



***“I was like intoxicated with this positivity”*: the politics of hope amongst participants in a trial of a novel spinal cord injury rehabilitation technology in South Africa**

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RESEARCH ON PRODUCTS AND DEVICES



“I was like intoxicated with this positivity”: the politics of hope amongst participants in a trial of a novel spinal cord injury rehabilitation technology in South Africa

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ABSTRACT

Purpose: This study discussed the reports by participants in a randomised controlled trial of a novel intervention for spinal cord injury (SCI) rehabilitation in Cape Town, South Africa.

Materials and methods: Sixteen participants were randomised to rehabilitation involving the use of robotic locomotor training, a novel technology, or to a group receiving an activity-based intervention. All participants were interviewed before the intervention and at six months follow-up.

Results: In a context in which rehabilitation services for SCI are virtually non-existent, all participants approached the study with enthusiasm and expressed gratitude for participation. They had high hopes for what the programme could achieve, with many believing, perhaps incorrectly, that the programme would help them walk independently again. While hope and enthusiasm are useful for adherence to experimental intervention studies, there is a danger, especially in poorly resourced contexts, for participants to experience considerable disappointment following false hope not being realised. This raises important ethical issues for researchers interested in the potential of new technologies to promote health in poorly resourced contexts.

Conclusions: For clinicians, the path between supporting positive emotions (which may lead to positive outcomes), and confronting unrealistic hope (which may lead to negative outcomes) may be difficult. Follow-up with participants after re-integration into their communities is important to determine long-term psychological impact.

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► IMPLICATIONS FOR REHABILITATION

- In low-resource contexts where there is a low level of access to rehabilitation services, such access in the context of a trial of a new intervention may engender hope in a group of people with spinal cord injury. This hope may increase when a new technology is used, as was the case in this study.
- Hope can be very helpful to people entering rehabilitation, but unrealistic hope and expectations may have negative implications in the longer term.
- In this study, expectations of participants centred, unrealistically, around regaining the ability to walk again, despite past experiences and medical advice suggesting otherwise.
- A thin line exists between supporting high expectations and confronting unrealistic hope. This conundrum is difficult for the clinician, as both inappropriate hope and undue pessimism about an intervention have the potential to cause harm.
- Participant follow-up after the end of any innovative trial is important, not just to monitor physical progress, but also, where necessary, to support participants through a potential period of disillusionment when they find their expectations have not been fully met.

Introduction

A spinal cord injury (SCI) is a debilitating injury that results in disruption of signal conduction across and below the point of lesion, leading to motor, sensory and/or autonomic impairment and functional restrictions [1]. Much of the psychological literature on SCI focusses on multiple trauma and adverse psychological

sequelae. Individuals who sustain a SCI not only experience the trauma of the injury, but a further series of multiple traumas as the losses associated with the physical injury become apparent [2]. The overwhelming lifestyle changes that follow a SCI often make it difficult for individuals to adjust emotionally [3], sometimes resulting in psychopathology, such as depressive, anxiety

and post-traumatic stress disorders [3,4]. Mood and anxiety disturbances are associated with lower levels of adjustment to SCI, self-neglect and decreased life satisfaction [5–8]. Furthermore, suicide is the leading cause of death in individuals with SCI younger than 55 years, with 75% of suicides occurring within 5 years of injury [4]. More recently, there is increasing interest not only in adverse sequelae of life-changing events but also on salutogenic issues such as posttraumatic growth [9,10]. Research questions have evolved over time that recognize the opportunity for growth and positive outcomes associated with trauma [11]. This positive psychology paradigm aims to identify the qualities that help individuals thrive, as opposed to focusing on their weaknesses [12]. Hope is an integral part of the positive psychology paradigm, with Snyder et al. defining hope as the belief that one can find pathways to desired goals and have the agency to use those pathways [13]. Hope has been widely studied within the SCI population [14–17].

Hope is an especially interesting issue to explore in the context of new technologies and treatments for any condition, including SCI. New technologies, especially those which promise to offer novel solutions to intractable problems, may be associated with a great deal of hope and optimism, some of which may be well placed but some unrealistic [18–21]. Just as a pathology approach to adjusting to sequelae of SCI may overlook positive change and posttraumatic growth, it is important within a positive psychology framework to consider the potential problem of false hope. As Jha notes, “The demarcating line between offering over-optimistic and truthful hope is rather thin” (p. 1) [22].

With these considerations in mind, and as part of a larger study, we explore here the experiences of a group of SCI participants in South Africa given the opportunity to be part of a trial of a novel technology. The broader study explored the use of exoskeletons in SCI rehabilitation. Exoskeletons, or robotic locomotor training (RLT), represent a promising development in the rehabilitation of SCI. These devices are relatively lightweight and small, essentially functioning as an orthosis [23]. Ekso™ is a commercially available exoskeleton that enables individuals with varying levels of paralysis to stand up and walk with a natural, full weight bearing, and reciprocal gait during sessions which are overseen by a health professional [24].

There is an important further contextual factor to consider in relation to this trial. Not only is the technology new, and currently expensive, the trial was conducted in South Africa, a country

which has, in common with many other low and middle-income countries, a relative lack of access to rehabilitative services in general [25–28]. For most people who survive SCI in these contexts, there may be some immediate acute care, but it is not uncommon for there to be no rehabilitative follow-up, for a range of reasons including overstretched health systems and unavailability of affordable accessible transport [28,29]. For a person with an SCI in South Africa to be part of a trial (even in a control group which does not use new technology like an exoskeleton) is unusual, and part of what becomes of interest here, apart from the new technology, is access to care which is not universally available, which may in itself have psychological meaning for participants [30].

Methods

The aim of this qualitative study is to document a group of participants' ($n=16$) lived experience of participating in a randomized controlled trial of two exercise-based interventions for individuals with SCI in Cape Town, South Africa. Participants were recruited from an intervention study which aimed to investigate the physiological effects of activity-based training (ABT) and robotic locomotor training (RLT). Both interventions consisted of three sessions per week for 24-weeks. RLT took place in an Ekso GT exoskeleton (California, USA), while ABT consisted of a combination of resistance, cardiovascular and flexibility training. These interventions were administered by registered biokineticists, under the supervision of a rehabilitation doctor.

Participants

The most common subgroup of SCI in Cape Town, South Africa was recruited, namely traumatic, motor incomplete (ASIA impairment scale C, D), with a neurological level of injury between C1 and C8 (cervical injury) [31]. All participants were dependent on a wheelchair as their primary source of mobility. As shown in Table 1, 16 participants were included into the analysis, eight randomly assigned to each intervention group (ABT and RLT). Motor vehicle accidents accounted for 62.5% of injury aetiology whilst stabbing, gunshot, rugby, motor-cycle, mountain bicycle and diving accounted for 12.5% each. Only one female qualified for inclusion into the trial.

Table 1. Characteristics of participants.

Participant	Age (years)	Time since injury (years)	Neurological level of Injury	AIS category	Aetiology	Sex	Intervention Group
Ethan	30	11	C4	C	Diving	Male	ABT
Calvin	46	26	C4	D	Gunshot	Male	RLT
Corey	32	15	C7	C	Sport–Rugby	Male	RLT
Mpho	47	3	C4	D	Motor-cycle	Male	ABT
James	43	23	C6	C	MVA	Male	RLT
Siya	56	15	C4	C	MVA	Male	RLT
Junior	29	10	C5	C	MVA	Male	ABT
Liam	60	2	C5	C	Mountain bike	Male	ABT
Hannah	46	20	C6	D	MVA	Female	ABT
Jacob	33	15	C6	C	MVA	Male	RLT
Samuel	26	2	C6	C	MVA	Male	ABT
Mateo	32	3	C5	D	MVA	Male	RLT
William	19	2	C5	C	MVA	Male	ABT
Mohammad	50	8	C7	D	MVA	Male	ABT
Lucas	27	9	C6	D	Stabbing	Male	RLT
Matthew	55	4	C5	D	MVA	Male	RLT
Average	39.4 ± 12.4	10.5 ± 7.9					

Data shown as mean ± SD. RLT: robotic locomotor training; ABT: activity-based training; AIS: ASIA impairment scale; MVA: motor vehicle accident.

Data collection

Data were collected via in-depth semi-structured individual interviews prior to starting the intervention and six-months later after completing the intervention. Interviews were conducted by registered psychologists, using open ended questions and providing space for participants to communicate freely [32]. In the initial interviews, participants were asked about the nature of their SCI, how it occurred, and how they had adjusted to the resulting impairments. They were also asked about their motives for joining the study, their expectations of the intervention, and their understanding of the aims of the research. They were asked to identify potential benefits of and barriers to their participation, as well as how these barriers might be overcome. They were also screened for symptoms of psychopathology. In the final interviews at the end of the intervention, participants were asked about their experience of participating, the perceived benefits of the intervention, whether or not their expectations had been met, as well as any difficulties experienced and how these were overcome. They were invited to give critical feedback and make recommendations for how the intervention might have been improved or made more client centred. Finally, they were asked what advice they would give to individuals who participated in these kinds of interventions in the future. Interviews lasted approximately 60 minutes and were audio recorded and transcribed verbatim.

Data analysis

Data were analyzed using an open-ended data-driven and inductive approach. Codes were identified using thematic analysis [33], with initial coding done independently by two researchers. The initial codes identified by the two researchers were then reconciled by a third person, so that triangulation of themes could be achieved. Themes were then grouped into superordinate themes, which were then independently reviewed and verified by a third author (JB). In this way four superordinate themes were identified, namely: (1) participants' experience of their SCIs and life before entering the research programme; (2) reactions to entering and experiencing the research programme; (3) the complexity of hope; and (4) expectations and experience of the exoskeleton itself. The results pertaining to the experience of the exoskeleton are based on eight of the participants as the remaining eight in the ABT group had not yet used the device at the time of the second interviewing.

The following strategies were used to improve the trustworthiness and credibility of the findings [34]: all authors reviewed the themes to ensure that they accurately reflected the interview content; JB conducted a confirmability audit to ensure that all interpretations were supported by interview data; verbatim quotes have been included to provide evidence for the findings; and data from all 16 interviews are included in an effort to avoid cherry-picking quotes from a selected subsample of interviews.

Ethics

Ethical clearance was obtained from the Health Sciences Research Ethics Committee at the University of Cape Town (384/2016). Signed informed consent was obtained from participants prior to data collection. Data were collected by registered psychologists in a private setting. De-identified data were securely stored on password protected computers. Procedures were

implemented to refer participants for psychological assessment and treatment if they expressed any distress as a result of the intervention or the interviews, or if they exhibited any signs of psychopathology. Pseudonyms have been used to protect participants' privacy.

Results

The experience of the SCI and life before entering the research programme

All participants' injuries were traumatic in nature. The majority were able to recall vivid details of their accident, years after it had occurred:

James: I was conscious through everything. You know when I went through the sun roof, I knew what was happening, I felt how I fell on my head, I heard my neck snap, it sounds like a stick, like a dry twig type of thing, everything dead immediately. So I knew exactly what was going on.

Some participants expressed difficulty with sleeping or had experienced difficulty in the past due to flashbacks of their accidents:

William: It brought back everything at once; it wasn't like piece by piece, it just hit me all at once. And I think for like two nights straight I struggled to sleep. I still kind of get nightmares sometimes now, but they are not as bad as they used to be. Like I always get put back in that seat because, I was sitting there for about half an hour before someone found me ... Um, ja, I sometimes wake up, with a fright, like a scare. Because some nights I dream I am back sitting in that car.

Most participants were prescribed anti-depressants after their injuries with some still remaining on their prescription:

Junior: ... I am still on it [anti-depressant]. From the day I broke my neck, I did go off of it for like a year, but I feel like I got more angry and irritable without it, than with it.

Participants described feelings of depression and anxiety. They spoke of "struggling" and "battling" against these emotions, and explained how these feelings eroded their hope and optimism.

Mpho: All of us have got this enemy from within, there's always this little voice inside you.

Mateo: I find when I am alone, and I am sure all the guys are alone, just thinking to yourself, and then there is a mind wall, there, then it's up to you really. Am I going to slip backwards and get upset about things or, so I start thinking about the future and start getting excited about things.

In the acute setting, the prognosis of their recovery provided by medical professionals was often seen as pessimistic, with some participants feeling resentful at being given a poor prognosis:

Mpho: I've been through hell, [laughs] I really I have been through hell, this four years of my life was like, I really started to believe the doctors.

A lack of independence created frustration, which was a key source of negative emotions such as irritability and depression:

James: I mean everybody gets depression now and then, you do get upset because you can't do certain things, you try to explain to somebody how to do something, and they just don't get it or they don't do the way you want it done.

Many participants were open about their experiences of suicidal thoughts:

Liam: To be honest I have often, often, often thought I have had enough; I am going to take myself out. Um, my mother-in-law, told me don't ever think about something like that, just think what it would do

to [daughter's name], and that's the only thing that's sort of, often has kept me here.

Reactions to entering and experiencing the research programme

Participation in this intensive and well-funded programme, whether in the RLT or the ABT group, was an unusual experience which was markedly different from their previous experience of rehabilitation. Participants explicitly expressed gratitude for being included in the intervention. As Ethan and Calvin put it:

Ethan: I don't know of anyone who would have given me three months of three, or thrice-a-week, exercise rehabilitation, physical rehabilitation. So I'm immensely grateful for that.

Calvin: Well the programme is a very good thing as quite a lot of people cannot pay for this kind of a programme, to get involved in a way; it is something which everybody needs, because there are a lot of people who cannot afford to pay for it.

Participants also valued access to transport, which had been provided to facilitate their getting to and from the intervention. As Samuel noted, even if he could use public transport, it was too dangerous:

Samuel: But it is too dangerous to take the train. What am I going to do if someone grabs my bag? There is not much I can do, is there?

The sense of being part of a group whose needs were being acknowledged and catered for helped engender an optimistic and grateful attitude:

Mpho: And when I came in here as well. The air was like laden with potential, like opportunities, that guy was like, I was like intoxicated with this positivity, the opportunities and everything here, the whole vibe in this place, the people, everybody in here you can see they are very driven, they are like, they have a purpose, and you can see all of them now they are sticking to it, and they are putting their all into it.

For some participants, participating in the programme accorded with their pre-existing hope that they would improve in function and even, for some, that they would walk again. All participants had incomplete tetraplegia, which carried the possibility of an improved prognosis for a return of function. The open-ended nature of their diagnosis fueled the drive to improve. They expressed motivation to pursue physical and emotional recovery, despite multiple years passing since their injuries:

James: I made the decision, you know what you are going to stay in here and lead a comfortable life, or you can try and better yourself, but it is going to be very difficult, fortunately, fortunately I took the difficult road.

Mateo: I know it [walking] is going to happen, it is really just up to me. Especially with myself and my physicality and my, like I can move and I can feel a lot compared to other guys, I've got different advantages to what they have...

Prior to joining the programme, especially given transport challenges, most participants had been socially isolated. Simply meeting and being in regular contact with others with SCI was experienced as beneficial:

Mpho: I think for me it was fantastic to see all these guys that are in a similar situation to I am, and just to see them accomplish, to be able to do something that they couldn't do before. Um, that you know, camaraderie, that peer-support and understanding.

Seeing improvements in physical functioning during the intervention, regardless of whether in the RLT or ABT group, provided

further motivation to attain greater goals. This was a source of excitement and optimism to participants:

Corey: It's like fireworks that's going on here inside of me, while I am talking, just knowing that yoh, anything is possible if you just can put your mind, if you just like renew your mind-set. And just build on positive thinking and stuff, then anything is possible, it's like, yes I was like watching movies and stuff like this, but now my life is like a reality.

The complexity of hope

Participants universally shared hope for recovery, and many were focused on the possibility of regaining the ability to walk:

Siya: I will stand up and walk, that's my greatest expectation. And it's, the science is there. There is some science. I will not, get off the programme until I walk. Laughs. I hope so.

It seemed that to some participants the wish to walk, even where the clinical evidence suggested that this was very unlikely and had been communicated as such to them, was non-negotiable:

Mateo: I know I will walk, I know I will, I expect to walk in five years, it has to happen.

Other participants expressed the need to be more realistic:

Lucas: Some people believe in faith, they can just get up and walk. Belief and faith is part of it, but you need to be realistic, you can't just get better after six months, because depending on the injury you might get better, but this is not going to be a miracle cure.

Ethan: You know, the thing is, because I have also been paralyzed and in a wheelchair for ten years, I also know that there isn't some miracle cure to spinal cord injuries.

Expectations and experience of the exoskeleton itself

Participants were interviewed both before and after using the exoskeleton. The differing time points provided insight into initial expectations in comparison to the actual experience of utilizing the exoskeleton as a rehabilitative tool. Within the context of a middle-income country where there is limited access to rehabilitation, the prospect of an exoskeleton was met with considerable curiosity, regardless of which group the participants would be randomized into:

Mohammad: When they advertised, they said the suit and I was thinking, great there's my opportunity now, to see what the suit can do and how it's going to benefit me.

Exoskeletons have received considerable media coverage within the SCI community, potentially influencing the participants' views of the device, and raising expectations. Some participants were clear on the need to have realistic expectations:

Ethan: I don't want to try it out because it's a suit, I want to try it, really try it out because of my hips. I really feel my hips and my legs need that walking rotation, it's not because it's a suit that comes from Germany and everyone thinks it's so fantastic.

Participants were long-term wheelchair users, the majority of whom had not been able to stand or take any steps for several years. Those who did have the experience of using the exoskeleton, experienced strong emotions, including exhilaration:

Mateo: Exhilarating, there's the word. It is really exciting, it's emotional. A couple of times I mean I actually was walking, like I got emotional, just knowing I am walking again, it triggers it again, in your mind, you are actually doing this, and, as I say a couple of times, I got tearful,

emotional, I am actually doing this, I was actually doing this. I am actually doing this.

However, participants also spoke of feeling vulnerable while in the exoskeleton. They said being upright and out of a wheelchair was frightening and was associated with a fear of falling.

Jacob: Um, what's the correct word? Fear? I was kind of scared, but also just, it's normal because somewhere in the back of my mind I still remember but it's like standing on the edge of a building looking down, if I were to describe it. Just a pit in your stomach, like wow ok, step back.

Participants perceived several benefits of the exoskeleton, including improvements in muscle strength, spasticity, breathing, posture, mood, circulation and bowel function.

Corey: The suit is also like helping with spasms and stuff, it's less spasms that you have, and it brings such amazing [benefits] to my health man, and so like the breathing stuff and she push me longer on distance and all that stuff because of the blood flowing and all. Because if you sit like this, all your organs is like this, but if you stand up then everything falls in place and you can like breath and stuff, and so it's for me like a, it so a good thing that they invent. Whoever invent that thing ... it's a cool thing man to for people like us in wheelchairs and ... to have that moment ... and see the other guys with the glints in their eyes and how they are liking it.

Discussion

All participants had experienced acute trauma as well as ongoing physical challenges in addition to social isolation and a lack of access to rehabilitation. For all of them, therefore, the mere participation in the trial offered a range of benefits far beyond the actual treatments offered. These included attention from a dedicated health care team, easy and regular access to services, and the sense of being part of a community of people with similar challenges. In this context, participants expressed gratitude for being in the study, and hope both for what this intervention could do and for the future.

The issue of hope in this context is, however, a complex one. First, from a clinical perspective it is not likely that the majority of these participants will walk again, but to many participants this belief in the possibility of walking seemed to be psychologically important and provided impetus and motivation to participate in the intervention. This creates something of a dilemma for a research team, especially as it has been established in related fields that reassurance and promises of recovery may be helpful in the short-term, however, unrealistic reassurance and lack of challenge to unrealistic expectations may be associated with disappointment and poorer long-term outcomes [35]. For clinicians, the path between supporting positive emotions (which may lead to positive outcomes) on the one hand, and confronting unrealistic hope (which may lead to negative outcomes) may be difficult. This difficulty is intensified when there is a commitment from the research team to engage participants as fully as possible within an intervention programme which requires considerable effort from participants. These issues take on particular salience in a context where a new technology may be associated with increased unrealistic optimism, and in a low-resourced context where, as our participant Ethan put it, "it's a suit that comes from Germany and everyone thinks it's so fantastic" – a reference to a widespread belief that technologies developed in high-income countries are invariably superior to what is generally available in countries with fewer resources. This belief may not always be well placed, with some technologies and assistive devices developed in wealthier countries being of limited use in low-income environments [36].

This does of course raise important ethical questions about a study such as ours and interventions of this nature. It was clear that part of the appeal of participation in this study was its provision of opportunities and infrastructure not available to our participants in the usual course of events. There is considerable debate in the international literature as to whether studies which offer technologies and treatments which cannot be contextually sustained after the studies have been completed may in effect violate the rights of participants by offering and then withdrawing care [37,38]. In our study, the research team did everything possible to be honest with participants and not to promise more than could be delivered, but this does not absolve us from considering this question. In terms of follow-up after the end of the study itself, we provided a 3-month post-trial care period with the major goal being reintegration into the community. Provision was made for continued (income level graded) subsidized access to physical rehabilitation and free psychological support after the study.

In some ways, the dilemmas associated with allowing for optimism and hope versus guarding against false hope are mirrored in the experiences of the exoskeleton itself. Participants expressed both wonder and exhilaration at use of the new technology and fear of falling and further injury, an issue which had to be sensitively managed by the biokineticists on the project. There is very little research documenting the experience of using an exoskeleton, and though our study does go some way to filling the research gap, there is clearly much more data that needs to be collected on this issue.

Overall, our participants experienced benefits from both forms of intervention, and we will report on the physical outcomes elsewhere. Across the two interventions, though, was a context of care to which participants, sadly, were not accustomed. It is important that we follow up with participants in the contexts of their lives after the interventions are complete. It is also crucial that we and others in the field work to improve access to appropriate services for an often neglected group of people who have experienced both acute trauma and the ongoing challenges of social isolation and lack of access to the best possible care.

Ethical approval

Ethical clearance was obtained from the Health Sciences Research Ethics Committee at the University of Cape Town (384/2016).

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Geolocation

Cape Town, Western Cape, South Africa.

Author contributions

RE was responsible for concept design, managing the interventions and writing the publication.

JB was responsible for concept design, conducting tests, collecting and analyzing data and writing of the publication.

CS was responsible for implementing the interventions and editing of the publication.

SW was responsible for concept design, co-supervising the study, supplying funding, and editing the publication.

WD was responsible for concept design, co-supervising the study and editing the publication.

YA was responsible as primary supervisor of the study, concept design, supplying funding and editing the publication.

LS was responsible for concept design, conducting tests, collecting and analyzing data and editing of the publication.

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