: Lived Experiences

This theme describes the lived experiences of people post-SCI. It was important to understand this information to explore the impact these experiences could have on a person's ability to engage with the self-help manual. This theme contains three subthemes, "life is a battle", deal with it or hide away" and "different to who I was before" that describe challenges that could hinder engagement with the "ACTing towards better living" manual.

Subtheme 3a: "Life is a battle"

Participants discussed the extent to which their lives had changed post-SCI and the impact this had on their experiences of day-to-day life. They discussed experiencing strong emotions and struggling with the idea of recovery, which was considered to be a potential barrier to accessing the self-help manual.

Seven participants described life after SCI in negative ways such as, "a battle" (Donald, LE), "business-like" (Nicole, LE) and "like throwing a grenade in my life" (Paul, LE). Strong emotional reactions were described, and anger was the most common, "I saw a lot of people there who were angry in the first few months" (Greg, LE), "you go through the anger process" (Mike, LE). Suggestions that anger stemmed from facing a new reality and grieving what has been lost post-SCI were made, "focus tends to be on what you've lost and what you can't do" (Mark, LE), "my life is unrecognisable" (Paul, LE), "my life as I saw it was going in that direction of an army career" (Donald, LE). The meaning made from the discussions with participants indicated how life-changing a SCI is and often has catastrophic consequences for planned life trajectories, resulting in feelings of loss, grief and anger.

Donald suggested that initially anger was challenging to overcome but became motivational in some way, and 'fuel' for an everyday battle, "you need that…(anger) to try again and try somewhere else" (Donald, LE). Donald offered this quote when describing his pursuit in accessing pubs without adequate disabled access in his wheelchair. In this scenario becoming angry and frustrated with the lack of access meant Donald didn't give up but continued to try other establishments eventually resulting in access. Donald's suggestions that his anger was a helpful alternative to other emotions which enabled him to keep trying could be useful when considering how strong emotions are framed within the self-help manual. Anger is commonly viewed as a negative emotion by many due to the often-associated negative consequences (Kjaervik & Bushman., 2024). ACT views anger not as an emotion to be struggled with but as a normal healthy emotion that only becomes problematic when the anger feeling is then reacted too with angry behaviours (Eifert et al., 2006). Framing anger in this way in the manual is likely to be useful when anger is such a common experience post-SCI. Ideas around dropping the struggle such as in the "psychological quicksand metaphor" (Appendix N) as mentioned in week 0 of the manual could be particularly helpful. This section could be improved by describing the types of scenarios likely to be experienced by people with a SCI that could result in anger, such as lack of access described by Donald.

Recovery was discussed by participants and Donald suggested this could be unattainable after SCI, "The emotional trauma that's going on within any spinal problem and… any length of time, and there's no such thing as recovery I can imagine" (Donald, LE). Whilst recovery isn't something the self-help manual aims to achieve there is a connotation that these materials aim to provide support to improve people's lives and wellbeing with a range of techniques. These beliefs that recovery is unattainable post-SCI could present as a barrier to engaging with self-help materials and this point was suggested by Greg, "So that was my first impression. What? What was? Whether somebody would even want to read it…it's a question of whether they could accept it" (LE). Being aware of the beliefs around recovery and acceptance of support post-SCI and how this could present as a barrier to engagement with self-help is important. Greg also discussed experiences of denial after his injury, "I think everybody is in denial for a short time after they're injured" (LE). Understanding that after SCI people can feel very angry or in denial and struggle to believe recovery or change is an option is important when considering adaptions for the manual. These types of beliefs and emotions are likely to present as significant barriers to engaging with the self-help manual and ensuring to normalise these experiences and incorporating the ACT ideas around dropping the struggle with these experiences is likely to be useful in increasing engagement for this population.

In summary, the experiences described by the participants in this study evidence the need for psychological support after SCI and the type of challenges expressed also fit with the aims of the ACT manual and the ACT approach. Despite this some barriers specific to the lived experience of participants post-SCI which could make engaging with this type of manual challenging, including experiences of anger, denial and ideas of unattainable recovery. Suggestions to normalise and name these experiences and describe the ACT approach of 'dropping the struggle' (Appendix N) with these experiences is likely to be helpful.

Subtheme 3b: 'Deal With it or Hide Away'

Mark and Donald described observing avoidance in people they had met post-SCI or using this strategy themselves:

"You'll come across people who won't go out. And it's sometimes it's fear of being seen in a wheelchair. And what? What are other people gonna think, um?" (Mark, LE), "Yeah. It's like a child and go up and touching something and hurting themselves and learning. I'm not gonna do that. Perhaps I've gone through that. There are so many things. I thought, no, avoid that. Not helpful" (Donald, LE).

These experiences were understood to be what ACT terms experiential avoidance. Experiential avoidance is when individuals avoid experiences, thoughts, emotions, memories or physical sensations that are aversive (Hayes et al., 2006) and suggests using this strategy in the long-term serves to move people away from living a valued life. Evidently people do use experiential avoidance as a coping strategy post-SCI and Nicole suggested this enabled her to continue working after her injury.

"But after my accident, I locked everything away for 16 years now…It enabled me to do 3 degrees work at the BBC for six years and cope with severe, unrelenting, overwhelming pain by just. Bulldozing my way through it" (Nicole, LE).

Nicole’s quote suggests by ignoring any pain or difficult emotions she was able to carry on with her life, however later suggested this only worked for a period of time, “It did eventually come out…inevitably after locking it away and then when it all started coming to the surface, there was no out” (Nicole, LE). It became clear that as suggested by the ACT manual experiential avoidance can be successful for a period of time but increases distress in the long-term which was an experience Nicole described. Dawn described a similar experience:

“Because so much is taken away in a practical sense…Your independence and things. You quickly want to get back in charge. Yeah. So you think…You don't actually want to stop and. Have to go all the way back and look at who you really are and. Where you need to get to…So that's quite tough” (Dawn, LE).

Dawn suggests an urge to get back in control of your life fuels the urge to move forward without processing any challenging feelings or thoughts after injury. She suggests encouraging people to do this could be difficult within the manual but despite the difficulty other participants suggested it was important to ensure this message is communicated. Paul suggested rather than avoiding his difficult emotions processing them through talking to others was helpful for him:

“This happened to me and talking about it, the advice I would give to anybody, is just…Just talk to people hasn’t got to be health professionals or anything like that. Just talk to, you know your next-door neighbour your postie anybody you can you need to get these things out. You can't. You just need to. You need to confront it. You need to deal with it rather than to hide it away” (Paul, LE).

Evidently, experiences of experiential avoidance post-SCI are common and many people have engaged in this technique only to realise it became harmful for them later down the line. Whilst Paul’s experiences indicated talking to others helped him, the ACT concepts and ideas around experiential avoidance contained in the self-help manual are likely to provide some benefit to participants too. Potentially, the pull to avoid could be particularly strong for those with SCI due to painful memories of what has been lost. This was suggested by Donald who threw away old sports trophies of past sporting achievements after his injury but later realised this was unhelpful, “Yeah. I remember the time when I spoke about my injury. I remember the time where I reflected on my past and realised that that wasn't helping when I got rid of stuff and so on” (Donald, LE).

Using real-life examples such as those described by participants within the “ACTing towards better living” manual and describing the negative impact experiential avoidance can have post-SCI would improve this section of the self-help manual. The ideas within the self-help manual provide an alternative to experiential avoidance that is believed to increase psychological flexibility, which is often linked to increased emotional wellbeing (Marshall & Brockman, 2016). However, it was also suggested by participants that avoidance can be helpful straight after injury to succeed in doing things without becoming too overwhelmed and this might be a helpful point to consider as people might need support to begin engaging with self-help material in the first place if their initial reaction is to avoid confronting difficult emotions. Potentially, a message suggesting inclusion of family members to encourage engagement with difficult emotions could be useful at the beginning of the “ACTing towards better living” manual or by incorporating use of this manual within a hybrid approach supported by professionals may reduce the likelihood of this avoidance.

Subtheme 3c: ‘Different person to who I was before’

The impact on a person’s identity post-SCI was something discussed by many participants and Jenny felt she was “quite a different person to the person I was before. I hope I will get back to that” (Jenny, LE). It is unclear based on Jenny’s quote what might have made her feel different post-SCI but Callum suggested being treated differently by others made him feel different:

“They think I'm a. An idiot, you know they, they talk to the person what's wrong with him, right. And that sort of thing. Yeah. You know, when they talk to you, you know, yeah, that thing doesn't take. Yeah. Does he take sugar? Have you heard that one?” (Callum, LE).

It seems that being treated differently by others can make us feel different and reinforces the changes experienced post-SCI that can so often be intertwined with our sense of self and identity. The concept of Self as Context (SAC) within ACT suggests we have a part of our selves at our core that remains static despite any external experiences even when our thoughts, feelings and emotions are ever-changing (Hayes et al., 2006). The concept seems particularly relevant to those with SCI based on what is understood from participants comments about feeling different after their injury.

Paul talked about not being able to do the things he used to do since being in a wheelchair stating, “I'm watching somebody else do it. I've become a spectator of my own life” (Paul, LE*)*. It seems in this instance Paul is indicating how he has moved to the periphery of his own life and when our ability to do things we used to do changes, it can impact our sense of self. Mark and Rachel discussed another factor that they believed had a strong link to sense of self:

“Can I support. My family, can I still pay the mortgage, can we still live in the house that we own. Because you do have questions about where do I fit into society, where am I gonna, what's my fit gonna be? Now, what does this look like?” (Mark, LE).

“Changes of role within the society, changes of role within the family, you know, all those kinds of stuff” (Rachel, P).

Both Mark and Rachel discuss sense of self being linked to roles within the family, but also within wider society and when these roles can no longer be fulfilled a person’s sense of self and identity can become uncertain. The link between sense of self and roles is suggested by those with lived experience and professionals. Callum also stated that his sense of self became intertwined with his disability, “you become a patient for life (Callum, LE).

In conclusion, participants discussed how their SCI impacted their sense of self because they were treated differently by others and could no longer engage in activities or roles they previously did because of their disability. Using the self-help manual to develop ideas around SAC could be very beneficial to those with SCI as it would build a sense of self that is separate from physical ability or the roles we fulfil which seems particularly relevant based on some of the experiences described by participants. Within the self-help manual currently there is a section on self as content and by personalising this section to explain that we are more than the things we do and the roles we fulfil would aid further exploration of these ideas which participants seem to be fused with currently. By adapting this section, the ideas around SAC would likely be much more concrete and by developing a stable SAC individuals will hopefully be able to transcend difficult internal experiences related to their change in identity that causes distress (Hayes et al., 2006).

4. Extended Discussion

This section includes a discussion about the extended results and will consider the findings of this research study in the context of existing literature. A further exploration of ideas for future research and how the findings of this study will contribute to clinical practice will also be offered.

It was clear from participants descriptions that life after SCI comes with significant changes and challenges that can result in strong emotions such as anger and denial. Literature exploring ACT and anger suggests that those who experience anger are more likely to be fused to anger provoking thoughts and are attached to the belief that they cannot control their anger indicating fusion to the conceptualised self (Eifert & Forsyth, 2011). Anger has also been found to provide a protective function related to experiential avoidance by providing an opportunity for people to avoid other unpleasant emotions by feeling angry instead (Eifert & Forsyth, 2011). This was also illustrated by participants in this study who described feeling angry when unable to access particular establishments and reported the anger helped them keep trying. Potentially anger is a more acceptable emotion than experiencing a sense of loss and grief after SCI or this could be part of the process of grieving post-SCI.

The Kubler-Ross Grief Cycle (1969) suggests a grieving individual will go through the stages of denial, anger, bargaining, depression and acceptance whilst processing their grief. Potentially, considering the experiences of those with a SCI in the context of the Grief Cycle (Kubler-Ross, 1969) and understanding that ACT can provide a protective function could be useful to explain within the self-help manual. There are caveats as The Grief Cycle (Kubler-Ross, 1969) has been criticised for being too simplistic and lacks empirical evidence (Stroebe, 2017). Furthermore, it must be understood that these stages are not always completed linearly and moving through these stages is individual for each person (Tyrell et al., 2023). Despite these criticisms, describing The Grief Cycle (Kubler-Ross, 1969) in the manual could help to normalise the experiences of individuals post-SCI potentially increasing engagement and offering an opportunity to explore where someone is in this cycle and encouraging them to consider different parts of the manual depending on their stage.

ACT could be a useful approach to support the difficulties related to anger and grief described by participants post-SCI especially in understanding the protective functions of anger. ACT aims to increase acceptance of difficult experiences alongside fostering greater psychological flexibility to encourage proactive engagement with your life (Dindo et al., 2017) which seems particularly relevant to the types of experiences explained by participants. ACT has already been found to have a medium to large effect on depressive symptoms, anxiety, quality of life, grief and psychological flexibility for those with a neurological disorder and SCI (Han et al., 2023) but investigating ACT via self-help methods would be useful.

The findings of this study indicated experiential avoidance can be a common coping strategy post-SCI to manage difficult experiences. This is consistent with previous research that also linked avoidant coping behaviours to increased depression and hopelessness in those with disabilities, chronic conditions and SCI (Ho et al., 2004; Kortte et al., 2009; Murberg et al., 2004; Pollard & Kennedy, 2007;). The high likelihood of avoidant coping strategies post-SCI could present as a challenge considering the manual is self-help as participants may be unlikely to engage with this type of material in the first place. Potentially, guided self-help comprising both self-directed and therapist-led modules might be most beneficial for this population given the evidenced difficulties with experiential avoidance. Research suggests incorporating therapist led modules for those with chronic conditions increased accountability and reduced non-adherence (Wilkin et al., 2023) providing further evidence for the inclusion of therapist-led modules in the self-help manual. The ACT self-help manual aims to foster psychological flexibility through six core processes and ACT suggests that acceptance is the opposite of experiential avoidance (Hayes et al., 2006). Developing a guided self-help manual specifically for the challenges described by individuals with a SCI seems very relevant due to the aims of ACT related to decreasing experiential avoidance which is clearly a difficulty for many after SCI.

The process of acceptance as described within the “ACTing towards better living” manual was identified as something likely to be particularly useful to a population of individuals with a SCI. The belief that acceptance is likely to be helpful in rehabilitation has been previously shown in the existing research alongside evidence to suggest acceptance has a significant link to increased quality of life post-SCI (Aaby et al., 2020; Dunn, 2016). However, this research did not control for symptoms of anxiety and depression therefore it is unclear if acceptance improves quality of life over and above a reduction in symptoms of depression and anxiety or if acceptance alone improves quality of life (Aaby et al., 2022). Some suggestions that the sections of the manual that discussed accepting a new reality and not engaging in avoidant behaviour could be particularly difficult if not impossible for some to engage with post-SCI. Research suggests that ‘letting go of control’ is weakly correlated to quality of life potentially due to the interplay of physical factors post-SCI that influence a person’s ability to let go, which is congruent with the views of participants in this study (Aaby et al., 2022). ‘Letting go of control’ comprises psychological factors such as, trying to avoid difficult emotions or thoughts which may reveal why these facets of acceptance are more challenging post-SCI. There were suggestions there is a strong pull post-SCI to avoid difficult emotions and focusing on clarifying values was identified as a more helpful strategy which fits with wider research into this area that this might be easier to engage with initially (Aaby et al., 2022). Providing links between the acceptance and values sections and intertwining ideas in these sections is likely to alleviate concerns and improve the usefulness of the manual.

Our sense of self and identity is developed in childhood by approaching varied contexts and experiences and pervades into adulthood, with links to our relationships, roles, employment and abilities (Erikson, 1980). The psychosocial impact of SCI is well known and has been found to negatively impact relationships, finances, employment, living situations and community integration which can result in poorer self-esteem and sense of self (Budd et al., 2022; Kalpakjian et al., 2015). The findings of this study also found a similar relationship with participants describing that their sense of self was impacted after SCI due to being treated differently by others, being unable to fulfil roles within the family or society and being unable to do activities they previously engaged with. It was understood that the sense of self that participants described in this study was closely related to what Hayes (2006) describes as the conceptualised self – which is who we think we are and who we think we should be. The conceptualised self (Hayes, 2006) is described as the verbal content that we tell ourselves we are based on our life experiences. When we become fused to these ideas our ability to be psychologically flexible reduces particularly when the narrative supports a negative conceptualised self (Zettle., 2016). When our ability to fulfil our self-conceptualisations changes such as in SCI, distress can occur and was described by participants who talked about no longer being “the breadwinner” which negatively impacted their sense of self and self-esteem post-SCI. Self as context (SAC) is the ACT concept that aims to teach participants by developing awareness a person can identify that they have a sense of self that is separate from their internal experiences (Hayes et al., 2006). The findings suggested by this population indicate self-identity can be strongly linked to physical ability which can change post-SCI. Potentially, developing the SAC sections within the manual is particularly important to increase the definition of self-identity to encompass more than physical roles and responsibilities for individuals post-SCI.

The section of the ACT manual that focuses on developing SAC is general and uses exercises to develop the observing self, describes the conceptualised self and uses exercises to develop self-awareness. By explaining SAC in the context of the examples and experiences given in this study, e.g., losing roles such as “I am no longer the breadwinner” and tailoring this section to describe how we can feel different because our ability has changed post-SCI is likely to improve this section and make the ideas more concrete, relevant and accessible to this population. SAC has a strong theoretical basis however empirical research to support the use of this concept in clinical treatment is limited (Godbee & Kangas, 2020; Zettle, 2016). Despite this, exploring SAC in individuals with a SCI could be an interesting topic for future research given its relevance as identified by the findings of this study.

In conclusion, the findings of this study indicate the presence of significant challenges post-SCI such as, experiencing anger, loss and grief. By understanding these experiences, we can modify the self-help manual to cater for these SCI-specific experiences. Potentially, including information from grief cycle literature could enhance personalisation which has been found to be a key motivator in increasing acceptability of and engagement with self-help materials (Walsh & Richards, 2015). Experiential avoidance was discussed as a key coping strategy post-SCI, which is in-keeping with prior research (Skinner et al., 2010). The presence of experiential avoidance indicates the need for this manual to be developed as ACT has been found to be a useful approach in reducing experiential avoidance (Zakiei et al., 2021), however this research was conducted with a different population. Experiential avoidance in those with SCI could present as a barrier to engaging with the self-help manual but inclusion of therapist-led modules could increase engagement with the manual and should be considered. Finally, the findings identified that potentially being fused to the conceptualised self can cause distress post-SCI, therefore developing SAC could be useful approach. Adaptations to this section could focus on describing the potentially damaging fusion between physical ability and identity, with activities focusing on developing a sense of self that transcends our physicality, roles and relationships which could be a helpful way forward post-SCI.

4.1. Contribution to Clinical Practice

This study aimed to understand whether ACT self-help was an acceptable approach for psychological support post-SCI. By gathering opinions on the acceptability of an existing ACT informed self-help manual conclusions were drawn about the acceptability of this approach and necessary adaptations to increase acceptability were also discussed. The findings of this study have provided an insight in to whether the ACT approach is deemed acceptable to those with SCI and no other research has focused on this subject as its sole aim. Much previous research has focused on efficacy of ACT with different populations but focusing on its acceptability could result in specific adaptations to the ACT model for specific populations that may increase engagement with the model and therefore potentially its efficacy. The second phase of this research will be to use the findings of this study to create a guided ACT informed self-help manual that could be specifically designed for the psychological challenges often faced after SCI. Previous research suggests psychological support can be challenging to access post-SCI (Fann et al., 2011) therefore developing a SCI specific ACT guided self-help manual could provide an effective and accessible way to support people psychologically after SCI.

4.2 Future Research

Areas for future research should involve adapting the existing self-help manual to create a SCI specific self-help manual and initially conducting focus groups to assess whether the acceptability has changed based on the findings and adaptations suggested by this research. Research should then focus on assessing the efficacy of the SCI specific manual in a population of adults with SCI. Based on the findings of this study incorporating therapist-led modules alongside check-ins to monitor progress and increase engagement is suggested as the best approach for those with SCI. It is hoped that by developing this resource individuals with SCI would have psychological support specific to them that could be delivered and accessed widely amongst spinal injury centres or within SCI community support services.

Reflection

Reflective thinking is a key part of the research process, it enables us to continuously improve practice and is a key proficiency in the role of a clinical psychologist (Health & Care Professions Council; HCPC, 2023; Mortari, 2015). Furthermore, reflecting on our own clinical practice enables us to make sense of our place in the world, understand our strengths and weaknesses and determine our place within any clinical and research work undertaken (Koshy et al., 2017). Below is a reflective piece of writing describing my experience of completing this research and the challenges and steps taken to work through my challenges.

From Single Case Design to Qualitative Research

The idea for this thesis initially began as a single case design study to explore efficacy of an existing ACT informed self-help intervention in a population of adults with a SCI. The rationale for this study came from an identified need for psychological support for this population and a belief that ACT self-help, which has had success in many other populations could be useful (French et al., 2017; Noreau et al., 2014; Shepherd et al., 2022). I received favourable opinion for this study from an ethics board and began my search for recruitment in the same manner that I recruited for this study however the outcome was very different. I struggled to recruit and had very little interest, with the one individual I recruited deciding they did not want to continue the intervention after week one. This participant said they found the intervention too confronting, and it was very distressing for them. At this point I knew I had to abandon my project and my options were to find another project or to change my existing project in some way. I began to reflect on the lack of response from my recruitment efforts alongside the response from the participant who decided not to continue. I realised that there must be something about this type of approach that alienated this population and maybe concerns about the existing manual could be too confronting and potentially unacceptable. I understood the lack of responses I received to be a research question when the same approach had been used in other chronic health conditions and recruitment had been successful. I began to wonder whether there was something different about the opinions of those with SCI on the acceptability of this type of psychological support.

I conducted a literature search and there was a dearth of literature in this area however some qualitative research had focused on exploring perspectives of those with chronic pain and irritable bowel disease on the ACT processes (Casey et al., 2020; Wilkin et al., 2023). I decided a qualitative approach to explore the opinions of this population on the existing self-help manual and the ACT informed ideas within it would be a better approach. Given that the idea for this new project came from both exploring the literature and finding little research exploring this area but also my own real-life experiences with this population, it was important for me to be aware of any pre-conceived ideas I could be bringing to this research.

I began writing a reflective journal with all my thoughts and this was useful to refer to and ensure the meaning made in this research wasn't overly influenced by these preconceptions. I also used my research supervisions as a place to reflect on any developing themes and thoughts and to ensure this was coming from the available data rather than unconsciously trying to make data fit my preconceived ideas. This was a very useful experience, and both my research supervisors asked many questions to enable me to reflect on this which was very useful. I recognise the importance of having others involved in your research as a sounding board and to consider and reflect on preconceived ideas or unconscious biases. One initial reflection from my reflective diary that I was aware of was that during the interview process I noticed that when asked if participants had tried out any techniques many said they had not and were reading it from a proofreading perspective. I thought this was an interesting reflection that indicated participants potentially required a degree of separation from the techniques discussed in the manual. I made sure to be aware of these reflections during my analysis, but this process led towards indications that high levels of experiential avoidance can be present post-SCI.

Qualitative Research

Another challenge for me was that I have not had a lot of experience conducting qualitative research so the process was very different and something I had to learn through doing. I have previously never considered why I have favoured quantitative research in the past however, through completing a piece of qualitative research I believe some of my own personality factors might have played into these decisions in the past and I was not aware.

The main challenge for me during this research was to let go of my positivist informed beliefs of right and wrong and uncovering the truth that exists within the data and instead become an active meaning maker within the process of my research. Initially, this was almost paralysing for me during the coding process and caused heightened anxiety which led to either avoidance or regular checking in with my supervisors to check I was doing things “right”. These behaviours hindered my research progress, and it took me some time to realise this was an anxiety response due to lack of confidence in my own abilities. I used the ACT model to conceptualise my difficulties and engaged in defusion techniques and mindfulness strategies to help me engage with my research. I often adopt a curious approach when engaging with clients in therapeutic settings and this was useful for me to remember when engaging with my research too. Another strategy that helped me to view things less concretely during the coding process was moving away from the laptop. When working on the laptop it was harder for me to change my initial thoughts and ideas as it felt more concrete. I decided to print off my individual codes and begin grouping them into themes and sub themes on my kitchen table (see appendix I for images of this process). For me by doing the theme generation in this way it allowed me to visualise the dataset as a whole but also it felt much easier to be fluid and move codes or compress codes and themes until I felt happy with them and felt they were well represented by the data.

I believe having this qualitative research experience has developed both my research and clinical skills as it has helped me develop in confidence and own my active role in whatever task I am engaging with. I think this will also help in my clinical work and allow me to reflect more on my influence with clients and that this is often a key part of the process as long as you are aware of the unconscious impact and can justify and reflect on this that is useful. I adopted a Critical Realist (CR; Bhaskar, 1986) position and there was some anxiety I experienced using this unfamiliar approach and understanding that any initial meaning made is provisional. It was also important to be reflective because my own experiences working in neurorehabilitation services and being aware that my past experiences may bias any meaning made from participant data. This is part of the RTA process, but I was clear to be aware of my preconceived ideas rather than ignoring them (Finlay, 2009).

During the qualitative analysis process, I realised I was taking a lot of time to code every piece of data. After a while I realised data from participants fell in to two categories, some data clearly referenced the manual within the interviews. Some of the comments participants made described direct adaptations which resulted in a more semantic analysis (Braun & Clark, 2019). In contrast participants discussed their experiences post-SCI and the impact this had on their life and ability to re-engage with their lives and relationships given the significant physical changes after their injury. These types of quotes required a latent analysis by the primary researcher to construct the meaning of their experiences and apply this to the manual and decide whether these quotes resulted in an acceptable manual for this population (Braun & Clark, 2019). These types of quotes often described experiences that felt very relevant to the ACT hexaflex or even described experiences such as experiential avoidance. When I began to understand this difference, I was able to begin switching the focus of my analysis to ensure I was focusing on data that answered my research questions which helped to speed up the process.

Wordcount: 13413 (excluding references, tables, figures & appendix).

References

Aaby, A., Ravn, S. L., Kasch, H., & Andersen, T. E. (2020). The associations of acceptance with quality of life and mental health following spinal cord injury: a systematic review. *Spinal cord*, *58*(2), 130–148. https://doi.org/10.1038/s41393-019-0379-9

Aaby, A., Ravn, S. L., Kasch, H., & Andersen, T. E. (2022). Using the Multidimensional Model of Acceptance to Investigate How Different Facets of Acceptance are Related to Quality of Life Following Spinal Cord Injury. *Journal of rehabilitation medicine*, *54* (2022). . https://doi.org/10.2340/jrm.v54.1055

Ahuja, C. S., Wilson, J. R., Nori, S., Kotter, M., Druschel, C., Curt, A., & Fehlings, M. G. (2017). Traumatic spinal cord injury. *Nature reviews Disease primers*, *3*(1), 1-21.

Arifin, S. R. M. (2018). Ethical considerations in qualitative study. *International journal of care scholars*, *1*(2), 30-33. https://doi.org/10.31436/ijcs.v1i2.82

Ataoğlu, E., Tiftik, T., Kara, M., Tunç, H., Ersöz, M., & Akkuş, S. (2013). Effects of chronic pain on quality of life and depression in patients with spinal cord injury. *Spinal cord, 51*(1), 23–26. https://doi.org/10.1038/sc.2012.51

Bhaskar, R., (1975) Forms of realism, *Philosophica, 15*. https://doi.org/10.21825/philosophica.82713

Biglan, A., & Hayes, S.C., (2016). Functional Contextualism and Contextual Behavioural Science. In Zettle, R., Hayes, S., C., Barnes-Holmes, D., & Biglan, A., (Eds), *The Wiley Handbook of Contextual Behavioural Science* (pp. 37-62). John Wiley & Sons.

Blackledge, J. T. (2003). An introduction to Relational Frame Theory: Basics and applications. *The Behavior Analyst Today, 3*(4), 421-433. https://doi.org/10.1037/h0099997

Borkovec, T. D., Abel, J. L., & Newman, H. (1995). Effects of psychotherapy on comorbid conditions in generalized anxiety disorder. *Journal of consulting and clinical psychology, 63*(3), 479.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* Sage Publications.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Budd, M. A., Gater, D. R., Jr, & Channell, I. (2022). Psychosocial Consequences of Spinal Cord Injury: A Narrative Review. *Journal of personalised medicine*, *12*(7), 1178. https://doi.org/10.3390/jpm12071178

Byrne, D. (2021). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity, 56*, 1391-1412. https://doi.org/10.1007/s11135-021-01182-y

Casey, M. B., Cotter, N., Kelly, C., Mc Elchar, L., Dunne, C., Neary, R., Lowry, D., Hearty, C., & Doody, C. (2020). Exercise and acceptance and commitment therapy for chronic pain: a case series with one-year follow-up. *Musculoskeletal Care*, *18*(1), 64-73. https://doi.org/10.1002/msc.1444

Costa, P., Perrouin-Verbe, B., Colvez, A., Didier, J., Marquis, P., Marrel, A., Amarenco, G., Espirac, B., & Leriche, A. (2001). Quality of life in spinal cord injury patients with urinary difficulties. Development and validation of qualiveen. *European urology*, *39*(1), 107–113. https://doi.org/10.1159/000052421

Craig, A., Tran, Y., & Middleton, J. (2009). Psychological morbidity and spinal cord injury: a systematic review. *Spinal cord*, *47*(2), 108–114. https://doi.org/10.1038/sc.2008.115

Cutuli, D. (2014). Cognitive reappraisal and expressive suppression strategies role in the emotion regulation: an overview on their modulatory effects and neural correlates. *Frontiers in systems neuroscience*, *8*, 110157. https://doi.org/10.3389/fnsys.2014.00175

Dindo, L., Van Liew, J. R., & Arch, J. J. (2017). Acceptance and Commitment Therapy: A Transdiagnostic Behavioral Intervention for Mental Health and Medical Conditions. *Neurotherapeutics*, *14*(3), 546–553. https://doi.org/10.1007/s13311-017-0521-3

Dunn, D. S. (2010). The social psychology of disability. In R. G. Frank, M. Rosenthal, & B. Caplan (Eds.), *Handbook of rehabilitation psychology* (2nd ed., pp. 379–390). American Psychological Association. https://doi.org/10.1037/15972-026

Dunn, D. S., Ehde, D. M., & Wegener, S. T. (2016). The foundational principles as psychological lodestars: Theoretical inspiration and empirical direction in rehabilitation psychology. *Rehabilitation Psychology*, *61*(1), 1. DOI: 10.1037/rep0000082

Edgley, A., Stickley, T., Timmons, S., & Meal, A. (2016). Critical realist review: exploring the real, beyond the empirical. *Journal of Further and Higher Education*, *40*(3), 316-330.

Eifert, G. H., Forsyth, J. P., & McKay, M. (2006). *Act on life not on anger: The new acceptance and commitment therapy guide to problem anger*. New Harbinger Publications.

Eifert, G., & Forsyth, J., P., (2011). The Application of Acceptance and Commitment Therapy to Problem Anger. *Cognitive and Behavioral Practice*, *18*(2), 241-250. https://doi.org/10.1016/j.cbpra.2010.04.004

Engblom-Deglmann, M. L., & Hamilton, J. (2020). The impact of spinal cord injury on the couple relationship: A grounded theory exploration of the adjustment process. *Journal of Couple & Relationship Therapy*, *19*(3), 250–275. https://doi.org/10.1080/15332691.2020.1746459

Erikson, E. H. (1994). *Identity and the life cycle*. WW Norton & company.

Fann, J. R., Bombardier, C. H., Richards, J. S., Tate, D. G., Wilson, C. S., & Temkin, N., (2011). Depression after spinal cord injury: comorbidities, mental health service use, and adequacy of treatment. *Archives of physical medicine and rehabilitation*, *92*(3), 352–360. https://doi.org/10.1016/j.apmr.2010.05.016

Fergus T. A. (2015). I Really Believe I Suffer from a Health Problem: Examining an Association Between Cognitive Fusion and Healthy Anxiety. *Journal of clinical psychology*, *71*(9), 920–934. https://doi.org/10.1002/jclp.22194

Finlay, L., (2009). Debating Phenomenological Research Methods. *Phenomenology & Practice, 3*(1), 6-25. https://doi.org/10.29173/pandpr19818

French, K., Golijani-Moghaddam, N., & Schröder, T. (2017). What is the evidence for the efficacy of self-help acceptance and commitment therapy? A systematic review and meta-analysis. *Journal of Contextual Behavioral Science*, *6*(4), 360-374.

Gillanders, D. T., Bolderston, H., Bond, F. W., Dempster, M., Flaxman, P. E., Campbell, L., Kerr, S., Tansey, L., Noel, P., Ferenbach, C., Masley, S., Roach, L., Lloyd, J., May, L., Clarke, S., & Remington, B. (2014). The development and initial validation of the cognitive fusion questionnaire. *Behavior therapy*, *45*(1), 83–101. https://doi.org/10.1016/j.beth.2013.09.001

Godbee, M., & Kangas, M. (2020). The Relationship Between Flexible Perspective Taking and Emotional Well-Being: A Systematic Review of the "Self-as-Context" Component of Acceptance and Commitment Therapy. *Behavior therapy*, *51*(6), 917–932. https://doi.org/10.1016/j.beth.2019.12.010

Goldstone, E., Farhall, J., & Ong, B. (2011). Life hassles, experiential avoidance and distressing delusional experiences. *Behaviour research and therapy*, *49*(4), 260–266. https://doi.org/10.1016/j.brat.2011.02.002

Greco, L. A., Lambert, W., & Baer, R. A. (2008). Psychological inflexibility in childhood and adolescence: development and evaluation of the Avoidance and Fusion Questionnaire for Youth. *Psychological assessment*, *20*(2), 93–102. https://doi.org/10.1037/1040-3590.20.2.93

Gross, A. C., & Fox, E. J. (2009). Relational frame theory: an overview of the controversy. *The Analysis of verbal behavior*, *25*(1), 87–98. https://doi.org/10.1007/BF03393073

Han, A., Wilroy, J. D., Jenkins, J., & Yuen, H. K. (2022). Effects of a coach-guided videoconferencing acceptance and commitment therapy intervention combined with psychoeducation on distressed individuals living with spinal cord injury: a preliminary mixed-methods study. *Disability and Rehabilitation*, *45(*4), 644–654. https://doi.org/10.1080/09638288.2022.2038283

Harris, R. (2009). *ACT Made Simple: An Easy-To-Read Primer on Acceptance and Commitment Therapy.* New Harbinger.

Harwood, T. M., & L'Abate, L. (2010). *Self-help in mental health: a critical review*. Springer. https://doi.org/10.1007/978-1-4419-1099-8.

Hayes, S. C. (2001). *Relational frame theory: A post-Skinnerian account of human language and cognition*. Plenum Press.

Hayes, S. C. & Strosahl, K. D. (2005) (Eds.), *A practical guide to Acceptance and Commitment. Therapy*. Springer-Verlag.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: model, processes and outcomes. *Behaviour research and therapy*, *44*(1), 1–25. https://doi.org/10.1016/j.brat.2005.06.006

Hayes, S. C., Wilson, K. G., Gifford, E. V., Follette, V. M., & Strosahl, K. (1996). Experiential avoidance and behavioral disorders: A functional dimensional approach to diagnosis and treatment. *Journal of consulting and clinical psychology*, *64*(6), 1152.

Health & care professions council (HCPC). (2015). *The standards of proficiency for practitioner psychologists*. Retrieved September 2024, from https://www.hcpc-uk.org/standards/standards-of-proficiency/practitioner-psychologists/

Ho, S. M., Chan, C. L., & Ho, R. T. (2004). Posttraumatic growth in Chinese cancer survivors. *Psycho-oncology*, *13*(6), 377–389. https://doi.org/10.1002/pon.758

Inge, K. J., Graham, C. W., Bogenschutz, M. D., Wehman, P., Erickson, D., & Seward, H. (2018). Barriers and facilitators to employment: As Reported by Individuals with Spinal Cord Injuries. *Journal of Rehabilitation, 84*(2), 22-32.

Jeyathevan, G., Cameron, J. I., Craven, B. C., Munce, S. E. P., & Jaglal, S. B. (2019). Re-building relationships after a spinal cord injury: experiences of family caregivers and care recipients. *BMC neurology*, *19*(1), 117. https://doi.org/10.1186/s12883-019-1347-x

John, O. P., & Gross, J. J. (2004). Healthy and unhealthy emotion regulation: Personality processes, individual differences, and life span development. *Journal of personality*, *72*(6), 1301-1334. 10.1111/j.1467-6494.2004.00298.x

Kalpakjian, C. Z., Tate, D. G., Kisala, P. A., & Tulsky, D. S. (2015). Measuring self-esteem after spinal cord injury: Development, validation and psychometric characteristics of the SCI-QOL Self-esteem item bank and short form. *The Journal of Spinal Cord Medicine*, *38*(3), 377-385. https://doi.org/10.1179/2045772315Y.0000000014

Kennedy, P., & Garmon-Jones, L. (2017). Self-harm and suicide before and after spinal cord injury: a systematic review. *Spinal cord*, *55*(1), 2–7. https://doi.org/10.1038/sc.2016.135

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of general psychiatry*, *62*(6), 593–602. https://doi.org/10.1001/archpsyc.62.6.593

Kjærvik, S. L., & Bushman, B. J. (2024). A meta-analytic review of anger management activities that increase or decrease arousal: What fuels or douses rage? *Clinical psychology review*, *109*, 102414. https://doi.org/10.1016/j.cpr.2024.102414

Kortte, K. B., Veiel, L., Batten, S. V., & Wegener, S. T. (2009). Measuring avoidance in medical rehabilitation. *Rehabilitation Psychology*, *54*(1), 91. DOI: 10.1037/a0014703Koshy, K., Limb, C., Gundogan, B., Whitehurst, K., & Jafree, D. J. (2017). Reflective practice in health care and how to reflect effectively. *International journal of surgery. Oncology*, *2*(6). doi: 10.1097/IJ9.0000000000000020

Kübler-Ross, E. (2011). *On Death and Dying.* Scribner.

Levin, M. E., Hildebrandt, M. J., Lillis, J., & Hayes, S. C. (2012). The impact of treatment components suggested by the psychological flexibility model: a meta-analysis of laboratory-based component studies. *Behavior therapy*, *43*(4), 741–756. https://doi.org/10.1016/j.beth.2012.05.003

Levin, M. E., MacLane, C., Daflos, S., Seeley, J., Hayes, S. C., Biglan, A., & Pistorello, J. (2014). Examining psychological inflexibility as a transdiagnostic process across psychological disorders. *Journal of contextual behavioral science*, *3*(3), 155–163. https://doi.org/10.1016/j.jcbs.2014.06.003

Li, Y., Bressington, D., & Chien, W. T. (2017). Systematic Review of Psychosocial Interventions for People With Spinal Cord Injury During Inpatient Rehabilitation: Implications for Evidence-

Based Practice. *Worldviews on evidence-based nursing*, *14*(6), 499–506. https://doi.org/10.1111/wvn.12238

Magee, J. C., Harden, K. P., & Teachman, B. A. (2012). Psychopathology and thought suppression: a quantitative review. *Clinical psychology review*, *32*(3), 189–201. https://doi.org/10.1016/j.cpr.2012.01.001

Marshall, E. J., & Brockman, R. N. (2016). The Relationships Between Psychological Flexibility, Self-Compassion, and Emotional Well-Being. *Journal of cognitive psychotherapy*, *30*(1), 60–72. https://doi.org/10.1891/0889-8391.30.1.60

McCaughey, E., Purcell, M., McLean, A., Fraser, M., Bewick, A., Borotkanics, R., J., & Allan, D., B., (2016). Changing demographics of spinal cord injury over a 20-year period: a longitudinal population-based study in Scotland. *Spinal Cord*, *54*(4), 270–276 https://doi.org/10.1038/sc.2015.167

McHugh, L., Barnes-Holmes, Y., & Barnes-Holmes, D. (2004). Perspective-taking as relational responding: A developmental profile. *The Psychological Record, 54*(1), 115-144. https://doi.org/10.1007/BF03395465

Monden, K. R., Philippus, A., Draganich, C., MacIntyre, B., & Charlifue, S. (2020). A qualitative exploration of perceived injustice among individuals living with spinal cord injury. *Rehabilitation Psychology, 65*(1), 54–62. https://doi.org/10.1037/rep0000301

Mortari, L. (2015). Reflectivity in research practice: An overview of different perspectives. *International journal of qualitative methods*, *14*(5), https://doi.org/10.1177/1609406915618

Murberg, T. A., Furze, G., & Bru, E. (2004). Avoidance coping styles predict mortality among patients with congestive heart failure: a 6-year follow-up study. *Personality and Individual Differences*, *36*(4), 757-766. https://doi.org/10.1016/S0191-8869(03)00130-2

National Health Service, Greater Glasgow and Clyde. (n.d.,) *Living with a Spinal Cord Injury*. Spinal Injuries Scotland. Retrieved October 1, 2024 from https://www.spinalunit.scot.nhs.uk/wp-content/uploads/2015/11/Living-with-a-Spinal-Cord-Injury.pdf

National Institute for Health and Care Excellence. (2016). *Spinal Injury: Assessment and Initial Management* [NICE Guideline no. 41]. https://www.nice.org.uk/guidance/ng41

National Institute of Neurological Disorders and Stroke. (2024). *Spinal Cord Injury*. United States Government. https://www.ninds.nih.gov/health-information/disorders/spinal-cord-injury

Noreau, L., Noonan, V. K., Cobb, J., Leblond, J., & Dumont, F. S. (2014). Spinal Cord Injury Community Survey: Understanding the Needs of Canadians with SCI. *Topics in spinal cord injury rehabilitation*, *20*(4), 265–276. https://doi.org/10.1310/sci2004-265

Oña, A., Athanasios, K., Tederko, P., Escorpizo, R., Arora, M., Sturm, C., Yang, S., & Barzallo, D. P. (2023). Unmet healthcare needs and health inequalities in people with spinal cord injury: a direct regression inequality decomposition. *International Journal for Equity in Health*, *22*(1), 56. https://doi.org/10.1186/s12939-023-01848-z

Oña, A., Strøm, V., Lee, B. S., Le Fort, M., Middleton, J., Gutenbrunner, C., & Pacheco Barzallo, D. (2021). Health inequalities and income for people with spinal cord injury. A comparison between and within countries. *SSM - population health*, *15*, 100854. https://doi.org/10.1016/j.ssmph.2021.100854

Pacheco Barzallo D. (2018). Place of residence & financial hardship: the situation of people with spinal cord injury. *International journal for equity in health*, *17*(1), 115. https://doi.org/10.1186/s12939-018-0818-9

Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping to physical and psychological health outcomes: a meta-analytic review. *Journal of behavioral medicine*, *25*(6), 551–603. https://doi.org/10.1023/a:1020641400589

Pollard, C., & Kennedy, P. (2007). A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: a 10-year review. *British journal of health psychology*, *12*(3), 347–362. https://doi.org/10.1348/135910707X197046

Prevedini, A. B., Presti, G., Rabitti, E., Miselli, G., & Moderato, P. (2011). Acceptance and commitment therapy (ACT): the foundation of the therapeutic model and an overview of its contribution to the treatment of patients with chronic physical diseases. *Giornale italiano di medicina del lavoro ed ergonomia*, *33*(1), 53–63.

Rawal, A., Park, R. J., & Williams, J. M. (2010). Rumination, experiential avoidance, and dysfunctional thinking in eating disorders. *Behaviour research and therapy*, *48*(9), 851–859. https://doi.org/10.1016/j.brat.2010.05.009

Richards, S., Waites, K., Chen, Y., Kogos, S., & Schmitt, M. M. (2004). The epidemiology of secondary conditions following spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation, 10*(1), 15-29. https://doi.org/10.1310/YXM3-85YW-8VUG-NNUR

Rogge, D., R., Daks, S., J., Dubler, A., B., & Saint, J., K., (2019). It’s all about the process: Examining the convergent validity, conceptual coverage, unique predictive validity, and clinical utility of ACT process measures. *Journal of Contextual Behaviour Science*, *14,* 90-102. https://doi.org/10.1016/j.jcbs.2019.10.001

Scelza, W. M., Kirshblum, S. C., Wuermser, L. A., Ho, C. H., Priebe, M. M., & Chiodo, A. E. (2007). Spinal cord injury medicine. 4. Community reintegration after spinal cord injury. *Archives of physical medicine and rehabilitation*, *88*(3), 71–75. https://doi.org/10.1016/j.apmr.2006.12.004

Schultz, K. R., Mona, L. R., & Cameron, R. P. (2022). Mental Health and Spinal Cord Injury: Clinical Considerations for Rehabilitation Providers. *Current physical medicine and rehabilitation reports*, *10*(3), 131–139. https://doi.org/10.1007/s40141-022-00349-4

Sekhon, M., Cartwright, M. & Francis, J.J. (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Services Research, 17*(88). https://doi.org/10.1186/s12913-017-2031-8

Sezer, N., Akkuş, S., & Uğurlu, F. G. (2015). Chronic complications of spinal cord injury. *World journal of orthopedics*, *6*(1), 24–33. https://doi.org/10.5312/wjo.v6.i1.24

Shepherd Centre. (n.d.). *Types and Levels of Spinal Injuries.* Retrieved September 26, 24 from *https://www.shepherd.org/programs/spinal-cord-injury/levels-and-types#:~:text=An%20incomplete%20spinal%20cord%20injury,patient's%20health%20and%20medical%20history*.

Shepherd, K., Golijani-Moghaddam, N., & Dawson, D. L. (2022). ACTing towards better living during COVID-19: The effects of Acceptance and Commitment therapy for individuals affected by COVID-19. *Journal of contextual behavioral science, 23*, 98–108. https://doi.org/10.1016/j.jcbs.2021.12.003.

Sidani, S., Epstein, D. R., Bootzin, R. R., Moritz, P., & Miranda, J. (2009). Assessment of preferences for treatment: validation of a measure. *Research in nursing & health*, *32*(4), 419–431. https://doi.org/10.1002/nur.20329

Skinner, T. C., Roberton, T., Allison, G. T., Dunlop, S., & Bucks, R. S. (2010). Experiential avoidance, mindfulness and depression in spinal cord injuries: A preliminary study. *The Australian Journal of Rehabilitation Counselling*, *16*(1), 27-35. https://doi.org/10.1375/jrc.16.1.27

Spinal Injuries Association. (2021). *What Matters: A report on what really matters to spinal cord injured people in the UK today. https://spinal.co.uk/wp-content/uploads/2021/10/SIA_What_Matters_Report_v4.pdf*

Staniszewska, S., Crowe, S., Badenoch, D., Edwards, C., Savage, J., & Norman, W. (2010). The PRIME project: developing a patient evidence-base. *Health Expectations, 13*(3), 312-322. DOI: 10.1111/j.1369-7625.2010.00590.x

Stroebe, M., Schut, H., & Boerner, K. (2017). Cautioning Health-Care Professionals. *Omega*, *74*(4), 455–473. https://doi.org/10.1177/0030222817691870

Tenny S, Brannan JM, Brannan GD. (2017) Qualitative Study. In: StatPearls. StatPearls Publishing, Treasure Island (FL).

Tough, H., Gross-Hemmi, M., Stringhini, S., Eriks-Hoogland, I., & Fekete, C. (2022). Who is at Risk of Loneliness? A Cross-sectional Recursive Partitioning Approach in a Population-based Cohort of Persons With Spinal Cord Injury. *Archives of physical medicine and rehabilitation*, *103*(2), 305–312. https://doi.org/10.1016/j.apmr.2021.08.018

Trindade, I. A., & Ferreira, C. (2014). The impact of body image-related cognitive fusion on eating psychopathology. *Eating behaviors*, *15*(1), 72–75. https://doi.org/10.1016/j.eatbeh.2013.10.014

Tsao, J. C., Mystkowski, J. L., Zucker, B. G., & Craske, M. G. (2002). Effects of cognitive-behavioral therapy for panic disorder on comorbid conditions: Replication and extension. *Behavior Therapy, 33*(4), 493-509.

Tsoukas, H. (1989). The Validity of Idiographic Research Explanations. *The Academy of Management Review*, *14*(4), 551–561. https://doi.org/10.2307/258558

Tyrell, P., Harberger, S., Schoo, C., & Siddiqui, W., (2023) Kubler-Ross Stages of Dying and Subsequent Models of Grief. In: StatPearls. StatPearls Publishing, Treasure Island (FL).

Venta, A., Sharp, C., & Hart, J. (2012). The relation between anxiety disorder and experiential avoidance in inpatient adolescents. *Psychological assessment*, *24*(1), 240–248. https://doi.org/10.1037/a0025362

Walsh, A., & Richards, D. (2017). Experiences and engagement with the design features and strategies of an internet-delivered treatment programme for generalised anxiety disorder: a service-based evaluation. *British Journal of Guidance & Counselling*, *45*(1), 16-31. https://doi.org/10.1080/03069885.2016.1153039

Watkins, P. L., & Clum, G. A. (Eds.). (2007). *Handbook of self-help therapies*. Routledge.

Weber, L., Voldsgaard, N. H., Holm, N. J., Schou, L. H., Biering-Sørensen, F., & Møller, T. (2021). Exploring the contextual transition from spinal cord injury rehabilitation to the home environment: a qualitative study. *Spinal cord*, *59*(3), 336–346. https://doi.org/10.1038/s41393-020-00608-y

Wilbanks, S. R., & Ivankova, N. V. (2014). Exploring factors facilitating adults with spinal cord injury rejoining the workforce: a pilot study. *Disability and Rehabilitation*, *37*(9), 739–749. https://doi.org/10.3109/09638288.2014.938177

Wilkin, K., Evans, S., Van Niekerk, L., Romano, D., Fuller-Tyszkiewicz, M., Knowles, S., Chesterman, S., Raven, L., & Mikocka-Walus, A. (2024). Moving Towards Acceptance and Values: A Qualitative Study of ACTforIBD Compared to IBD Psychoeducation. *Journal of clinical psychology in medical settings*, *31*(2), 245–257. https://doi.org/10.1007/s10880-023-09999-5

Wilson, C. S., DeDios-Stern, S., Bocage, C., Gray, A. A., Crudup, B. M., & Russell, H. F. (2022). A systematic review of how spinal cord injury impacts families. *Rehabilitation Psychology*, *67*(3), 273–303. https://doi.org/10.1037/rep0000431

Woolrich, R. A., Kennedy, P., & Tasiemski, T. (2006). A preliminary psychometric evaluation of the Hospital Anxiety and Depression Scale (HADS) in 963 people living with a spinal cord injury. *Psychology, Health & Medicine, 11*(1), 80–90. https://doi.org/10.1080/13548500500294211

World Health Organization (2013). *International Perspectives on Spinal Cord Injury.* The International Spinal Cord Society. https://iris.who.int/bitstream/handle/10665/94192/who_nmh_vip_13.03_eng.pdf;jsessionid=44E23010E28B368CEEC717DD7EA2EB69?sequence=1

Wyndaele, M., & Wyndaele, J. J. (2006). Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey?. *Spinal cord*, *44*(9), 523–529. https://doi.org/10.1038/sj.sc.3101893

Xiong, A., Lai, X., Wu, S., Yuan, X., Tang, J., Chen, J., Liu, Y., & Hu, M. (2021). Relationship Between Cognitive Fusion, Experiential Avoidance, and Obsessive-Compulsive Symptoms in Patients with Obsessive-Compulsive Disorder. *Frontiers in psychology, 12*. https://doi.org/10.3389/fpsyg.2021.655154

Zakiei, A., Khazaie, H., Rostampour, M., Lemola, S., Esmaeili, M., Dürsteler, K., Brühl, A. B., Sadeghi-Bahmani, D., & Brand, S. (2021). Acceptance and Commitment Therapy (ACT) Improves Sleep Quality, Experiential Avoidance, and Emotion Regulation in Individuals with Insomnia-Results from a Randomized Interventional Study. *Life*, *11*(2), 133. https://doi.org/10.3390/life11020133

Zettle, R. D., (2016). The Self in Acceptance and Commitment Therapy. In. Kyrios., M., Moulding, R., Doron, G., Bhar, S., S., Nedeljkovic, M., & Mikulincer, M., (Eds), *The Self in Understanding and Treating Psychological Disorders* (pp. 50-57). Cambridge University Press.

Appendix

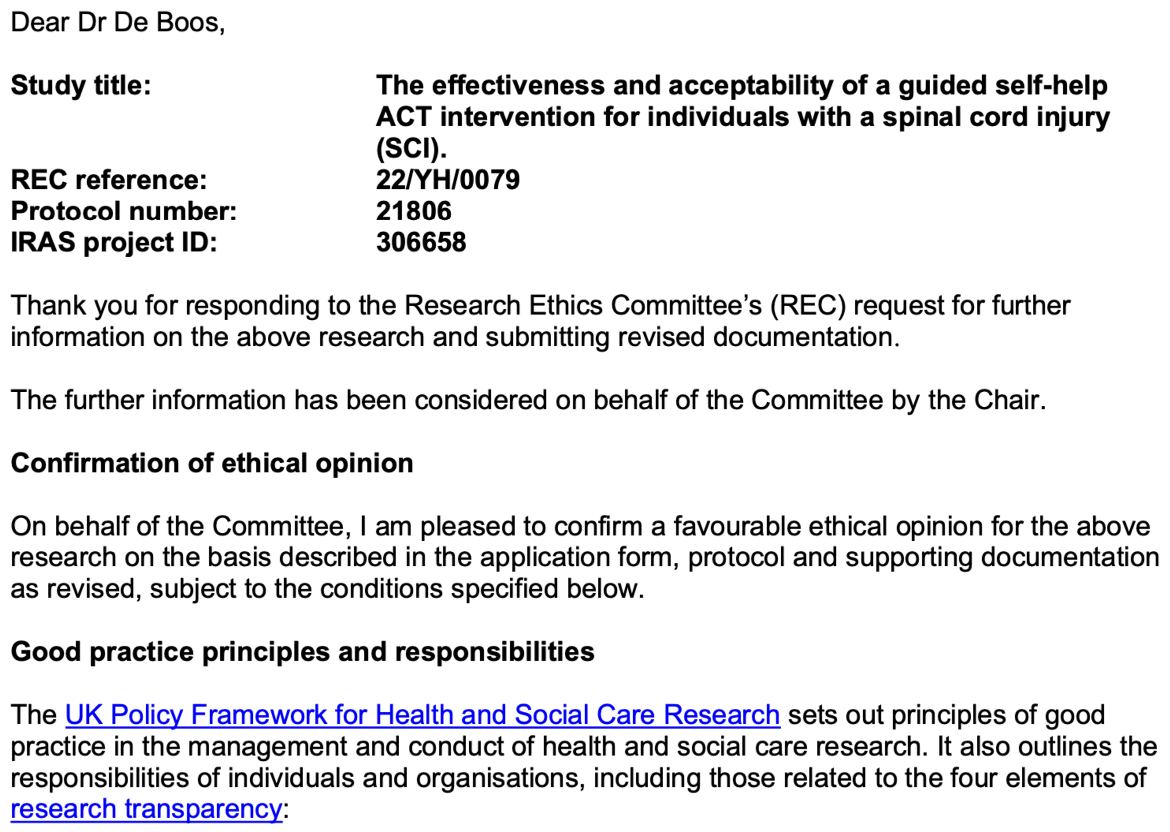
Appendix A: Journal Submission Author Guidelines

This paper is formatted for submission to the ‘Neuropsychological Rehabilitation’ Journal.

Guidelines for authors planning to submit to this journal can be found via the hyperlink below:

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=pnrh20

Appendix B: Favourable Opinion Letter



Dear Dr De Boos,

Study title: **The effectiveness and acceptability of a guided self-help ACT intervention for individuals with a spinal cord injury (SCI).**
REC reference: **22/YH/0079**
Protocol number: **21806**
IRAS project ID: **306658**

Thank you for responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

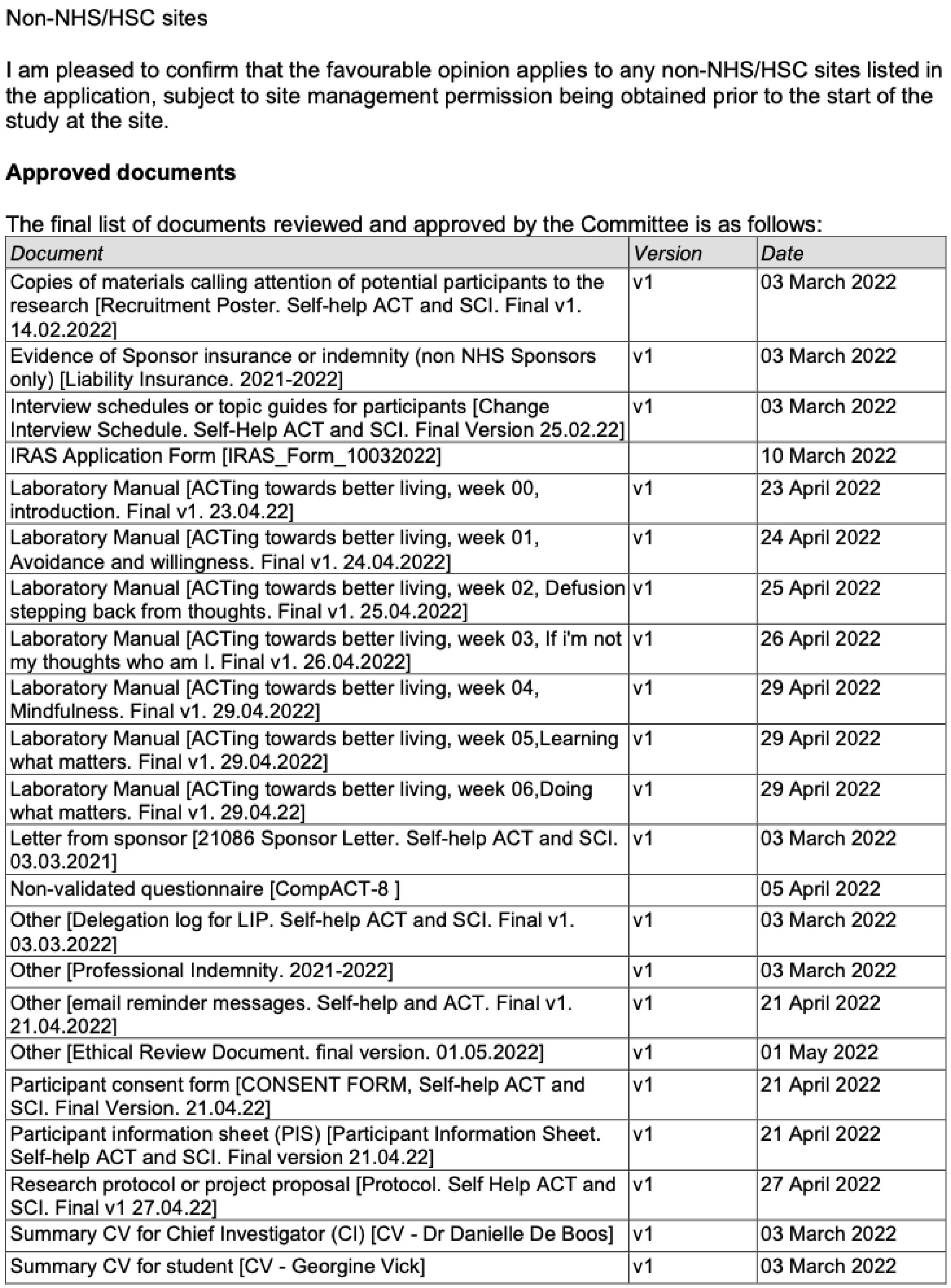
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).



Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Recruitment Poster. Self-help ACT and SCI. Final v1. 14.02.2022]	v1	03 March 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Liability Insurance. 2021-2022]	v1	03 March 2022
Interview schedules or topic guides for participants [Change Interview Schedule. Self-Help ACT and SCI. Final Version 25.02.22]	v1	03 March 2022
IRAS Application Form [IRAS_Form_10032022]		10 March 2022
Laboratory Manual [ACTing towards better living, week 00, introduction. Final v1. 23.04.22]	v1	23 April 2022
Laboratory Manual [ACTing towards better living, week 01, Avoidance and willingness. Final v1. 24.04.2022]	v1	24 April 2022
Laboratory Manual [ACTing towards better living, week 02, Defusion stepping back from thoughts. Final v1. 25.04.2022]	v1	25 April 2022
Laboratory Manual [ACTing towards better living, week 03, If i'm not my thoughts who am I. Final v1. 26.04.2022]	v1	26 April 2022
Laboratory Manual [ACTing towards better living, week 04, Mindfulness. Final v1. 29.04.2022]	v1	29 April 2022
Laboratory Manual [ACTing towards better living, week 05,Learning what matters. Final v1. 29.04.2022]	v1	29 April 2022
Laboratory Manual [ACTing towards better living, week 06,Doing what matters. Final v1. 29.04.22]	v1	29 April 2022
Letter from sponsor [21086 Sponsor Letter. Self-help ACT and SCI. 03.03.2021]	v1	03 March 2022
Non-validated questionnaire [CompACT-8]		05 April 2022
Other [Delegation log for LIP. Self-help ACT and SCI. Final v1. 03.03.2022]	v1	03 March 2022
Other [Professional Indemnity. 2021-2022]	v1	03 March 2022
Other [email reminder messages. Self-help and ACT. Final v1. 21.04.2022]	v1	21 April 2022
Other [Ethical Review Document. final version. 01.05.2022]	v1	01 May 2022
Participant consent form [CONSENT FORM, Self-help ACT and SCI. Final Version. 21.04.22]	v1	21 April 2022
Participant information sheet (PIS) [Participant Information Sheet. Self-help ACT and SCI. Final version 21.04.22]	v1	21 April 2022
Research protocol or project proposal [Protocol. Self Help ACT and SCI. Final v1 27.04.22]	v1	27 April 2022
Summary CV for Chief Investigator (CI) [CV - Dr Danielle De Boos]	v1	03 March 2022
Summary CV for student [CV - Georgine Vick]	v1	03 March 2022

Summary CV for supervisor (student research) [CV - Mark Gresswell]	v1	03 March 2022
Validated questionnaire [Outcome measures HADS. Self-Help ACT and SCI. Final Version 14.02.22]	v1	14 February 2022
Validated questionnaire [Outcome measures PQ. Self-Help ACT and SCI. Final v1 14.02.22]	v1	14 February 2022
Validated questionnaire [Outcome measures Wemwbs. Self-help ACT and SCI. Final version. 14.02.22]	v1	14 February 2022
Validated questionnaire [Outcome measures WhoQol Bref. Self-help ACT and SCI. Final version. 14.02.22]	v1	14 February 2022

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 306658   Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

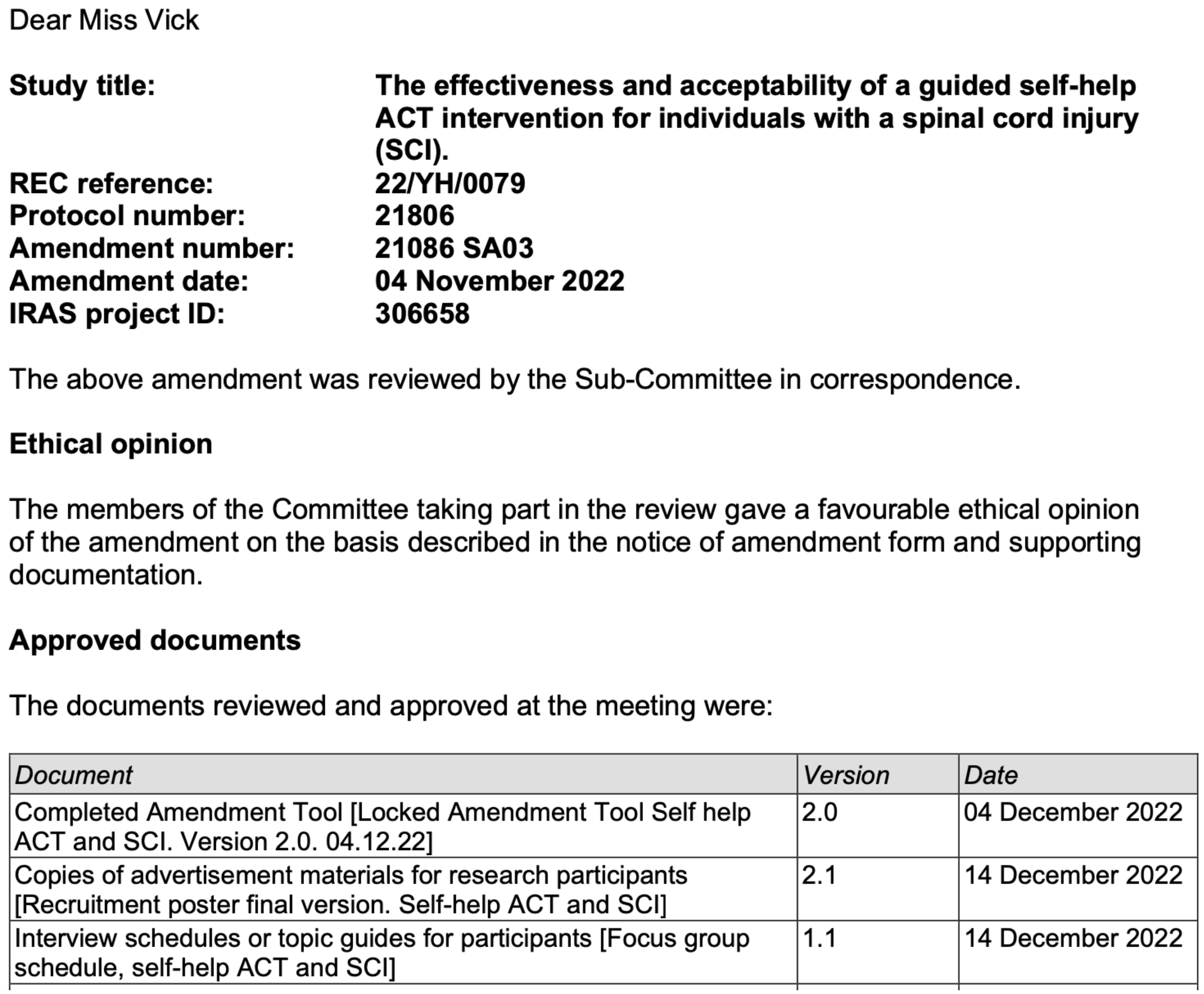
PP. /

Dr Nana Theodorou
Chair

Email:leedseast.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Appendix Bi: Favourable Opinion Letter after Substantial amendment



Dear Miss Vick

Study title:	**The effectiveness and acceptability of a guided self-help ACT intervention for individuals with a spinal cord injury (SCI).**
REC reference:	**22/YH/0079**
Protocol number:	**21806**
Amendment number:	**21086 SA03**
Amendment date:	**04 November 2022**
IRAS project ID:	**306658**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Locked Amendment Tool Self help ACT and SCI. Version 2.0. 04.12.22]	2.0	04 December 2022
Copies of advertisement materials for research participants [Recruitment poster final version. Self-help ACT and SCI]	2.1	14 December 2022
Interview schedules or topic guides for participants [Focus group schedule, self-help ACT and SCI]	1.1	14 December 2022

Participant information sheet (PIS) [Participant Information Sheet. Self-help ACT and SCI. final version 2. 23.11.22]	2.0	23 November 2022
Research protocol or project proposal [PROTOCOL. Self-help ACT and SCI]	2.1	14 December 2022

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 306658: **Please quote this number on all correspondence**

Yours sincerely
pp

Miss Kate Woodrow
Chair

E-mail: leedseast.rec@hra.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Appendix C: Study Poster

WE NEED YOU!

Have your say, your opinions matter!

We are creating a self-help manual for individuals who have had a spinal cord injury (SCI).

Who can help?

- People with lived experience of a SCI.
- Carers/family of people with a SCI.
- Clinicians working with people with a SCI.

How?

- By taking part in a short semi-structured Interview or focus group.

Want more information

Please contact:

georgina.vick@nottingham.ac.uk

V2.1 14.12.22

Appendix D: Email Template

Thank you for your email and thank you for sharing your experiences with me.

My research is to develop a self-help manual that will hopefully be useful to provide psychological support for individuals who have had a spinal cord injury. This will be developed in consultation with people who have lived experience of a spinal cord injury, their carers or family and professionals who work in this field.

Your participation would involve reading through an existing manual and giving your opinions on this in a semi-structured interview which would last around 1 hour and then if you would like to be involved in a focus group you can do this too.

I will attach the participant information sheet to this email with all the information about the study and please see below the link to the consent form if you are interested.

https://forms.office.com/e/rCwr3BprQA

If you want to discuss this further or need any more information, please do not hesitate to email me.

Appendix E: Information Sheet for participants

Participant Information Sheet

Final Version v2. 23.11.22

IRAS project ID: 306658

Title of study: Developing and evaluating a guided self-help ACT intervention for individuals with a Spinal Cord Injury

Name of Principal Investigator: Danielle De Boos

Name of Chief Investigator: Georgina Vick

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what taking part would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Feel free to talk to people you know about the study if you wish and ask us if there is anything that is not clear.

What is the purpose of the study?

I am completing a project to create a guided self-help programme based on ideas from Acceptance and Commitment Therapy (ACT) for a population of people who have a Spinal Cord Injury. This study aims to develop a guided self-help programme with the aim of meeting the needs of people coping with the consequences of having a spinal cord injury. This intervention will then be discussed to gain initial opinions of acceptability through focus groups. It is hoped this study will result in a useful self-help programme that might be helpful to people who have a spinal cord injury. This project is part of the Trent Doctorate in Clinical Psychology being completed by the researcher.

Why have I been invited?

You may have responded to an email forwarded to you by the charity, Backup, or you could have been told about this study by someone working with you from an outpatient clinic. We are looking for individuals who have suffered a spinal cord injury, their family and carers and professionals working with individuals with a spinal cord injury. We are seeking people that have a good understanding of written and spoken English.

What will it involve if I do take part?

If you decide to take part in this study, the study comprises two phases, although which phase you choose to take part in is optional. The first phase will involve engaging in a semi-structured interview with the focus of determining the needs of individuals with a spinal cord injury, looking through the current guided self-help manual and providing your opinion on how this could be modified to your specific needs or the needs of individuals with a spinal cord injury, and whether you feel acceptance and commitment therapy would be useful to you or your family member/client. The second phase would involve being part of a focus group to look through the modified self-help manual and provide your opinion on the initial acceptability of this self-help manual and also your opinions on the clinical utility of this manual. You are not required to take part in both phases of this study and the decision is up to you whether you would like to be a part of both phases or just one. You do not have to provide a rationale for this you can just let the researcher know when providing consent. Both the semi-structured interview and focus groups will be audio recorded and transcribed in order to enable analysis of this information. Once audio recordings have been transcribed the original will be destroyed and all interview and focus group transcriptions will be stored on the secure university drive. Quotes from the transcript of interviews/ focus groups may be used in the write-up of the project to provide further detail however any patient identifiable information will be excluded to ensure anonymity. Participants will be able to request a copy of the transcript of the interviews/focus groups via emailing the researcher, if required. Both interviews and focus groups can be completed online or in person and this would be agreed prior to commencement of each phase.

Do I have to take part?

No, this decision is up to you. If you do decide you would like to take part, you will be asked to provide written consent after reading this information sheet and before beginning this study. You will also have the right to withdraw at any point during the study without providing a reason, however any data we collect up until this point will be kept. This will not affect your legal rights. You can withdraw by emailing myself on georgina.vick@nottingham.ac.uk or my supervisors on danielle.deboos@nottingham.ac.uk or mgresswell@lincoln.ac.uk quoting your name and stating that you choose to withdraw from this project. This will mean your identity will be disclosed to the research team member you choose to contact however this will remain confidential.

Expenses and payments

Participants will be able to claim travel expenses whenever this is necessary.

What are the potential disadvantages and risks of taking part?

Taking part in this study means you will have to give up a portion of your time to complete the semi-structured interviews (approximately 60 minutes) and if you chose to take part in the focus groups (approximately 60-90 minutes).The topics covered in the self-help materials will be related to your thoughts and feelings which could be difficult for you. However, you do not have to provide opinion on anything you do not feel comfortable doing and will be supported during the interview by the researcher whenever required. Some people do not feel distressed. In the unlikely event you are struggling severely we will be able to advise you on how best to seek support.

What are the potential advantages and benefits of taking part?

We cannot promise the study will be helpful to you, but you would be part of the development of a directed self-help manual that may help improve psychological wellbeing for individuals in future. Furthermore, the literature on effectiveness of interventions for individuals with a spinal cord injury is limited and your participation will provide much needed insight into what is helpful for this population. You will also be provided with a £10 shopping voucher for taking part in either an interview or focus group and a £20 voucher for taking part in both.

What happens when the research study stops?

The data collected in this study will be used to answer the research question and will be written up confidentially. You will be offered the details of mental health services/helplines if you require it, however some of you may still be under the care of your outpatient department and will be able to access support through them too if needed. You will be able to request a copy of the completed project if desired.

Will my taking part in this project be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept securely by the University of Nottingham so that we are able to provide you with a summary of results on completion of the study if you request this, this can be requested by emailing the researcher, all details will be deleted after this. This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk we may feel it necessary to report this to the appropriate persons.

What if there is a problem?

If you are concerned about this study, you can speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the university.

In the event that something does go wrong, and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs.

What will happen to the results of the research study?

This study will be submitted as a requirement for the research element of the DClinPsy programme and submitted for publication. None of your responses and results will be identifiable included in the write up of this research will not be identifiable to you. A copy of the study findings can be provided by [trainee name] on request.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we cannot change study records and this information may have already been used for analysis and could still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

Who is organising and funding the research?
This research is being organised and funded by the University of Nottingham.

Who has reviewed the study?
All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Research Ethics Committee.

Contact details:

Researcher:

georgina.vick@nottingham.ac.uk

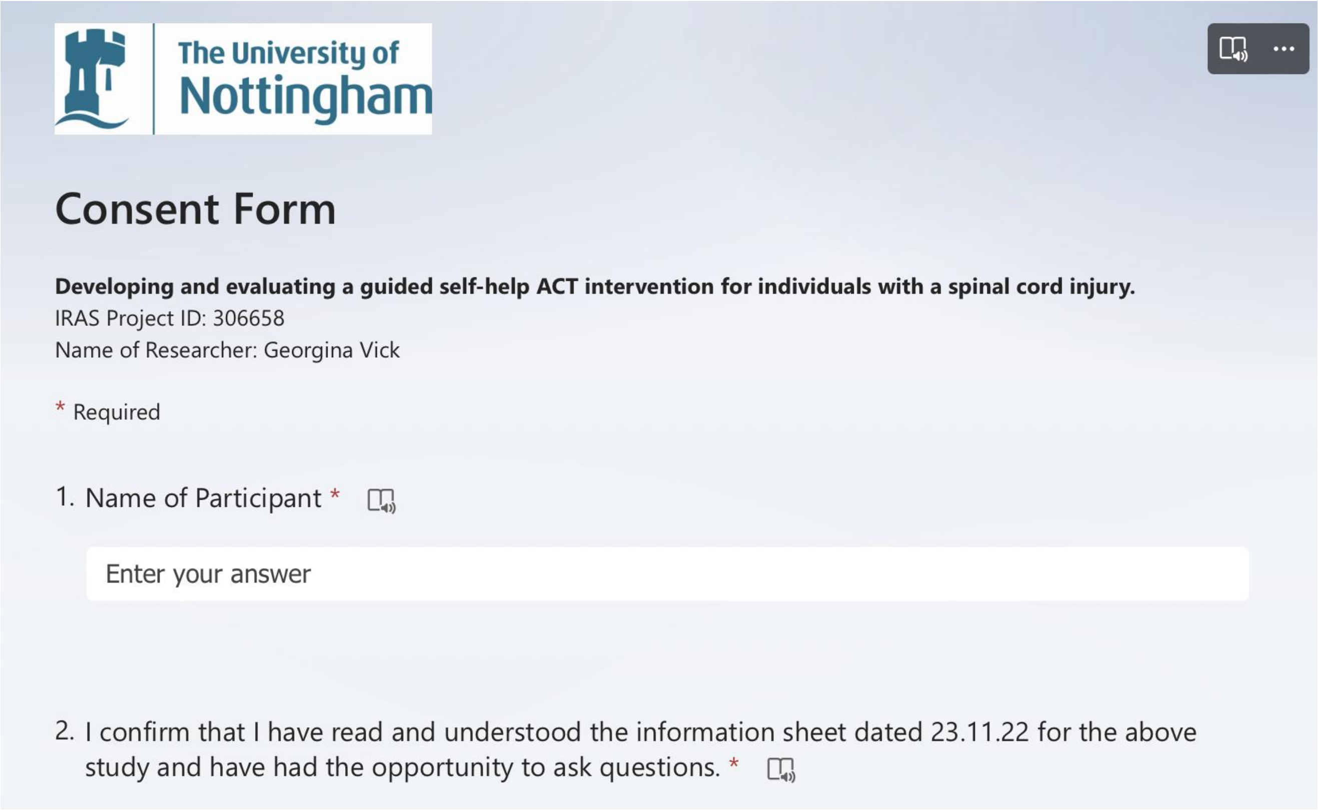
Supervisors:

danielle.deboos@nottingham.ac.uk

mgresswell@lincoln.ac.uk

Thank you for your time.

Appendix F: Participant Consent Form



Consent Form

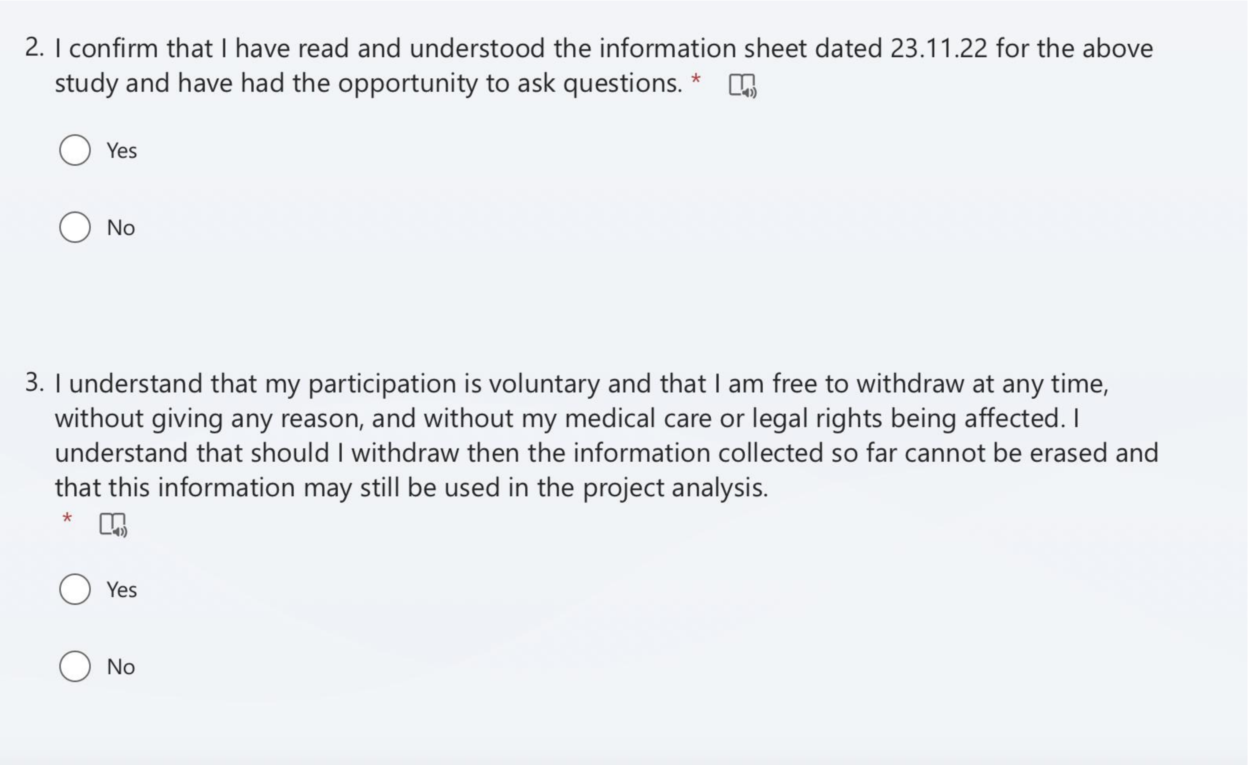
Developing and evaluating a guided self-help ACT intervention for individuals with a spinal cord injury.
IRAS Project ID: 306658
Name of Researcher: Georgina Vick

* Required

1. Name of Participant *

Enter your answer

2. I confirm that I have read and understood the information sheet dated 23.11.22 for the above study and have had the opportunity to ask questions. *



2. I confirm that I have read and understood the information sheet dated 23.11.22 for the above study and have had the opportunity to ask questions. *

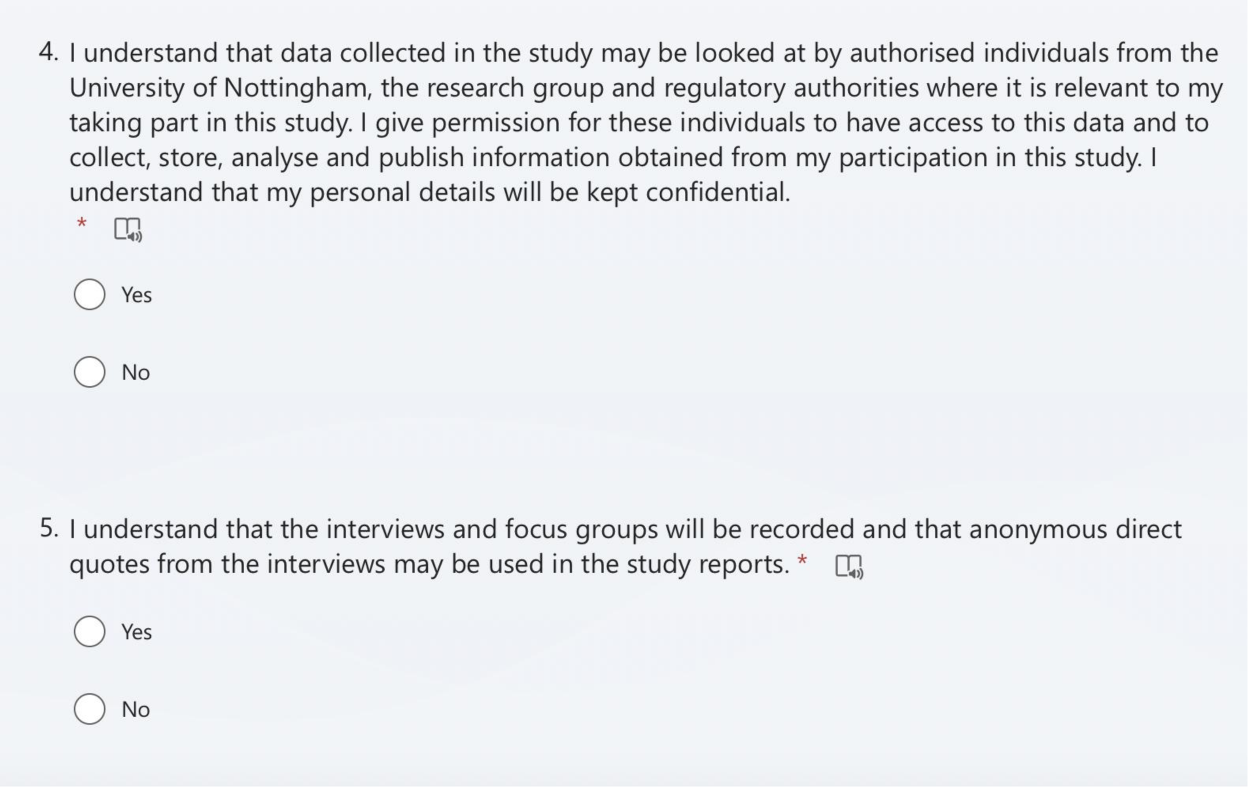
○ Yes

○ No

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. *

○ Yes

○ No



4. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. *

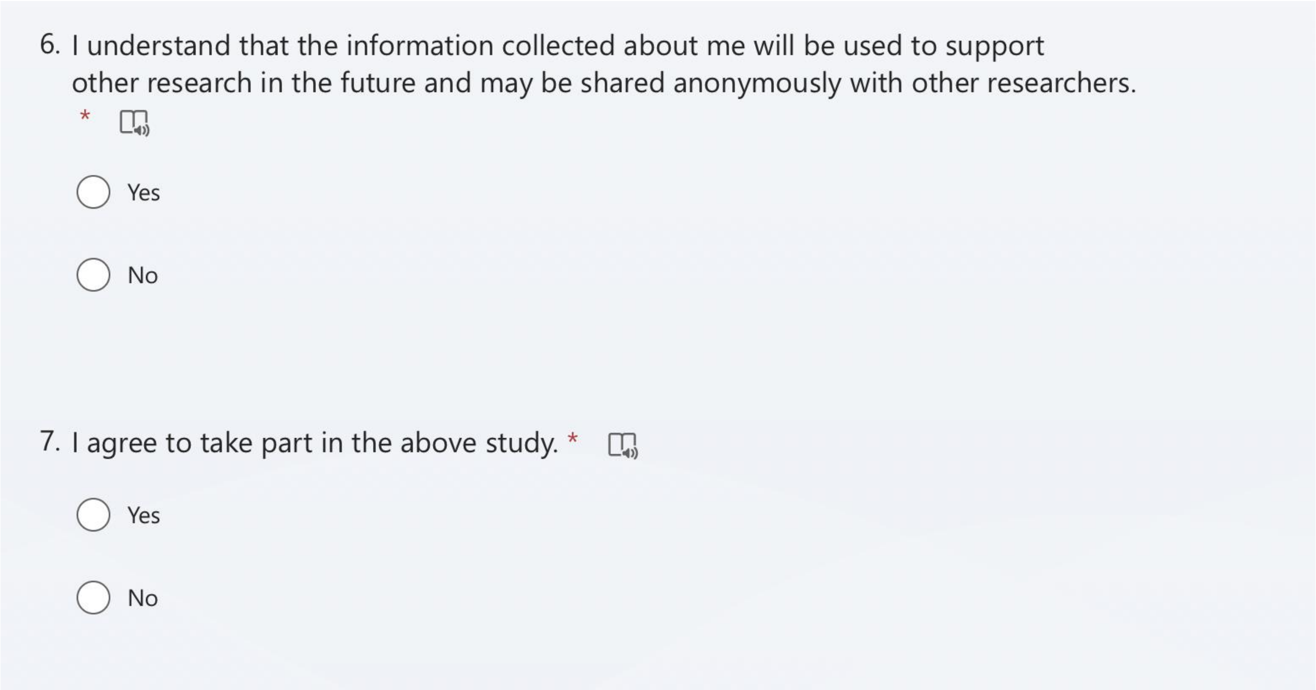
○ Yes

○ No

5. I understand that the interviews and focus groups will be recorded and that anonymous direct quotes from the interviews may be used in the study reports. *

○ Yes

○ No



6. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. *

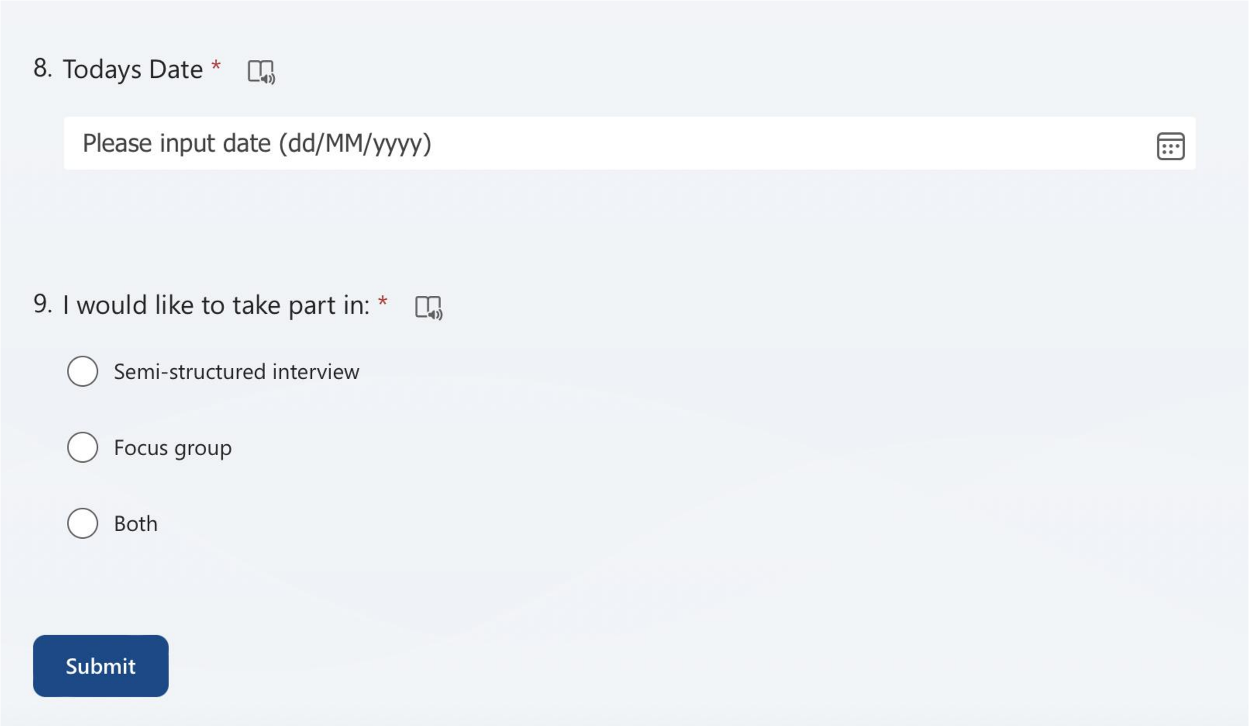
○ Yes

○ No

7. I agree to take part in the above study. *

○ Yes

○ No



8. Todays Date *

Please input date (dd/MM/yyyy)

9. I would like to take part in: *

○ Semi-structured interview

○ Focus group

○ Both

Appendix G: Semi-structured interview schedule

ACT and SCI: Semi Structured Interview Schedule V1.1 14.12 .22

- Introduce researcher and roles and re-cap on purpose of interview (to gather information regarding their views of the self-help material).
- To gather demographic details of participant, age, type of injury, gender, role if clinician, ethnicity, who they care for if carer.
- Researcher to introduce self-help material week by week.

- **Week 0: Introduction**
- What are your initial thoughts on this section?
- This is the introductory material to socialise you to the model. Do you feel this material helped you to get a general understanding of the ACT model?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?
- Which exercise was your favourite?
- Which exercise was your least favourite?

- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?
- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.
- **Week 1: Avoidance and willingness**
- What are your initial thoughts on this section?
- This is the first week that focuses on avoidance and willingness. Do you feel this material helped you to get a general understanding of experiential avoidance?
- Do you feel this concept is relevant to you?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?
- Which exercise was your favourite?
- Which exercise was your least favourite?
- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?
- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.
- **Week 2: Defusion: Stepping back from thoughts**
- What are your initial thoughts on this section?
- This is the second week that focuses on defusion. Do you feel this material helped you to get a general understanding of thought defusion?
- Do you feel this concept is relevant to you?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?

- Which exercise was your favourite?
- Which exercise was your least favourite?
- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?
- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.
- **Week 3: If I'm not my thoughts then who am I?**
- What are your initial thoughts on this section?
- This is the third week that focuses on developing a sense of self. Do you feel this material helped you to get a general understanding of that concept and would help you to develop this?
- Do you feel this concept is relevant to you?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?
- Which exercise was your favourite?
- Which exercise was your least favourite?
- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?
- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.
- **Week 4: Mindfulness being in the present moment**
- What are your initial thoughts on this section?

- This is the fourth week that focuses on mindfulness. Do you feel this material helped you to get a general understanding of mindfulness and would help you to develop this skill?
- Do you feel this concept is relevant to you?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?
- Which exercise was your favourite?
- Which exercise was your least favourite?
- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?
- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.
- **Week 5: Learning what matters**
- What are your initial thoughts on this section?
- This is the fifth week that focuses on values. Do you feel this material helped you to get a general understanding of values?
- Do you feel this concept is relevant to you?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?
- Which exercise was your favourite?
- Which exercise was your least favourite?
- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?

- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.
- **Week 6: Doing what matters**
- What are your initial thoughts on this section?
- This is the sixth week that focuses on valued action. Do you feel this material helped you to get a general understanding of valued action?
- Do you feel this concept is relevant to you?
- Do you feel the exercises in this section would be relevant/helpful to you/your patients/the person you care for?
- Which exercise was your favourite?
- Which exercise was your least favourite?
- When considering the challenges, you/your patient/the person you care for might have faced as a result of your/their injury do you think this information would be relevant to you/your patient/family?
- Are there any changes you would make to this section?
- Are there any parts of this section you feel are not relevant or might be harmful to consider?
- Initial opinions will prompt further discussion around the existing self-help material and how this can be modified to meet the needs of this population.

General Questions:

- How engaging did you find this format?
- How accessible do you think this format is for someone with a spinal cord injury?
- Do you think delivering this material weekly with a weekly check-in would be a useful way to deliver this material?
- At what stage of your recovery do you think this material would be most useful?

Appendix H: Deductive Framework

Deductive coding frame

Acceptability

- Affective attitude e.g., how pp's feel about the intervention.
- Burden – perceived amount of effort required to participate.
- Ethicality – Extent to which intervention is good fit with individuals value system and their opinion on perceived fit for wider SCI community.
- Perceived effectiveness – Extent to which intervention is perceived as likely to achieve its purpose/psychological needs of population.
- Intervention coherence – extent to which pp understands intervention and how it works.
- Opportunity costs – extent to which benefits, profits or values must be given up to engage in intervention.
- Self-efficacy – PP confident they can perform behaviours required to engage in intervention.

Appendix I: Theme generation

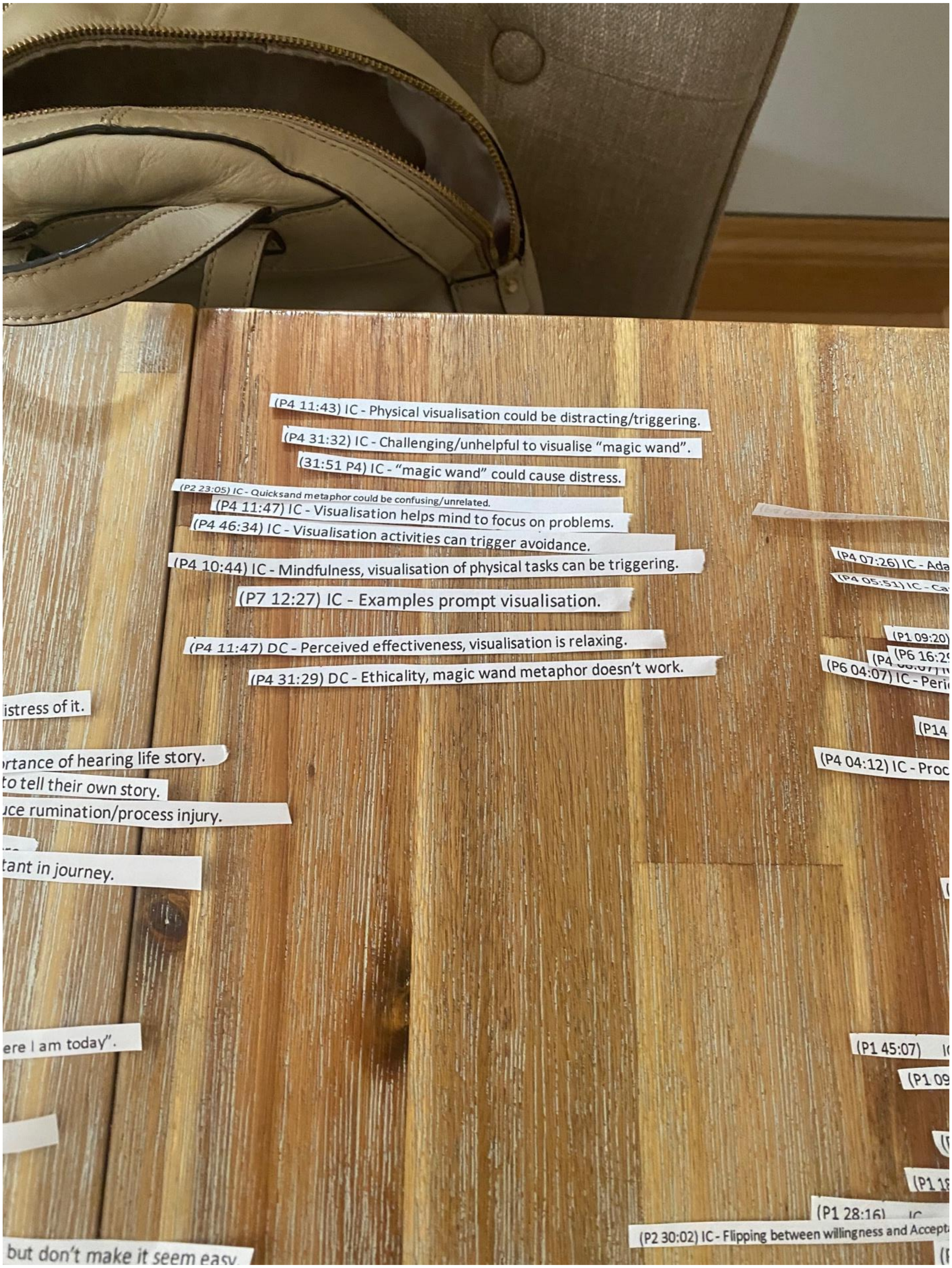

Additional support
access
Impact of mental attitude

on could be distracting/triggering.
elpful to visualise "magic wand".
could cause distress.
focus on problems.
gger avoidance.
sical tasks can be triggering.
visualisation.
alisation is relaxing.
nd metaphor doesn't work.

Acceptance.

beginning of journey and importance of being introduced "right".
(P4 07:26) IC - Adaptations, gentle, offering not forceful tone when talking about acceptance.
(P4 05:51) IC - Can move some way to accepting injury but certain things/memories can prompt distress.
(P1 09:20) DC Perceived effectiveness, existing activities prompt acceptance.
(P6 16:29) IC - Acceptance to be introduced later after initial depressed period.
IC - Acceptance should be approached carefully and presented as a journey.
(P6 04:07) IC - Period of adjustment both physically and mentally needs to occur prior to acceptance.
(P14 04:39) IC - Acceptance takes time.
(P4 04:12) IC - Process of acceptance, either take your own life or accept where you are and begin to move forward.
(P6 13:10) IC - some acceptance is good but too much can be damaging.
(P4 06:59) IC - Acceptance is difficult message to offer but needs to be said.
(P6 11:19) IC - Too much acceptance could be defeatist.
(P5 22:29) IC - Greaving process can take years.
(P4 21:52) IC - Getting rid of physical reminders doesn't remove memories.
(P6 09:57) IC - Prompting acceptance could be challenging.
(P6 16:49) IC - Can introduce service level acceptance earlier.
(P1 45:07) IC Impact/importance of level of acceptance on ability to engage with manual.
(P1 09:34) DC Perceived effectiveness, intervention "starting point of acceptance".
(P1 44:43) IC Impact/importance of level of acceptance on ability to engage.
(P6 16:03) IC - earlier acceptance is suggested harder it is to accept.
(P1 18:27) IC Acceptance can take years, ability to face up to injury can take years.
(P1 28:16) leans more focus. engageme
(P2 30:02) IC - Flipping between willingness and Acceptance as concepts could be confusing.
(P3 00:43) IC - Manual prompts willingness.
(P4 05:33) IC - Not possible to achieve total acceptance after SCI.
(P5 22:13) IC - Avoidance and acceptance part of grieving process.
(P6 36:39) IC - Acceptance framed as making the most of this not nothing you can do about (resigned to it).
(P6 14:46) IC - Being told to accept SCI can be too hard.
ree of acceptance necessary to avoid bitterness.
07:42) IC - ability to return to "normal" life post injury and capability of developing acceptance
(P8 27:36) DC - Ethicality, acceptance is good fit.
(P4 05:33) DC - Ethicality, acceptance is important.
(P1 09:20) IC Acceptance as a journey after SCI.
11:09) IC - SCI journey has to be lived before acceptance.
12:22) IC - Acceptance useful in early recovery
(P8 08:07) IC - Barriers to acceptance early post-SCI.
(P4 20:36) IC - Likely to take time to move forward post-injury.
(05:53) IC - Typically acceptance takes a year minimum.
(P1 18:21) IC Acceptance takes time, intervention is starting point.
(P8 10:51) IC - Move towards acceptance comes as you live through it.
(P9 04:09) IC - work through stages of grief towards acceptance.
(P4 06:43) DC - Ethicality, acceptance is required.
(P8 07:27) DC - Ethicality, in early days post-sci, acceptance may be challenging.
(P4 19:20) IC - Need to let go to move
(P9 06:37) IC - Need time to process grief before acceptance.
(P8 07:18) DC
IC - Going past the point of acceptance could le

(P7 22:06) IC - p
(P7 3
(P1 20:36)
(P7 39:36) IC
(P7 36:31) IC - Adap
(P4 24:58) I
(P1 04:46)
(P1 09:



(P4 11:43) IC - Physical visualisation could be distracting/triggering.

(P4 31:32) IC - Challenging/unhelpful to visualise “magic wand”.

(31:51 P4) IC - “magic wand” could cause distress.

(P2 23:05) IC - Quicksand metaphor could be confusing/unrelated.

(P4 11:47) IC - Visualisation helps mind to focus on problems.

(P4 46:34) IC - Visualisation activities can trigger avoidance.

(P4 10:44) IC - Mindfulness, visualisation of physical tasks can be triggering.

(P7 12:27) IC - Examples prompt visualisation.

(P4 11:47) DC - Perceived effectiveness, visualisation is relaxing.

(P4 31:29) DC - Ethicality, magic wand metaphor doesn’t work.

istress of it.

rtance of hearing life story.

to tell their own story.

uce rumination/process injury.

tant in journey.

ere I am today”.

but don’t make it seem easy.

(P4 07:26) IC - Ada

(P4 05:51) IC - Ca

(P1 09:20)

(P6 16:2

(P4

(P6 04:07) IC - Peri

(P14

(P4 04:12) IC - Proc

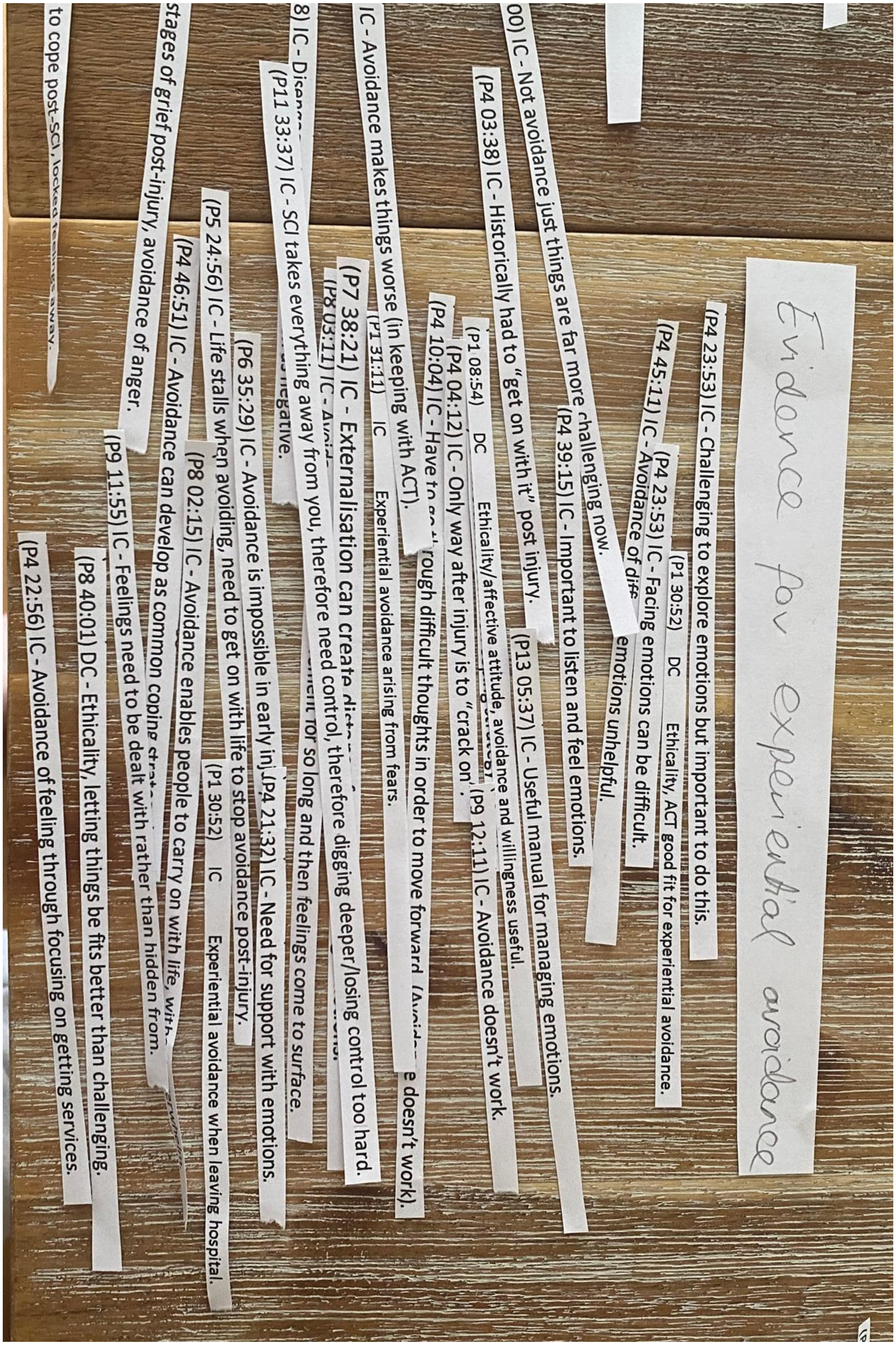
(P1 45:07) IC

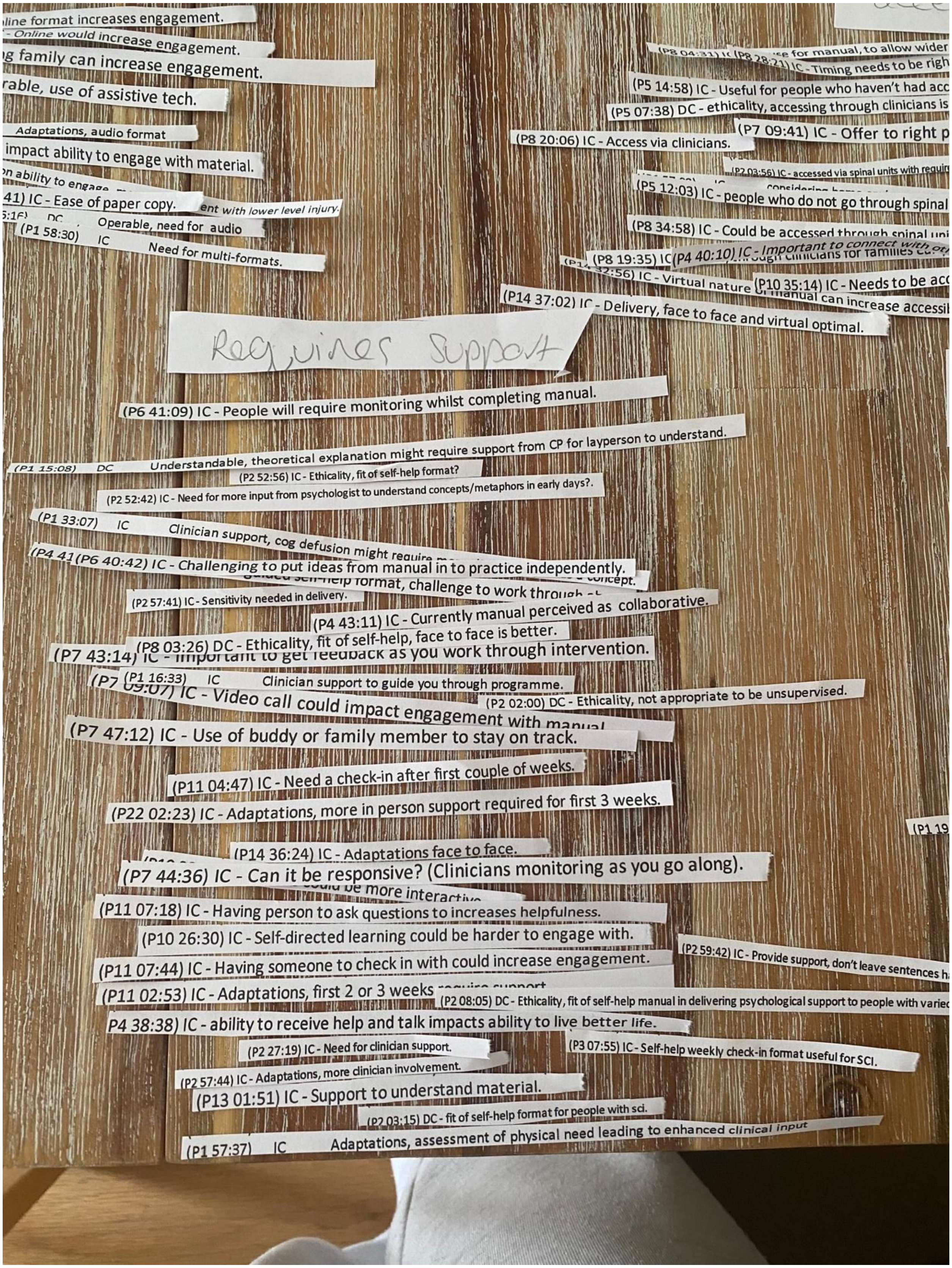
(P1 09

(P1 18

(P1 28:16) IC

(P2 30:02) IC - Flipping between willingness and Accept


Evidence for experiential avoidance
(P4 23:53) IC - Challenging to explore emotions but important to do this.
(P1 30:52) DC Ethicality, ACT good fit for experiential avoidance.
(P4 23:53) IC - Facing emotions can be difficult.
(P4 45:11) IC - Avoidance of diff
emotions unhelpful.
(P4 39:15) IC - Important to listen and feel emotions.
00) IC - Not avoidance just things are far more challenging now.
(P13 05:37) IC - Useful manual for managing emotions.
(P4 03:38) IC - Historically had to "get on with it" post injury.
(P9 12:11) IC - Avoidance doesn't work.
(P1 08:54) DC Ethicality/affective attitude, avoidance and willingness useful.
(P4 04:12) IC - Only way after injury is to "crack on".
(P4 10:04) IC - Have to
rough difficult thoughts in order to move forward
e doesn't work).
IC - Avoidance makes things worse (in keeping with ACT).
(P1 31:11) IC Experiential avoidance arising from fears.
(P7 38:21) IC - Externalisation can create
(P8 03:11) IC - Avoid
(P11 33:37) IC - SCI takes everything away from you, therefore need control, therefore digging deeper/losing control too hard.
8) IC - Disen
negative.
for so long and then feelings come to surface.
(P6 35:29) IC - Avoidance is impossible in early inj
(P4 21:32) IC - Need for support with emotions.
(P1 30:52) IC Experiential avoidance when leaving hospital.
(P5 24:56) IC - Life stalls when avoiding, need to get on with life to stop avoidance post-injury.
(P8 02:15) IC - Avoidance enables people to carry on with life, with
(P4 46:51) IC - Avoidance can develop as common coping
stages of grief post-injury, avoidance of anger.
(P9 11:55) IC - Feelings need to be dealt with rather than hidden from.
to cope post-SCI, locked feelings away.
(P8 40:01) DC - Ethicality, letting things be fits better than challenging.
(P4 22:56) IC - Avoidance of feeling through focusing on getting services.



line format increases engagement.

- Online would increase engagement.

g family can increase engagement.

rable, use of assistive tech.

Adaptations, audio format

impact ability to engage with material.

n ability to engage

41) IC - Ease of paper copy.

ent with lower level injury.

DC Operable, need for audio

(P1 58:30) IC Need for multi-formats.

(P8 04:31) I

se for manual, to allow wider

(P8 28:21) IC - Timing needs to be righ

(P5 14:58) IC - Useful for people who haven't had acc

(P5 07:38) DC - ethicality, accessing through clinicians is

(P8 20:06) IC - Access via clinicians.

(P7 09:41) IC - Offer to right p

(P2 03:56) IC - accessed via spinal units with requir

considering

(P5 12:03) IC - people who do not go through spinal

(P8 34:58) IC - Could be accessed through spinal uni

(P8 19:35) IC

rough clinicians for families

(P4 40:10) IC - Important to connect with ot

32:56) IC - Virtual nature of manual can increase accessi

(P10 35:14) IC - Needs to be acc

(P14 37:02) IC - Delivery, face to face and virtual optimal.

Requires Support

(P6 41:09) IC - People will require monitoring whilst completing manual.

(P1 15:08) DC Understandable, theoretical explanation might require support from CP for layperson to understand.

(P2 52:56) IC - Ethicality, fit of self-help format?

(P2 52:42) IC - Need for more input from psychologist to understand concepts/metaphors in early days?.

(P1 33:07) IC Clinician support, cog defusion might require

(P4 41

(P6 40:42) IC - Challenging to put ideas from manual in to practice independently.

guided self-help format, challenge to work through

concept.

(P2 57:41) IC - Sensitivity needed in delivery.

(P4 43:11) IC - Currently manual perceived as collaborative.

(P8 03:26) DC - Ethicality, fit of self-help, face to face is better.

(P7 43:14) IC - Important to get feedback as you work through intervention.

(P1 16:33) IC Clinician support to guide you through programme.

(P7 09:07) IC - Video call could impact engagement with manual

(P2 02:00) DC - Ethicality, not appropriate to be unsupervised.

(P7 47:12) IC - Use of buddy or family member to stay on track.

(P11 04:47) IC - Need a check-in after first couple of weeks.

(P22 02:23) IC - Adaptations, more in person support required for first 3 weeks.

(P1 19

(P14 36:24) IC - Adaptations face to face.

(P7 44:36) IC - Can it be responsive? (Clinicians monitoring as you go along).

could be more interactive

(P11 07:18) IC - Having person to ask questions to increases helpfulness.

(P10 26:30) IC - Self-directed learning could be harder to engage with.

(P2 59:42) IC - Provide support, don't leave sentences h

(P11 07:44) IC - Having someone to check in with could increase engagement.

(P11 02:53) IC - Adaptations, first 2 or 3 weeks require support

(P2 08:05) DC - Ethicality, fit of self-help manual in delivering psychological support to people with varied

P4 38:38) IC - ability to receive help and talk impacts ability to live better life.

(P2 27:19) IC - Need for clinician support.

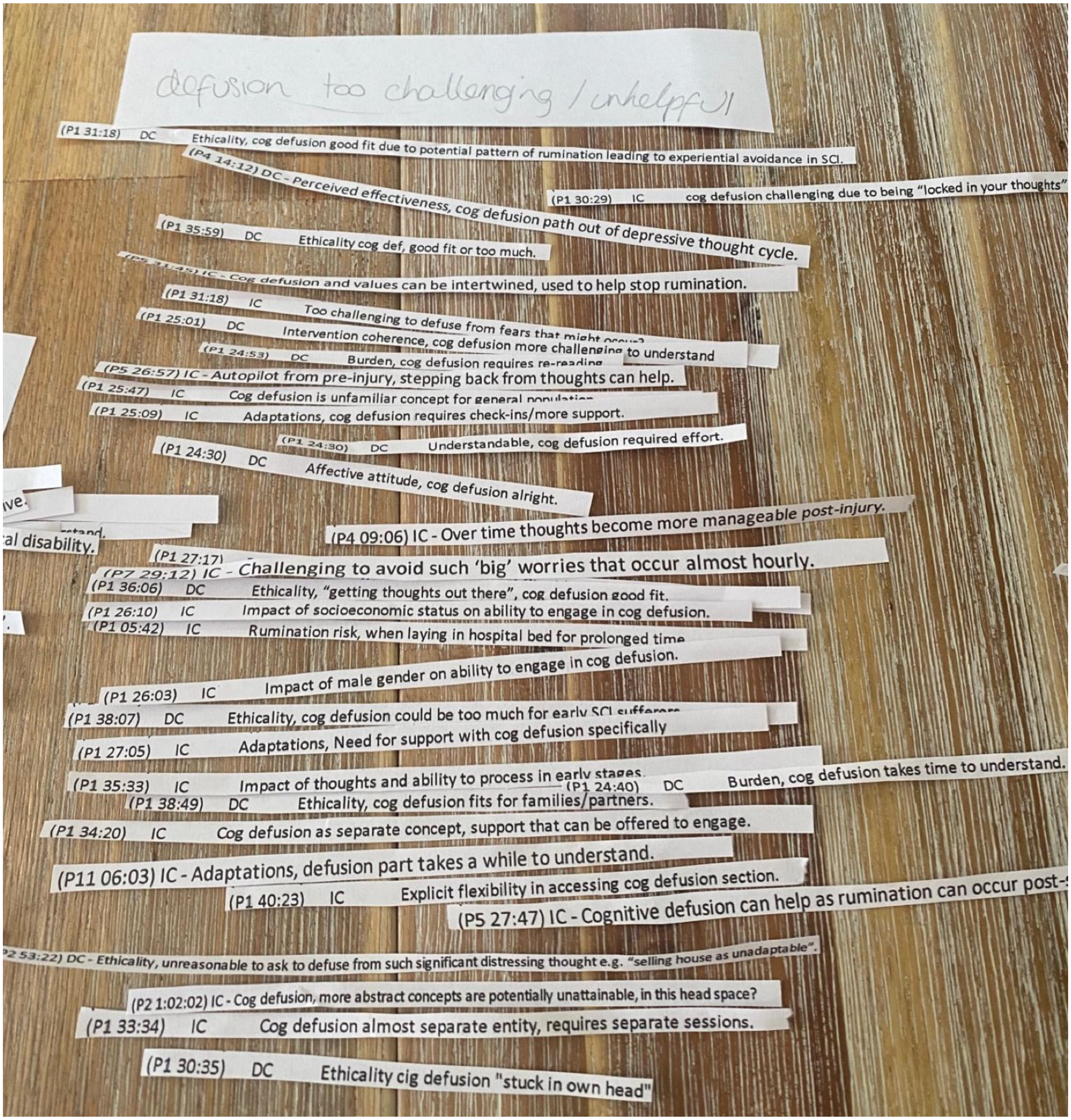
(P3 07:55) IC - Self-help weekly check-in format useful for SCI.

(P2 57:44) IC - Adaptations, more clinician involvement.

(P13 01:51) IC - Support to understand material.

(P2 03:15) DC - fit of self-help format for people with sci.

(P1 57:37) IC Adaptations, assessment of physical need leading to enhanced clinical input



defusion too challenging / unhelpful

(P1 31:18) DC Ethicality, cog defusion good fit due to potential pattern of rumination leading to experiential avoidance in SCI.

(P4 14:12) DC - Perceived effectiveness, cog defusion path out of depressive thought cycle.

(P1 30:29) IC cog defusion challenging due to being "locked in your thoughts"

(P1 35:59) DC Ethicality cog def, good fit or too much.

(P5 31:45) IC - Cog defusion and values can be intertwined, used to help stop rumination.

(P1 31:18) IC Too challenging to defuse from fears that might occur?

(P1 25:01) DC Intervention coherence, cog defusion more challenging to understand

(P1 24:53) DC Burden, cog defusion requires re-reading

(P5 26:57) IC - Autopilot from pre-injury, stepping back from thoughts can help.

(P1 25:47) IC Cog defusion is unfamiliar concept for general population

(P1 25:09) IC Adaptations, cog defusion requires check-ins/more support.

(P1 24:30) DC Understandable, cog defusion required effort.

(P1 24:30) DC Affective attitude, cog defusion alright.

ve.

stand.

al disability.

(P4 09:06) IC - Over time thoughts become more manageable post-injury.

(P1 27:17)

(P7 29:12) IC - Challenging to avoid such 'big' worries that occur almost hourly.

(P1 36:06) DC Ethicality, "getting thoughts out there", cog defusion good fit.

(P1 26:10) IC Impact of socioeconomic status on ability to engage in cog defusion.

(P1 05:42) IC Rumination risk, when laying in hospital bed for prolonged time

(P1 26:03) IC Impact of male gender on ability to engage in cog defusion.

(P1 38:07) DC Ethicality, cog defusion could be too much for early SCI sufferers

(P1 27:05) IC Adaptations, Need for support with cog defusion specifically

(P1 35:33) IC Impact of thoughts and ability to process in early stages.

(P1 24:40) DC Burden, cog defusion takes time to understand.

(P1 38:49) DC Ethicality, cog defusion fits for families/partners.

(P1 34:20) IC Cog defusion as separate concept, support that can be offered to engage.

(P11 06:03) IC - Adaptations, defusion part takes a while to understand.

(P1 40:23) IC Explicit flexibility in accessing cog defusion section.

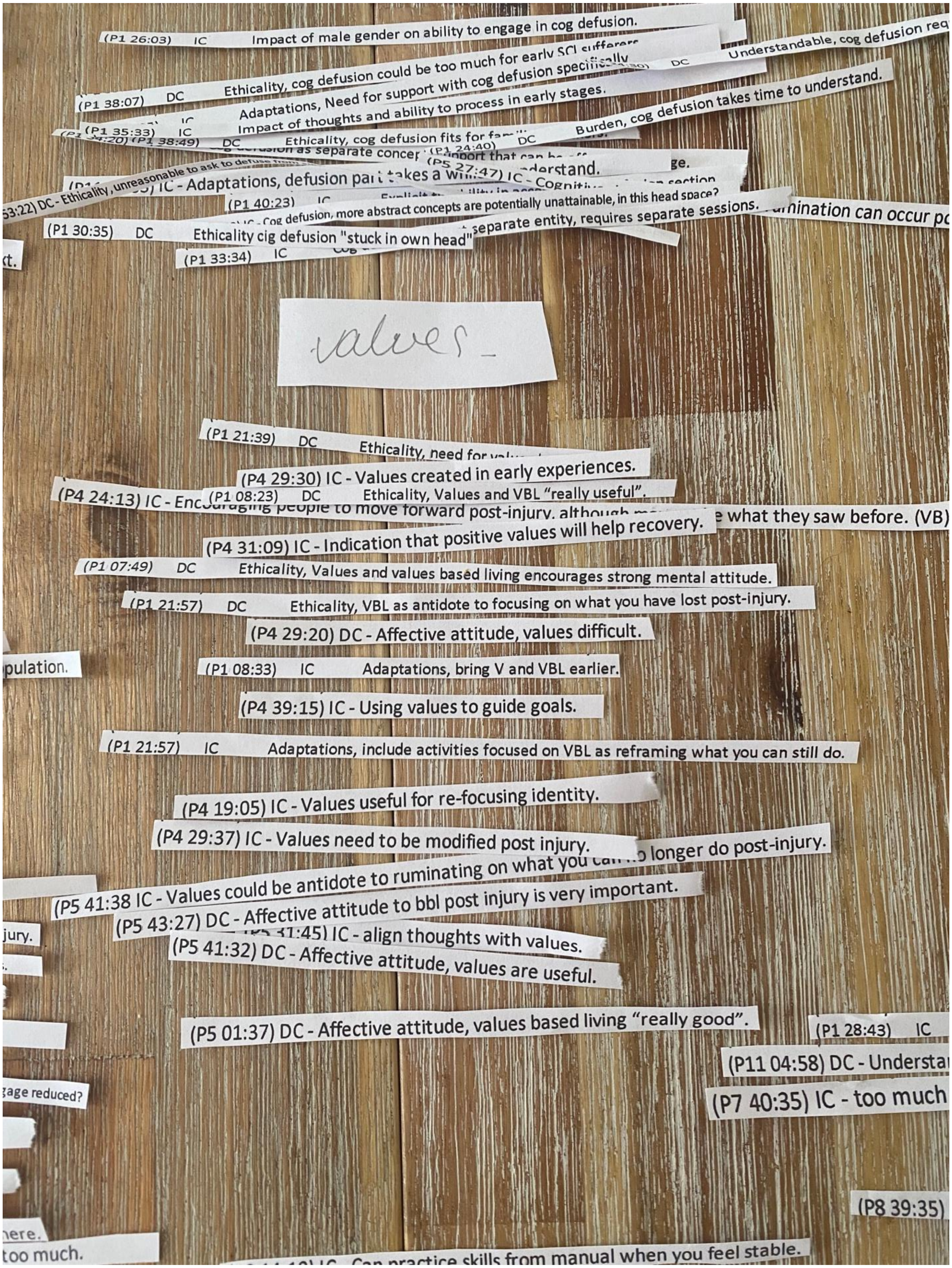
(P5 27:47) IC - Cognitive defusion can help as rumination can occur post-

2 53:22) DC - Ethicality, unreasonable to ask to defuse from such significant distressing thought e.g. "selling house as unadaptable".

(P2 1:02:02) IC - Cog defusion, more abstract concepts are potentially unattainable, in this head space?

(P1 33:34) IC Cog defusion almost separate entity, requires separate sessions.

(P1 30:35) DC Ethicality cig defusion "stuck in own head"



(P1 26:03) IC Impact of male gender on ability to engage in cog defusion.

(P1 38:07) DC Ethicality, cog defusion could be too much for early SCI sufferers

Adaptations, Need for support with cog defusion specifically

DC Understandable, cog defusion req

(P1 35:33) IC Impact of thoughts and ability to process in early stages.

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(P1 40:23) IC

IC - Cog defusion, more abstract concepts are potentially unattainable, in this head space?

separate entity, requires separate sessions.

mination can occur po

(P1 30:35) DC Ethicality cig defusion "stuck in own head"

(P1 33:34) IC

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values_

(P1 21:39) DC Ethicality, need for valu

(P4 29:30) IC - Values created in early experiences.

(P1 08:23) DC Ethicality, Values and VBL “really useful”.

(P4 24:13) IC - Enc

people to move forward post-injury, although

e what they saw before. (VB)

(P4 31:09) IC - Indication that positive values will help recovery.

(P1 07:49) DC Ethicality, Values and values based living encourages strong mental attitude.

(P1 21:57) DC Ethicality, VBL as antidote to focusing on what you have lost post-injury.

(P4 29:20) DC - Affective attitude, values difficult.

pulation.

(P1 08:33) IC Adaptations, bring V and VBL earlier.

(P4 39:15) IC - Using values to guide goals.

(P1 21:57) IC Adaptations, include activities focused on VBL as reframing what you can *still* do.

(P4 19:05) IC - Values useful for re-focusing identity.

(P4 29:37) IC - Values need to be modified post injury.

(P5 41:38 IC - Values could be antidote to ruminating on what you can no longer do post-injury.

(P5 43:27) DC - Affective attitude to bbl post injury is very important.

jury.

31:45) IC - align thoughts with values.

(P5 41:32) DC - Affective attitude, values are useful.

(P5 01:37) DC - Affective attitude, values based living “really good”.

(P1 28:43) IC

(P11 04:58) DC - Understa

gage reduced?

(P7 40:35) IC - too much

(P8 39:35)

here.

too much.

IC - Can practice skills from manual when you feel stable.


Relevant
MDT / family uses
Manual prompts moving forward
Physical/negative language bad fit
Tone patronising/ off-putting
Negative opinions
Burden currently disengaging
Metaphors alienating
defusion too challenging / un

Appendix J: Leaves on a stream as described in the ACT manual

ACTIVITY: Floating Leaves on a Moving Stream

This activity is similar to the 'Mind Train' and builds on these ideas.

This will be an eyes-closed activity. First, read the instructions and then when you are sure you understand them, close your eyes and do the activity. If you prefer, you can listen to a recording of this activity. The recording is 7 minutes long and can be found here:

https://www.youtube.com/watch?v=vjKltKKSur8&list=PLhTRvI3XBB58bd-Ms3mSnSgzFUo-uHXTg&index=3&t=0s

Leaves on a Stream ACT- Stop Overthinking- Anxiety Skill #30 (by Therapy in a Nutshell).

Imagine a beautiful slow-moving stream. The water flows over the rocks, around trees, descends downhill, and travels through a valley. Once in a while, a big leaf drops into the stream and floats away down the river. Imagine you are sitting beside that stream on a warm, sunny day, watching the leaves float by.

Now become conscious of your thoughts. Each time a thought pops into your head, imagine that it is written on one of those leaves. Then let the leaf float away down the stream. If you think in words, put them on the leaf as words. If you think in images, put them on the leaf as an image. The goal is to stay beside the stream and allow the leaves on the stream to keep flowing by. Don't try to make the stream go faster or slower; don't try to change what shows up on the leaves in any way. If the leaves disappear, or if you mentally go somewhere else, or if you find that you are in the stream or on a leaf, just stop and notice that this has happened. File that knowledge away and then once again return to the stream, watch a thought come into your mind, write it on a leaf, and let the leaf float away down the stream.

Continue doing this for at least five minutes. If the instructions are clear to you now, go ahead and close your eyes and do the activity.

What did you experience before starting the activity?

What did you experience during activity?

What did you experience now the activity is over?

It is normal for your mind to wander or for the stream not to ‘flow’, particularly if this activity is new.

You can think of the moments when the stream wouldn’t flow as moments of cognitive fusion, while the moments when the stream does flow are moments of cognitive defusion. Many times we become fused to a thought without even being aware of it. Thoughts about this activity can be especially “sticky.” If you thought “I’m not doing this right” or “this activity doesn’t work for me,”, or even “I’m not having any thoughts” these too are thoughts that you may become fused to quite easily. In many cases, you may not even notice them as thoughts, however as you practice you will notice these more easily.

You may want to repeat this activity regularly to see whether you find you can stay with the activity for longer and to practice defusing from your thoughts.

Appendix K: Less abstract cognitive defusion technique

ACT defusion techniques *(First Psychology Scotland)*

Sometimes we struggle with ‘negative thoughts’. Often, we’re told to ‘think positive’, ‘challenge thoughts’ or ‘try not to think about it’. Sometimes this can work! However, we might sometimes become locked in a loop of trying to feel better despite being trapped by the thoughts.

But who told you the thought was negative? When we identity a thought as negative, we have a natural desire to get rid of it. But in truth, our thoughts are neither positive nor negative, but can be either helpful or unhelpful.
When we can get enough distance from our minds we can make decisions to pay attention to what’s helpful, while ignoring thoughts if they are unhelpful.

Defusion helps you look AT the thought, instead of trying to look FROM the thought. Applying cognitive defusion techniques helps develop psychological flexibility by identifying unhelpful thoughts and being able to see them merely as ‘words inside your head’.

The purpose of these techniques is not to undermine what goes on in your mind, or to force you to be positive. But to create some distance between you and your thoughts. This will allow you to devote more time to your values and what is important to you. This does take practice, but if we want to do something ‘right’ we have to be prepared to do it wrong first. If your brain has immediately said ‘this won’t work’...well thank your brain for that, and defuse that thought too!

Defusion techniques

Mental language

What might be a typical negative thought you have about yourself? Got one? For example:

‘I’m not good enough’

How do you feel when you think about that statement? Notice what happens if you get into the habit of adding ‘I’m having the thought’ infront of the thought:

‘I’m having the thought I’m not good enough’.

You’re not trying to change the thought, or challenge it, or control or argue with it. Maybe add ‘I’m noticing in front of that:

‘I’m noticing I’m having the thought I’m not good enough’

How does that feel compared to the first statement?

Appendix L: Magic wand metaphor as described in the ACT manual

ACTIVITY: The magic wand.

Imagine we have a magic wand. I wave the wand and magically, all the painful thoughts and feelings you are experiencing are not a problem anymore. They’re still there, but magically you can cope with them and they aren’t affecting you.

What would you be **doing** differently? How would you **act differently** towards others? What would you **start doing more of, or what would you stop doing**? If we were to watch a video of you, **what would we see** that would be different?
Do any of these things give you clues into what might make your life more meaningful?

Appendix M: Annoying neighbour metaphor as described in the ACT manual

Neighbour Brian

You can think of willingness in the same way you would think of an unwelcome guest. Here is a 4 minute video talking about this:

https://www.youtube.com/watch?v=VYht-guymF4

The Unwelcome Party Guest - an Acceptance & Commitment Therapy (ACT) Metaphor (by Joe Oliver).

The video talks about what happens when an unwelcome guest turns up at your party, and how spending all of your time trying to get rid of the unwelcome guest takes the fun out of the party.

What this metaphor is about is all the feelings and memories and thoughts that show up that you don't like. There are many ‘Brian’s at your door. If you wait for them to go away before enjoying the party, you will never enjoy it. The issue is how you respond your own painful experiences (your Brian’s).

Appendix N: Psychological Quicksand as described in the ACT Manual

SUFFERING: PSYCHOLOGICAL QUICKSAND

Imagine you came across someone in the middle of a patch of quicksand. The person is shouting, "Help, get me out," and is beginning to do what people usually do when they are stuck in something they fear: struggle to get out. When people step into something they want to get out of, 99.9% of the time the best action to take is to walk, step, or jump out of trouble.

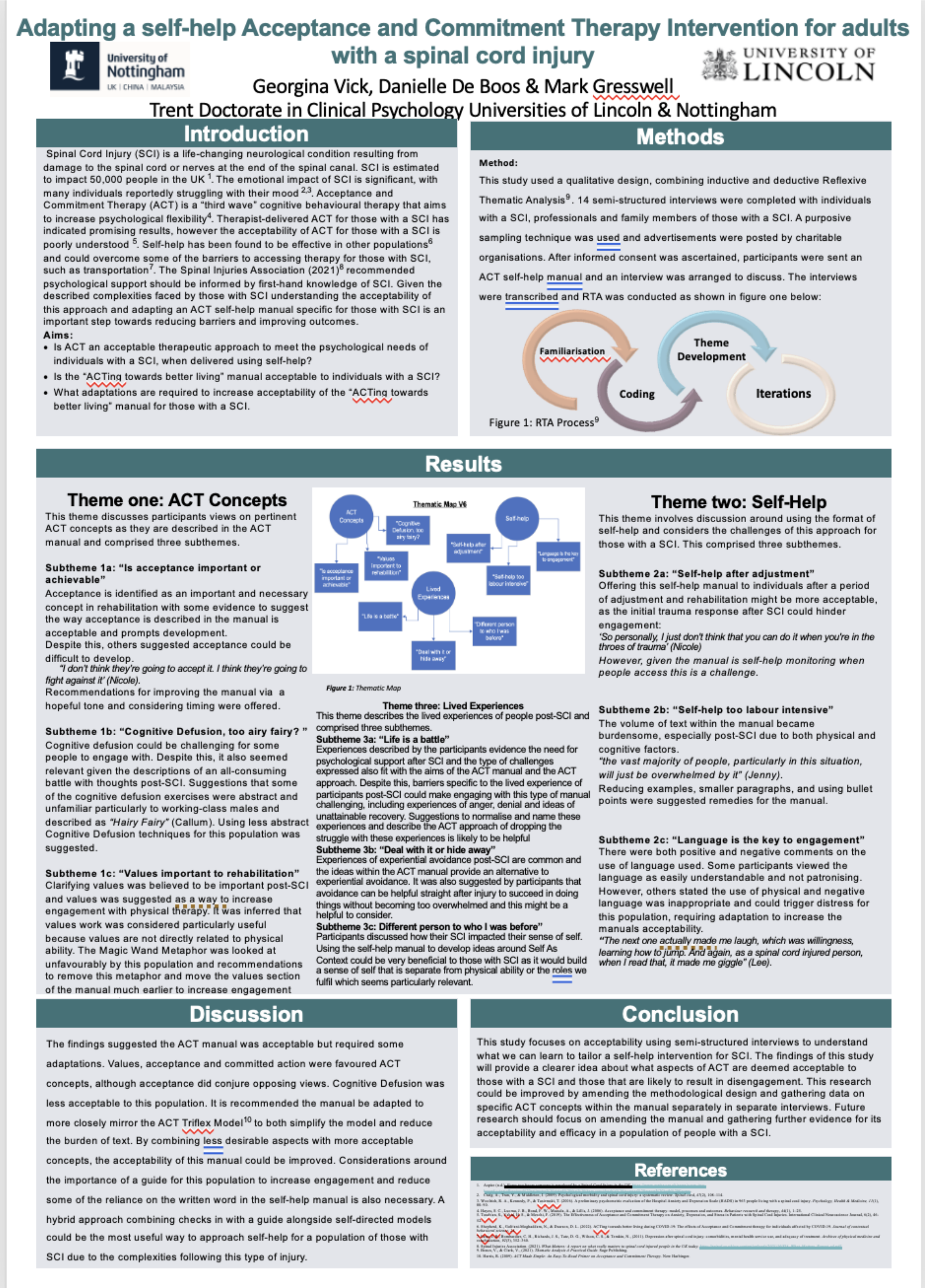
But with quicksand, the more the person struggles – the deeper they will sink.

So what should you do? If you know how quicksand works, you would **tell the person to stop struggling and to lie flat, like a starfish, to maximize contact with the surface of the quicksand.** The person would stop sinking deeper and might even be able to roll to safety. And yet, it is extremely counterintuitive to maximize body contact with the quicksand. Someone struggling to get *out* of the quicksand might not realize that the wiser and safer action to take would be to get *with* the quicksand.

Psychological pain is a lot like this, and it can sometimes feel endless. Exactly when will the quicksand of a distressing memory completely vanish?

This self-help guide isn't written to help you free yourself from the quicksand you find yourself in, but to get with it. The issues that you've struggled with might still be around (or they might not), but does it matter, if you are living your life to the fullest?

Appendix O: Research Poster



Adapting a self-help Acceptance and Commitment Therapy Intervention for adults with a spinal cord injury

Georgina Vick, Danielle De Boos & Mark Gresswell
Trent Doctorate in Clinical Psychology Universities of Lincoln & Nottingham

Introduction

Spinal Cord Injury (SCI) is a life-changing neurological condition resulting from damage to the spinal cord or nerves at the end of the spinal canal. SCI is estimated to impact 50,000 people in the UK [1]. The emotional impact of SCI is significant, with many individuals reportedly struggling with their mood [2,3]. Acceptance and Commitment Therapy (ACT) is a "third wave" cognitive behavioural therapy that aims to increase psychological flexibility[4]. Therapist-delivered ACT for those with a SCI has indicated promising results, however the acceptability of ACT for those with a SCI is poorly understood [5]. Self-help has been found to be effective in other populations[6] and could overcome some of the barriers to accessing therapy for those with SCI, such as transportation[7]. The Spinal Injuries Association (2021)[8] recommended psychological support should be informed by first-hand knowledge of SCI. Given the described complexities faced by those with SCI understanding the acceptability of this approach and adapting an ACT self-help manual specific for those with SCI is an important step towards reducing barriers and improving outcomes.

Aims:

- Is ACT an acceptable therapeutic approach to meet the psychological needs of individuals with a SCI, when delivered using self-help?
- Is the "ACTing towards better living" manual acceptable to individuals with a SCI?
- What adaptations are required to increase acceptability of the "ACTing towards better living" manual for those with a SCI.

Methods

Method:

This study used a qualitative design, combining inductive and deductive Reflexive Thematic Analysis[9]. 14 semi-structured interviews were completed with individuals with a SCI, professionals and family members of those with a SCI. A purposive sampling technique was used and advertisements were posted by charitable organisations. After informed consent was ascertained, participants were sent an ACT self-help manual and an interview was arranged to discuss. The interviews were transcribed and RTA was conducted as shown in figure one below:

Figure 1: RTA Process[9]

Results

Theme one: ACT Concepts

This theme discusses participants views on pertinent ACT concepts as they are described in the ACT manual and comprised three subthemes.

Subtheme 1a: "Is acceptance important or achievable"

Acceptance is identified as an important and necessary concept in rehabilitation with some evidence to suggest the way acceptance is described in the manual is acceptable and prompts development.
Despite this, others suggested acceptance could be difficult to develop.

"I don't think they're going to accept it. I think they're going to fight against it' (Nicole).

Recommendations for improving the manual via a hopeful tone and considering timing were offered.

Subtheme 1b: "Cognitive Defusion, too airy fairy? "

Cognitive defusion could be challenging for some people to engage with. Despite this, it also seemed relevant given the descriptions of an all-consuming battle with thoughts post-SCI. Suggestions that some of the cognitive defusion exercises were abstract and unfamiliar particularly to working-class males and described as *"Hairy Fairy"* (Callum). Using less abstract Cognitive Defusion techniques for this population was suggested.

Subtheme 1c: "Values important to rehabilitation"

Clarifying values was believed to be important post-SCI and values was suggested as a way to increase engagement with physical therapy. It was inferred that values work was considered particularly useful because values are not directly related to physical ability. The Magic Wand Metaphor was looked at unfavourably by this population and recommendations to remove this metaphor and move the values section of the manual much earlier to increase engagement

Figure 1: Thematic Map

Theme three: Lived Experiences

This theme describes the lived experiences of people post-SCI and comprised three subthemes.

Subtheme 3a: "Life is a battle"

Experiences described by the participants evidence the need for psychological support after SCI and the type of challenges expressed also fit with the aims of the ACT manual and the ACT approach. Despite this, barriers specific to the lived experience of participants post-SCI could make engaging with this type of manual challenging, including experiences of anger, denial and ideas of unattainable recovery. Suggestions to normalise and name these experiences and describe the ACT approach of dropping the struggle with these experiences is likely to be helpful

Subtheme 3b: "Deal with it or hide away"

Experiences of experiential avoidance post-SCI are common and the ideas within the ACT manual provide an alternative to experiential avoidance. It was also suggested by participants that avoidance can be helpful straight after injury to succeed in doing things without becoming too overwhelmed and this might be a helpful to consider.

Subtheme 3c: Different person to who I was before"

Participants discussed how their SCI impacted their sense of self. Using the self-help manual to develop ideas around Self As Context could be very beneficial to those with SCI as it would build a sense of self that is separate from physical ability or the roles we fulfil which seems particularly relevant.

Theme two: Self-Help

This theme involves discussion around using the format of self-help and considers the challenges of this approach for those with a SCI. This comprised three subthemes.

Subtheme 2a: "Self-help after adjustment"

Offering this self-help manual to individuals after a period of adjustment and rehabilitation might be more acceptable, as the initial trauma response after SCI could hinder engagement:

'So personally, I just don't think that you can do it when you're in the throes of trauma' (Nicole)

However, given the manual is self-help monitoring when people access this is a challenge.

Subtheme 2b: "Self-help too labour intensive"

The volume of text within the manual became burdensome, especially post-SCI due to both physical and cognitive factors.

"the vast majority of people, particularly in this situation, will just be overwhelmed by it" (Jenny).

Reducing examples, smaller paragraphs, and using bullet points were suggested remedies for the manual.

Subtheme 2c: "Language is the key to engagement"

There were both positive and negative comments on the use of language used. Some participants viewed the language as easily understandable and not patronising. However, others stated the use of physical and negative language was inappropriate and could trigger distress for this population, requiring adaptation to increase the manuals acceptability.

"The next one actually made me laugh, which was willingness, learning how to jump. And again, as a spinal cord injured person, when I read that, it made me giggle" (Lee).

Discussion

The findings suggested the ACT manual was acceptable but required some adaptations. Values, acceptance and committed action were favoured ACT concepts, although acceptance did conjure opposing views. Cognitive Defusion was less acceptable to this population. It is recommended the manual be adapted to more closely mirror the ACT Triflex Model[10] to both simplify the model and reduce the burden of text. By combining less desirable aspects with more acceptable concepts, the acceptability of this manual could be improved. Considerations around the importance of a guide for this population to increase engagement and reduce some of the reliance on the written word in the self-help manual is also necessary. A hybrid approach combining checks in with a guide alongside self-directed models could be the most useful way to approach self-help for a population of those with SCI due to the complexities following this type of injury.

Conclusion

This study focuses on acceptability using semi-structured interviews to understand what we can learn to tailor a self-help intervention for SCI. The findings of this study will provide a clearer idea about what aspects of ACT are deemed acceptable to those with a SCI and those that are likely to result in disengagement. This research could be improved by amending the methodological design and gathering data on specific ACT concepts within the manual separately in separate interviews. Future research should focus on amending the manual and gathering further evidence for its acceptability and efficacy in a population of people with a SCI.

References