



## Patients' perceptions of participating in self-directed activities outside supervised occupational and physiotherapy within inpatient and home-based rehabilitation settings: a qualitative study

Emma Dorward, Alicia Devlin, Natasha K. Brusco, Fiona Dulfer, Sara L. Whittaker, Sandra Reeder & Christina L. Ekegren

To cite this article: Emma Dorward, Alicia Devlin, Natasha K. Brusco, Fiona Dulfer, Sara L. Whittaker, Sandra Reeder & Christina L. Ekegren (16 Apr 2024): Patients' perceptions of participating in self-directed activities outside supervised occupational and physiotherapy within inpatient and home-based rehabilitation settings: a qualitative study, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2024.2341872](https://doi.org/10.1080/09638288.2024.2341872)

To link to this article: <https://doi.org/10.1080/09638288.2024.2341872>



© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



[View supplementary material](#)



Published online: 16 Apr 2024.



[Submit your article to this journal](#)



Article views: 357










[View related articles](#)



[View Crossmark data](#)

# Patients' perceptions of participating in self-directed activities outside supervised occupational and physiotherapy within inpatient and home-based rehabilitation settings: a qualitative study

Emma Dorward<sup>a,b,\*</sup> , Alicia Devlin<sup>a,c,\*</sup> , Natasha K. Brusco<sup>a</sup> , Fiona Dulfer<sup>d</sup> , Sara L. Whittaker<sup>a</sup> , Sandra Reeder<sup>e</sup>  and Christina L. Ekegren<sup>a,b</sup> 

<sup>a</sup>Rehabilitation, Ageing and Independent Living (RAIL) Research Centre, School of Primary and Allied Health Care, Monash University, Frankston, Australia; <sup>b</sup>Neuroscience Brain Recovery Rehabilitation Team, Alfred Health, Melbourne, Australia; <sup>c</sup>Peter James Centre, Eastern Health, Burwood East, Australia; <sup>d</sup>Physiotherapy Department, Cabrini Health, Malvern, Australia; <sup>e</sup>Department of Neuroscience, Central Clinical School, Monash University, Melbourne, Australia

## ABSTRACT

**Purpose:** To investigate patients' perceptions of participating in self-directed activities, outside supervised occupational and physiotherapy, within rehabilitation settings.

**Methods:** Semi-structured interviews were undertaken with 16 patients and in three instances, their carers, from three health services in Victoria, Australia, two offering inpatient and one offering home-based rehabilitation care. A thematic analysis was performed using a framework approach.

**Results:** Themes identified included the role of the clinicians in encouraging patients and instilling confidence, giving feedback and "just being there"; considerations in program delivery, including different formats, support from peers and relatives, and program familiarity and flexibility; patients' different intrinsic driving and limiting forces, including following orders, seeing results, desiring autonomy and having an "inner athlete"; and the environment, including functional activities, space, equipment, time and availability.

**Conclusions:** Patients and their carers reported positive experiences of participating in self-directed therapy programs within rehabilitation settings, with programs perceived as beneficial in optimising recovery. Patients reported a range of driving and limiting factors in relation to completing self-directed activities. Understanding these factors, relating to the patient, their environment and other people, is critical for clinicians so that they can modify their delivery accordingly, ensuring uptake and sustained implementation of self-directed activities in rehabilitation care.

## > IMPLICATIONS FOR REHABILITATION

- Patients and their carers reported positive experiences of participating in self-directed therapy programs within rehabilitation settings.
- Self-directed therapy programs were seen to be beneficial in optimising recovery and helping patients return to previous levels of function.
- Understanding patients' specific driving and limiting factors in relation to completing self-directed activities, is critical for clinicians so that they can modify their delivery accordingly, ensuring uptake and sustained implementation of self-directed therapy in rehabilitation care.

## ARTICLE HISTORY

Received 1 September 2023

Revised 28 March 2024

Accepted 6 April 2024

## KEYWORDS



Rehabilitation; self-management; independent practice; health services; qualitative


## Introduction

Patients admitted for rehabilitation who participate in more occupational and physiotherapy as part of their usual care achieve better health outcomes and have shorter rehabilitation admissions [1,2]. However, patients in rehabilitation hospitals commonly receive considerably less than the amount of therapy recommended for best practice, often due to insufficient staff-patient ratios [2,3]. It has been shown that prescribing self-directed therapy activities for rehabilitation inpatients can increase therapy time by up to 100 min per week [3]. In both stroke-specific, and diagnostically diverse, inpatient rehabilitation populations,

self-directed therapy programs have also been shown to result in additional functional improvements [3,4].

Despite these benefits, previous research conducted in neurological rehabilitation settings, has highlighted that challenges exist for both patients and clinicians with regard to participating in, and implementing, self-directed therapy programs [5–9]. Qualitative research with stroke-affected patients has found that barriers to participation in self-directed therapy include the physical rehabilitation environment and a lack of opportunity to practice [5–7,9]. Clinicians have also described inadequate ward environments and "passive rehabilitation cultures" as barriers to implementation [6], but have highlighted that they have an important role to play in

**CONTACT** Christina L. Ekegren  [christina.ekegren@monash.edu](mailto:christina.ekegren@monash.edu)  Rehabilitation, Ageing and Independent Living (RAIL) Research Centre, School of Primary and Allied Health Care, Monash University, 47-49 Moorooduc Highway, Frankston 3199, Australia

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09638288.2024.2341872>.

\*Emma Dorward and Alicia Devlin are joint first authors.

© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

facilitating patient participation by creating meaningful activities that reflect patient-centred goals and provide structure to daily patient routines [7,9]. *via* an in-depth survey, patients with traumatic brain injury reported safety concerns, a lack of direction, and a lack of confidence as significant barriers to participating in self-directed programs, while physiotherapists in these settings cited patients' poor motivation, fatigue, pain and cognitive impairments as the main barriers to participation [8]. Carers' and relatives' perspectives have also been sought in these studies [6,8] which have found that, while they are willing to assist with self-directed therapy, carers and relatives often lack knowledge on how best to do this [6,8].

Although these studies provide important information about how to achieve sustained participation and implementation of self-directed therapy activities as part of routine rehabilitation practice, they have all been conducted in neurological rehabilitation settings. Therefore, further knowledge is still needed about how to overcome these barriers in diagnostically diverse, *i.e.*, mixed, rehabilitation populations. While a recent study did investigate barriers and facilitators to participating in a self-directed therapy program on mixed rehabilitation wards, data were collected *via* brief free-text responses within an online survey, which did not enable an in-depth or detailed exploration of themes through guided questioning and the opportunity for participant elaboration afforded by semi-structured interviews [10].

An opportunity to conduct an in-depth qualitative investigation of the barriers and facilitators to participating in self-directed therapy programs recently arose within the conduct of a multi-site randomised controlled trial of the "My Therapy" program, which took place across several rehabilitation hospitals with a diagnostically diverse sample of patients [11]. This program was designed to encourage and enable independent practice opportunities for patients *via* provision of a set of personalised physiotherapy exercises and occupational therapy activities, prescribed in consultation with patients by physiotherapists and occupational therapists, which could be performed independently and safely outside of supervised physiotherapy and occupational therapy sessions. My Therapy has previously been shown to be safe, feasible and effective for improving rehabilitation outcomes [3,12]. With the current trend towards Australian hospitals offering home-based, in addition to inpatient rehabilitation [13], the trial took place in both home-based and inpatient wards, enabling this nested qualitative study to collect data across both settings. Therefore, the aim of this qualitative study was to investigate patients' perceptions of participating in self-directed activities, outside supervised occupational and physiotherapy, within mixed, inpatient and home-based rehabilitation settings.

## Methods

### Study design

This qualitative descriptive study was nested within a larger, stepped wedge cluster randomised trial [11]. Reporting followed the Standards for Reporting Qualitative Research (SRQR) checklist [14]. The study received multi-site approval from the Alfred Hospital Human Research Ethics Committee (HREC) (ID: 69610), with site specific approvals subsequently received from each of participating health services (Alfred Hospital, ID 758/20; Eastern Health, ID S21-004-69610; and Cabrini Health, ID 11-04-03-21).

The stepped wedge trial took place within four (two public and two private) health services in metropolitan Melbourne, Australia, and aimed to evaluate the effectiveness and cost-effectiveness of a self-directed rehabilitation program ("My

Therapy") within inpatient and home-based rehabilitation settings [11]. In previous pilot research, the My Therapy program increased the amount of occupational therapy and physiotherapy undertaken by patients undergoing hospital-based rehabilitation by 100 min per week and resulted in improved functional outcomes at discharge [3]. As part of the larger stepped wedge trial ( $n=3,200$ ), patients were provided by their treating occupational therapist and physiotherapist with a tailored, written program of activities and exercises, supported with images. Digital delivery of programs was not included in the trial. Programs were commonly a subset of physical or cognitive activities practiced in supervised therapy sessions, provided they could be completed safely and independently without supervision or assistance, and were practiced in addition to usual care. Exercises and activities were chosen by the therapist, based on patients' goals, with the patient attempting to do something every day. The program also included a feedback mechanism between therapist and patient (*e.g.*, a record of task completion), to ensure accountability, was regularly reviewed and modified by treating therapists and was documented in the medical record. Dosage was recommended by occupational therapists and physiotherapists (most commonly once or twice daily) but was ultimately patient-led. Patients' families, visitors and the ward's multi-disciplinary team were able to support participation in My Therapy by providing reminders and encouragement. Although two of the participating wards were home-based, these operated *via* a "bed-substitution" or "virtual-ward" model, with patients receiving the same level of therapist contact and oversight as if they were admitted inpatients. The only difference with this model of care was that all therapy was provided to patients within their homes.

A consumer representative with recent experience of inpatient rehabilitation was included on the steering committee from the outset of the trial. They attended quarterly steering committee meetings and responded to ad-hoc requests from investigators throughout the trial. As well as providing feedback and input on the wording and format of selected participant-facing materials, they emphasised the importance of collecting participant feedback which led to this additional nested qualitative study, completed at the end of the trial.

### Participants and recruitment

Three out of four of the health services participating in the larger trial agreed to be part of this nested qualitative study. One of these health services provided a home-based, bed-substitution rehabilitation service, with the other two providing an inpatient service. Within each health service, participants were recruited from one of two adult general inpatient or home-based rehabilitation "wards."

Potential participants were identified by site coordinators in consultation with treating occupational therapists and/or physiotherapists, being eligible for inclusion if they: (i) were aged 18+ years; and (ii) had received a My Therapy program during their rehabilitation admission on one of the participating wards. Participants were excluded if they (i) did not speak at least a conversational level of English; (ii) had difficulties with comprehension/communication; or (iii) a moderate to severe cognitive impairment. The level of cognitive impairment was determined through liaison with the treating occupational therapist, physiotherapist, and/or nurse as well as by reviewing the medical record to ascertain patients' level of cognitive impairment *via* formal test scores (commonly using the Functional Independence Measure (FIM™) [15] or the Functional Autonomy Measurement System (SMAF)) [16]. Although patients with moderate or severe cognitive impairment

were included in the larger stepped wedge trial, they were not included in this qualitative study due to the cognitively demanding nature of the interview, requiring good memory recall. It could not be ensured that a carer would be available in all circumstances to assist with responses due to the absence of a carer, unwillingness of a carer to participate, or the visitor restrictions in place within hospitals during the COVID-19 pandemic. At the time of recruitment, participants were either nearing the end of their inpatient rehabilitation admission (either inpatient or home-based) or had recently been discharged from rehabilitation care.

Initial contact with participants was made by site coordinators in-person (inpatient participants) or *via* telephone (home-based participants) to provide a verbal explanation about the research project and gain an expression of interest of involvement. Written, informed consent was subsequently obtained. Interviews were scheduled for a suitable time and conducted in-person, either on the hospital ward or in the participant's home in a suitable location for comfort and privacy. Carers (e.g., relatives or other unpaid informal carers) were also invited to participate in interviews, where approved by participants, to support their understanding or provide clarification. However, interview questions were directed at participants. Written, informed consent was also obtained from any carers present during interviews.

Purposive sampling of participants ensured diversity of age, gender, rehabilitation diagnosis and the admitting health service. The sample size was guided by the estimated information power needed to generate new knowledge with reference to the aims of the study [17]. For this study, adequate information power was determined by meeting the aims of the study, engaging people with diverse experiences and backgrounds, and employing appropriate methods of analysis, with a target of five to seven patients per health service, and their carers, where possible. The interviewers (ED, AD and FD) met fortnightly with the senior author (CE) throughout the recruitment and data collection period to ensure that the sample was inclusive of a diverse range of participants, with respect to age, gender and diagnosis. In addition, interview quality and content were discussed to establish whether interviews were covering an adequately broad and diverse range of experiences in order to address the broad aim of the study [17]. From these discussions, the authorship team were confident that the information power of the final sample was sufficient for achieving the aims of the study.

### Data collection

Semi-structured interviews were conducted in-person by the site coordinators for each of the three participating health services (ED, AD and FD) in July and August 2022. The site coordinators were experienced rehabilitation occupational therapists (AD) and physiotherapists (ED and FD) trained in qualitative research and interview techniques by SR, an experienced qualitative researcher, and CE, project manager and mixed-methods researcher. The site coordinators were provided with an interview guide ([Supplementary Material](#)) that was developed with a focus on understanding participants' perspectives of participating in self-directed therapy activities during rehabilitation, the barriers and enablers to participation and participants' opinions about the sustainability of the program post-discharge. The interview guide was developed by the whole authorship team, including the individuals employed as site coordinators on the main trial (ED, AD and FD), who were able to provide input based on their knowledge of implementing My Therapy on participating wards. The guide was then reviewed and further refined by an experienced qualitative researcher (SR) to ensure that the interview questions were worded appropriately and addressed

the aims of the study. The interview guide was not piloted with patients, family members or consumer representatives prior to data collection. All interviews were audio-recorded, uploaded to a secure database and transcribed by one of the authors (FD).

### Data analysis

Interview transcripts were analysed thematically using the Framework Method [18]. Transcribed interviews were first uploaded to NVivo 20 (QSR International, Doncaster) for analysis. Five randomly selected transcripts were then read in detail by three of the authors (ED, AD, CE) and an initial coding framework developed by each of them based on inductive coding of themes which corresponded to the aims of the study, as well as other meaningful content highlighted in the interviews. The frameworks were then pooled, reorganised, and refined by collaboration and discussion between these three authors. During this iterative process, additional themes were also identified by the authors until a working analytical framework was formed, and the remaining interview transcripts coded accordingly. This working framework underwent several iterations until the investigators were satisfied that the themes reflected the content and meaning of interviews with respect to the project aims.

Credibility and trustworthiness were achieved through multiple author discussions and feedback from the larger authorship team regarding the identified themes [19]. Researcher subjectivity was addressed by a vocationally diverse interviewing and authorship team (nursing, occupational therapy, and physiotherapy) with diverse research, clinical and health policy experience, who challenged assumptions and any bias during the analysis process [19]. Memos were recorded during data collection and analysis to support reflexivity and detailed records of coding decisions were kept [20]. Other than in their role as site coordinators, interviewers had no prior relationship with the participants or their carers.

### Results

A total of 16 interviews were conducted across three health services. The median (IQR) interview duration was 18 (13 to 22) minutes. Of the 16 participants interviewed, 10 were female and 6 were male, with a mean (SD) age of 75 (12) years, and with diverse diagnoses ([Table 1](#)). Carers were involved in three interviews. One carer was a wife, one a daughter and one a son. In two cases, the carer was living with the participant, and the other made daily visits to the participant during their inpatient stay.

Table 1. Participant characteristics ( $n=16$ ).

Characteristics	n (%)
Age group (years)	
<69	5 (31%)
70–79	6 (38%)
>79	5 (31%)
Female gender	10 (63%)
Rehabilitation setting	
Inpatient hospital	11 (69%)
Home-based	5 (31%)
Health service	
1	5 (31%)
2	7 (44%)
3	4 (25%)
Primary diagnosis	
Orthopaedic injury or surgery	7 (44%)
Deconditioning, cancer, cardiac	7 (44%)
Stroke	2 (12%)

Four main themes were identified in relation to participation in self-directed therapy activities: the role of clinicians; considerations in program delivery; patients have different driving and limiting forces; and the environment can help or hinder. From these themes 14 sub-themes were identified (Figure 1).

Within the presentation of supporting quotes, participants are identified by an identifying code (e.g., HP1, F, O), with abbreviations defined as: HP (home-based participant) or IP (inpatient participant); F (female) or M (male); O (orthopaedic injury or surgery), D (deconditioning, cancer, cardiac) or S (stroke); F (family).

**Theme 1: The role of clinicians in facilitating participation in self-directed therapy activities**

Participants spoke of the important role of clinicians in facilitating their participation in self-directed therapy activities. However, the perceived role differed across participants, with some participants requiring more direct input and supervision than others.

**Encouragement and instilling confidence**

Participants described varying levels of motivation towards completing their self-directed programs. However, they reported that receiving encouragement from clinicians to complete their self-directed programs was very motivating. It was common for participants to feel a sense of uncertainty in their own abilities following injury or illness, and therefore, it was critical that clinicians took the time to explain and reassure participants about what they were asking them to do. There was consensus amongst participants that regular and positive encouragement from clinicians improved their morale and lifted spirits.

She [the clinician] helped with his confidence... she is saying to him, yes, you have got the strength to do that. Now, I'll just show you how to do it. F2

The rehabilitation team phoned up every day to see how I was getting on ... and I thought that was fantastic, caring, actually, that really

lifted my spirits ..., what it encouraged me to, to get on and get better. HP1, F, O

Further to this, participants described the confidence they felt when clinicians encouraged them to progress the intensity of their self-directed programs. Giving participants permission to listen to their bodies and respond accordingly helped them to recognise their own abilities and how they had progressed.

She also said to don't limit yourself to this. If you feel that you've got the energy and the strength to do more, push yourself, push yourself to get stronger. HP5, M, D

Participants also appreciated other hospital staff noticing their efforts and encouraging them.

Everyone who walked into the room, coffee lady, nurse, physio [they] saw me doing my exercises and they all sort of egg you on, and say "oh you're doing it, oh good for you." So it was good to get that that sort of feedback just to keep you going. IP16, F, D

**Giving feedback**

Participants were able to describe the impact of feedback from clinicians on developing an understanding of their own performance. Regular and positive feedback appeared to help participants identify the progress they were making and, in turn, encourage them to keep going.

I mean, today, she watched me walk from one chair to another. And I did it. She goes, "Oh, that's better than yesterday." I thought wow. IP13, F, S

The physio has commented in the past, "I can see you're doing your exercises because I've seen how much you've improved." So it works. IP16, F, D

**Just "being there" and supervising**

Participants often described the advantages of a clinician's ongoing presence and supervision while they completed their

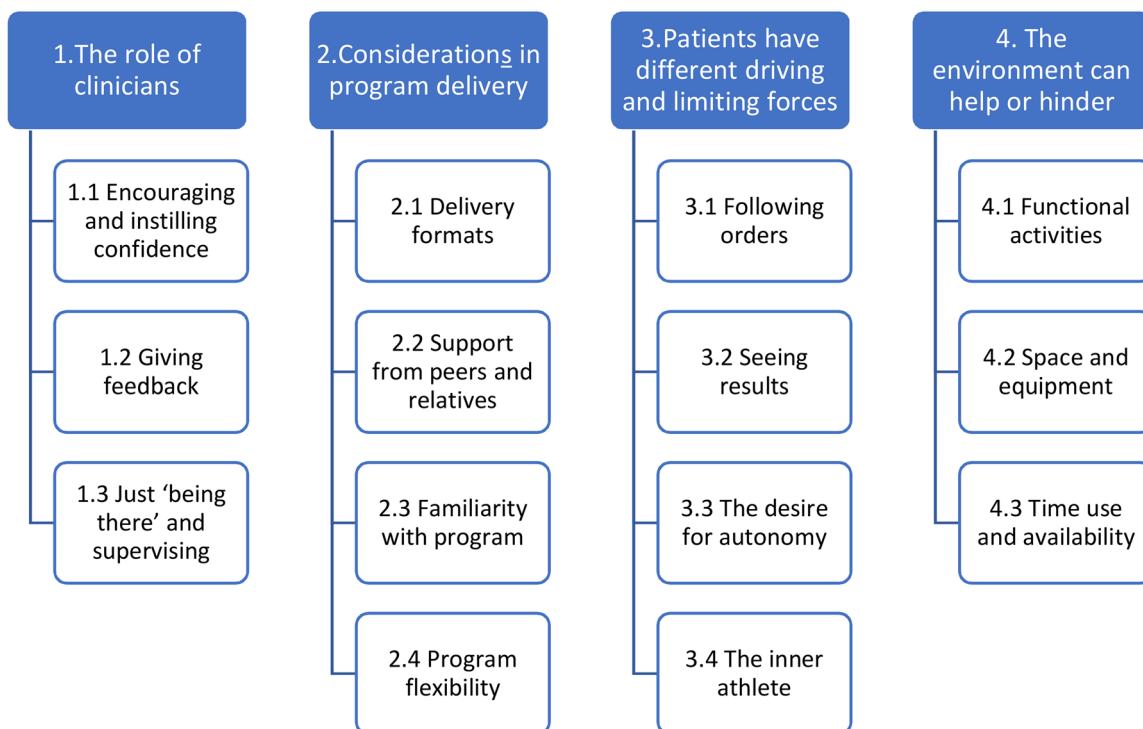


Figure 1. Overview of themes and subthemes.

programs, reporting that the presence of clinicians helped in building accountability and consistency with participation in their program.

I think it's easier when there's someone watching you... I think you try harder if somebody's watching it. HP3, F, O

I'm not the type of person that's got a great initiative to do things on my own... Because you know, if no one's there watching you, you can sort of just give into it. But someone there, wow that's another thing. IP15, F, O

## **Theme 2: Considerations for program delivery to optimise participation in self-directed therapy activities**

Participants provided valuable feedback about how self-directed therapy programs should be delivered to optimise adherence. These considerations included the practical aspects of how the program was physically delivered, the support provided, and the tailoring offered.

### **Program delivery formats**

Although some participants reported not relying on a written copy of their program, several described the advantages of having clear, written instructions, and easy-to-follow diagrams. Only one participant requested the programs be emailed to them in electronic format. Handouts with clear and succinct instructions supported with simple diagrams were praised by participants and appeared to increase adherence to their programs.

If I've got instructions in front of me, I just follow them. IP13, F, S

I thought the instructions were very good. You got a diagram from the start and then the aim of it what it was... I thought it's self-explanatory and very clear. IP9, M, O

Although inclusion of a self-report completion record was a core feature of the My Therapy program, few participants commented on this. However, one participant was able to describe how reassuring it was to reflect on their completion records and identify that their activity levels reflected treatment cycles.

And of course, it clearly showed that the days after my chemotherapy, I did less. Which was good for me to see as well. IP16, F, D

### **Enlisting support from peers and relatives**

Participants and carers recognised the importance of relatives in encouraging program participation, both in hospital and after being discharged home from hospital.

Oh they do remind when we're in therapy, don't forget when you're in your chair, you can do this, this and this. And we remind mum when we come with both my daughter and myself. F3

My partner will be there. And don't you worry. He'll make me do them. IP6, F, D

Participants also found the presence of patient peers motivating.

[Patient's name] next door ... she's got MS. She can do it and so can I. So we did it. IP13, F, S

However, other participants perceived unwanted pressure and judgment from staff and peers if privacy wasn't afforded.

No I did it on my own with the curtain closed so no one can see me... I didn't want to make a fool of myself saying you're doing that wrong, because everyone's different. IP16, F, D

### **Familiarity with the program**

Participants consistently commented on the advantages of having a consistent and familiar program to follow. Not only could they describe the importance of knowing what to do, it was clear that having confidence that what they were doing was correct yielded a more positive association with the program. None of the participants in the study reported a sense of boredom or lack of challenge from consistency in programs. Instead, the consistency in activities and exercises helped to diminish some barriers to participating, as the program seemed to get easier.

Good familiarity helps. When you know what you have to do, then it's better. IP14, F, S

If you know what you're doing? Yeah, that's the important thing. IP11, F, D

It was common for participants to value completing the exercise with the clinician initially within a supervised session, as this built awareness and confidence in their own skills and ability to complete their program independently.

She spoke to me and then showed me what to do. I thought okay, go and go. I could do it. IP13, F, S

### **Program flexibility**

Although some participants preferred to be directed by clinicians, there were many participants and carers who recognised and valued the autonomy they were given regarding program completion. Participants most appreciated the ability to control which activities were completed and how many times per day. Participants valued the opportunity to make these decisions without judgment or criticism and felt supported if variability in participation occurred across days or the week, based on how they were feeling.

Certainly, with the My Therapy program, I can pick and choose what I want to do. IP9, M, O

And I particularly like that there's no pressure and no judgement. So, if you have an off day and you only do one exercise instead of five, then that's okay. IP16, F, D

Yes, you could easily alter it. And I think that it's a good program. Because it's flexible. HP5, M, D

Some participants could recognise their involvement in the process of planning their self-directed programs, a key value underpinning program development.

She just asked. So, what are you wanting? What do you want to achieve next? And then she'd build it into the program. HP5, M, D

## **Theme 3: Patients have different driving and limiting forces relating to self-directed therapy activities**

Participants spoke about a range of intrinsic, or personal, factors that either motivated them to complete their programs, or limited their completion. Often participants linked these driving forces to pre-existing personality traits, values, or goals.

### **Following orders**

Some participants were compelled to complete their self-directed programs because of a sense of duty or a desire to follow the orders of their clinicians. These participants described having faith in the expertise of the clinician. With this faith came a clear belief

that the specifically designed programs posed no risk and hence, there was no reason to not adhere to the instruction given. Generally, participants were comforted by the expertise of the clinicians, stating that they were “qualified” to prescribe effective, safe programs and make appropriate decisions regarding their individual’s needs, capacities, and limitations.

Coming to rehab I’ve got to just do what they asked me to do. Otherwise, what’s the purpose? IP15, F, O

I think if there were any risks, they wouldn’t give them to me and I can always stop... I follow their lead and I do what they say unless, again, I can’t... They know what they’re doing. I don’t. IP6, F, D

There was also recognition of the importance of the patient understanding the need for safety and that there was a level of responsibility on the patient to obey the instructions provided and not deviate from these. Hence, knowing and working within their own limits and capacities was important both from a benefit and safety perspective.

I suppose there’s always a risk of falling or over balancing in some way... But also, if there’s a team behind them, a physio team, that they’ve provided sufficient information or understanding to the person too. IP12, F, D

### *Seeing results and achieving goals*

Making progress and seeing results was a strong motivator for participants in completing their self-directed programs. A commonly held goal was returning to what was perceived to be their “normal” and getting back to their “old self.” These goals were also reiterated by the carers that were present at the time of interview. With these goals in sight, some described no requirement for extra encouragement to complete programs regularly, as these goals were enough.

It makes me feel good because I’m actually doing something that’s going to help me get better. And then get back to work. Or go for a run or whatever. HP2, M, O

Quicker I do, the quicker I go. IP14, F, S

In particular, participants spoke about wanting to get home from hospital, returning to their premorbid functional level and being independent in managing activities of daily living in the household

I have a dog. I cannot wait to get my hands [on] him... Get the coffee and half hour back again, that sort of walk, and I’ve got neighbours and friends who will come and do some gardening. We all potter around in the garden together. IP12, F, D

Some participants also spoke about making physical gains, including building muscle strength and improving mobility. There was also a general feeling that the more exercise you did, the more you improved. Improvement was seen as proportional to the amount of time spent doing exercises and activities as prescribed.

I’m finding it helps me. It’s making me stronger. So that makes me want to do it. IP6, F, D

The benefits are that you recover a lot quicker, quicker. You build up muscles. Or get things moving a lot quicker than you would if you didn’t. IP16, F, D

Many participants recognised their progress when they discovered that the exercises and activities were becoming easier, and therefore, that their program was becoming more challenging, described as “it grew with me.”

In the beginning, some of the exercises were very hard because of the muscle wastage... As you progress, you could see, you’re progressing too... I couldn’t do that, three days ago, or I couldn’t do that last week... And as I got stronger, there were more strenuous exercises added to it. So, it grew with me. IP16, F, D

### *The desire for autonomy*

Some participants were driven to complete their self-directed programs because of their desire for autonomy, underpinned by self-reliance, an inherent determination and self-motivation. Often these character traits were described as being part of who they were before their rehabilitation admission. Participants used words such as “head-strong” and “mindset” when describing their personalities. There were many aspects of the desire for autonomy that overlapped with the desire to be at home and be independent.

If you don’t help yourself, nobody can do it for you... you really do need to have that, that something in you that says, “Come on.” IP16, F, D

I think it’s all based at the individual. If you don’t make the effort, it doesn’t matter how many people are around you, they’re not going to be really helpful. IP10, M, D

Another viewpoint was an almost defiant independence.

I’ll do it myself and show them, prove them wrong. I don’t need you; I’ll do it myself. IP13, F, S

I’ve told myself to be strong and just do it. IP13, F, S

### *The inner athlete*

The term “inner athlete” has been coined previously [21] and here, describes people with past experience of and a level of knowledge in exercise, health and fitness. Pre-existing exercise habits, enjoyment of exercise regimes and a commitment to a pre-existing program were important factors in adherence to the self-directed therapy program. The overarching theme was the belief that “inner athlete” traits would result in progress and desired outcomes.

Prior to all of this, I was doing exercise classes and physically moving around. So, it wasn’t new to me and it was comfortable. IP12, F, D

I don’t need a prompt to do that... I just do them anyway. I’m used to walking and I do exercises anyway. It was a real shock to me to have something like this occur, and to be thwarted in being able to do exercise. HP1, F, O

Those who described “inner athlete” qualities also seemed to encompass the long-term view of management over short term gains to live a “useful, healthy life.”

It’s like a model car that has to be in for service. The body is the same. You have to keep on working on it. You know, it doesn’t work otherwise. I think, it’s something that should be taught much more, the very thought of doing exercises as a living part of you. I think that is the important part. That should be instilled into people. IP11, F, D

and

With absolute conviction... I think it’s a thing that you have to do all your life. But particularly, when as you get older, it’s even more important. For rehabilitation, for doing anything and everything, being active and independent. IP11, F, D

### *Theme 4: The environment can help or hinder participation in self-directed therapy activities*

The final theme centred on how the environment can help or hinder participation in self-directed therapy activities. The five participants who had received rehabilitation in the home,

highlighted different environmental influences than those who had received rehabilitation as inpatients.

#### **Functional activities within a self-directed therapy program**

Participants who received their rehabilitation (and their self-directed programs) in their own homes spoke about being able to integrate daily activities into their programs. For these individuals, practicalities and functional tasks made up a large proportion of their self-directed programs. Activities such as stair climbing became more than just a repetitive exercise, as did kitchen, bathroom and laundry-based activities.

The stair exercise is to get up there. It's not just an exercise. HP3, F, O

He's actually doing movements that he's going to need for day to day... It's more important that you can actually do things at home, like get around, do normal tasks. F2

One carer (daughter) spoke about the lack of opportunity for functional activities in the hospital, because of hospital-based carers and nurses not having the time to assist with mobility.

The idea is to have her ready for coming home and ready for coming home is number one walking and number two going to the bathroom more... It's just a matter of, you need to walk, you need to stand, it's good for your body and strengthens your upper body and your lower body to be able to go and then your body functions better with going to the toilet too you because you're actually physically walking, and that's exercise too... I know they don't have time. And that's why my daughter and I come so much. F3

#### **Space and equipment**

Space and access to equipment was seen as an important factor facilitating program adherence. Some home-based participants felt like they weren't able to do their exercises properly at home, without specialised equipment.

You don't really feel like you're doing [the exercises] so much when you're holding on to the kitchen bench HP3, F, O

However, others, considering the transition to home, recognised that they wouldn't need specialised equipment in order to continue their self-directed program post-discharge.

No, I can't think of anything that I have at home that I don't have here. Really, I mean, all you need is a chair and some time. IP16, F, D

#### **Time use and availability**

For many participants, completing a self-directed therapy program was seen as an opportunity to fill their time, structure their day and alleviate moments of boredom. This was particularly true for those participants who had a greater level of functional independence, whether they were in the hospital or at home.

I think you just do it. Because while you're in here, you want something to do. And this is gives you the opportunity to do something. IP10, M, D

It gives me structure. It gives me a goal. I know that at a certain point in the morning, in the afternoon, I just need to do these exercises. It gives me structure, fills your time. HP2, M, O

Rehabilitation inpatients recognised the need to work around their scheduled time in supervised therapy sessions, needing to scale up or down the time attributed to their self-directed programs.

For three days, I did every exercise. But I scaled them down after the first two because then I was having physio twice a day with the physios. I still walk around the ward when I've got free time. IP9, M, O

## **Discussion**

This study has highlighted patients' perceptions of engaging in a self-directed therapy program within rehabilitation settings. Overall, patients understood the value of completing self-directed programs, in addition to supervised therapy, for improving outcomes and resuming previous activities. Patients perceived that clinicians had an important role in supporting their participation, by instilling confidence along with providing encouragement and feedback. Equally important was the benefit of the clinician "just being there." With respect to program delivery, programs that were familiar and adaptable to the patient were favoured, as were clear, written instructions. The important role of patient peers, carers, family and visitors in assisting and supporting practice was also highlighted. Patients' intrinsic driving and limiting factors were diverse, ranging from just following orders to desiring autonomy. More engaged patients displayed "inner athlete" qualities stemming from knowledge, their background, and an inbuilt belief system in the benefits of self-directed activity. Functional activities that could be easily integrated into daily routines were favoured and environmental factors such as space, equipment, and time availability were also considered important.

High levels of patient motivation have previously been reported as a pre-cursor to engagement in self-directed therapy programs, with staff perceiving low intrinsic motivation levels as a significant barrier [10]. Although patients' prior knowledge, experience and beliefs may considerably influence their level of motivation, findings from this study suggest that clinicians can be highly influential in building patients' motivation. For example, encouraging patient autonomy, providing program flexibility, recognising improvement, integrating everyday activities into programs, and specifically linking programs to client-focused goals can help build individual motivation towards a self-directed program. In addition to motivation, self-confidence has been shown to be a key factor facilitating patients' participation in self-directed therapy. Similar to previous studies, participants in this study described the direct impact that clinicians could have on increasing their confidence levels, *via* clear instructions, feedback, encouragement and regular program reviews, further reinforcing the vital role clinicians have in supporting patients to engage in self-directed practice [5,8].

The ward environment has previously been found to influence opportunities for additional self-directed therapy within inpatient rehabilitation settings [7,10]. Specifically, Janssen et al. found that orienting patients to places on the ward where they could complete their self-directed activities was critical to their confidence in engaging in these activities [7]. This factor should be considered for future implementation of self-directed therapy activities in inpatient settings. In our study, the increased opportunity to integrate routine activities into My Therapy self-directed programs was acknowledged as an advantage for participants completing the program in their home environment. However, previous research has found that adherence to exercise programs is generally higher in supervised settings [22]. Therefore, it is important to ensure that adequate monitoring, oversight and encouragement is given to patients outside supervised inpatient settings. With regard to the presence of others on the ward we found diversity of opinion amongst participants, with some preferring privacy to complete their programs and others responding more positively to the presence of patient peers and staff. In previous studies, support from family has also been reported as critical in facilitating adherence to self-directed rehabilitation activities and, for patients in the home setting, the presence of family could be considered another important facilitator of adherence [7,8].

However, it is recommended that if families are to be involved in this way, that they should be provided with training to improve their confidence in assisting their relatives to complete activities safely [8].

Our aim was to explore the perspectives of a diverse group of patients receiving rehabilitation *via* in-depth semi-structured interviews. Compared to a previous study on this topic using an online survey [10], this approach allowed for a deeper exploration and understanding of both positive and negative experiences of engaging in a self-directed therapy program within rehabilitation settings. Overall, the sample recruited for this nested qualitative study was representative of the sample in the main clinical trial, being two-thirds female, primarily aged between 70 and 79 years, with slightly more participants admitted under a home-based model of rehabilitation (25% vs ~10%) and similar proportions of participants with orthopaedic conditions and stroke. Nonetheless, there were certain patient types who were absent from our evaluation. Specifically, because we only recruited participants who had been provided with a self-directed therapy program, the perspectives of patients who were not provided with programs were not captured. This could be beneficial to explore in future research, in order to understand barriers to program prescription. Although we did not exclude patients with mild cognitive impairment, participants in this study did not have any cognitive deficits. This may indicate that therapists are more cautious when considering provision of self-directed programs to patients with any level of cognitive impairment. Furthermore, given the exclusion of patients with moderate to severe cognitive impairment, our findings do not represent the views of this group. Due to their unique needs, future research should seek to understand the perspectives of this group, and their carers. Similarly, patients with a non-English speaking background were also not represented in this study. This warrants further exploration to ensure findings are representative of usual rehabilitation cohorts. It would have also been beneficial to collect quantitative data on participants' adherence to their programs (e.g., daily duration of self-practice), and compare this to the larger trial cohort, in order to understand whether this was a more or less participatory group. Additionally, in future studies, further exploration of carers' perspectives would provide deeper insights on how carers can be engaged to support self-directed therapy activities. However, it is also suggested that carers and patients be interviewed separately to avoid their potential influence on each other when responding to questions.

There are several implications of our findings for clinical practice in rehabilitation settings. Although literature consistently supports the need for patient autonomy and independence to facilitate participation in self-directed therapy activities [5,7,10], this study reinforces that patients continue to recognise the vital role clinicians have in supporting them to develop these attributes. Given the diversity of driving forces amongst participants in this study, it is important that therapists seek to understand patients' individual strengths and motivating factors to ensure that program delivery is suitable for individual needs. Clinicians should be encouraged to explore individual preferences, such as environmental conditions, feedback mechanisms and the level of carer engagement desired. This is consistent with the philosophy of person centredness in rehabilitation [9], which can be fostered *via* collaborative goal setting to ensure rehabilitation activities are meaningful to patients. Further to this, our findings indicate that programs that are familiar to patients, are clearly delivered, provided in a range of appropriate formats are likely to lead to successful uptake of self-directed rehabilitation programs.

## Conclusions

Patients reported positive experiences of participating in self-directed therapy programs within inpatient and home-based rehabilitation settings, with programs perceived as beneficial in optimising recovery. Patients reported a range of driving and limiting factors in relation to completing self-directed activities. Understanding these factors, relating to the patient, their environment and other people, is critical for clinicians so that they can modify their delivery accordingly, ensuring uptake and sustained implementation of self-directed activities in rehabilitation care.

## Acknowledgments

We gratefully acknowledge the participants of this research and clinicians from Alfred Health, Cabrini Health and Eastern Health for their participation and assistance. We acknowledge the My Therapy Steering Committee, including consumer representative, Mr. Vince Rovtar, in contributing to the clinical trial of My Therapy.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

The clinical trial of My Therapy was funded by a National Health and Medical Research Council (NHMRC) Partnership Grant (NHMRC Partnership Grant APP1191881). In addition, each of the three participating health services (Alfred Health, Cabrini Health and Eastern Health) made cash and in-kind contributions.

## ORCID

Emma Dorward  <http://orcid.org/0009-0005-5513-6487>  
 Natasha K. Brusco  <http://orcid.org/0000-0002-8825-5109>  
 Sara L. Whittaker  <http://orcid.org/0000-0001-7002-185X>  
 Sandra Reeder  <http://orcid.org/0000-0001-7942-0179>  
 Christina L. Ekegren  <http://orcid.org/0000-0002-7656-6209>

## References

- [1] Peiris CL, Shields N, Brusco NK, et al. Additional physical therapy services reduce length of stay and improve health outcomes in people with acute and subacute conditions: an updated systematic review and meta-analysis. *Arch Phys Med Rehabil*. 2018;99(11):2299–2312. doi:10.1016/j.apmr.2018.03.005.
- [2] Foley N, McClure JA, Meyer M, et al. Inpatient rehabilitation following stroke: amount of therapy received and associations with functional recovery. *Disabil Rehabil*. 2012;34(25):2132–2138. doi:10.3109/09638288.2012.676145.
- [3] Brusco NK, Tilley L, Walpole B, et al. Feasibility of increasing the dosage of inpatient occupational therapy and physiotherapy rehabilitation via independent tasks and exercises: 'My therapy'. *Aust Occup Ther J*. 2019;66(6):739–752. doi:10.1111/1440-1630.12614.
- [4] Harris JE, Eng JJ, Miller WC, et al. A self-administered graded repetitive arm supplementary program (GRASP) improves arm function during inpatient stroke rehabilitation: a multi-site randomized controlled trial. *Stroke*. 2009;40(6):2123–2128. doi:10.1161/STROKEAHA.108.544585.

- [5] Chin LF, Rosbergen ICM, Hayward KS, et al. A self-directed upper limb program during early post-stroke rehabilitation: a qualitative study of the perspective of nurses, therapists and stroke survivors. *PLoS One*. 2022;17(2):e0263413. doi:10.1371/journal.pone.0263413.
- [6] Eng XW, Brauer SG, Kuys SS, et al. Factors affecting the ability of the stroke survivor to drive their own recovery outside of therapy during inpatient stroke rehabilitation. *Stroke Res Treat*. 2014;2014:626538. doi:10.1155/2014/626538.
- [7] Janssen H, Bird ML, Luker J, et al. Stroke survivors' perceptions of the factors that influence engagement in activity outside dedicated therapy sessions in a rehabilitation unit: a qualitative study. *Clin Rehabil*. 2022;36(6):822–830. doi:10.1177/02692155221087424.
- [8] Leung J, Fereday S, Sticpewich B, et al. Extra practice outside therapy sessions to maximize training opportunity during inpatient rehabilitation after traumatic brain injury. *Brain Inj*. 2018;32(7):915–925. doi:10.1080/02699052.2018.1469046.
- [9] Last N, Packham TL, Gewurtz RE, et al. Exploring patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation. *Disabil Rehabil*. 2022;44(16):4201–4210. doi:10.1080/09638288.2021.1881830.
- [10] Brusco NK, Walpole B, Kugler H, et al. Barriers and facilitators to implementing self-directed therapy activities in inpatient rehabilitation settings. *Aust Occup Ther J*. 2023;70(5):617–626. doi:10.1111/1440-1630.12891.
- [11] Brusco NK, Ekegren CL, Taylor NF, et al. Self-managed occupational therapy and physiotherapy for adults receiving inpatient rehabilitation ('My Therapy'): protocol for a stepped-wedge cluster randomised trial. *BMC Health Serv Res*. 2021;21(1):977. doi:10.1186/s12913-021-07002-1.
- [12] Brusco NK, Kugler H, Dulfer F, et al. Including exercise self-management as part of inpatient rehabilitation is feasible, safe and effective for patients with cognitive impairment. *J Rehabil Med - Clinical Communications*. 2022;5:1000076.
- [13] Poulos RG, Cole AM, Warner KN, et al. Developing a model for rehabilitation in the home as hospital substitution for patients requiring reconditioning: a Delphi survey in Australia. *BMC Health Serv Res*. 2023;23(1):113. doi:10.1186/s12913-023-09068-5.
- [14] O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245–1251. doi:10.1097/ACM.0000000000000388.
- [15] Hamilton B, Laughlin J, Granger C, et al. Interrater agreement of the seven-level functional independence measure (FIM). *Arch Phys Med Rehabil*. 1991;72:790.
- [16] Hebert R, Carrier R, Bilodeau A. The functional autonomy measurement system (SMAF): description and validation of an instrument for the measurement of handicaps. *Age Ageing*. 1988;17(5):293–302. doi:10.1093/ageing/17.5.293.
- [17] Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26(13):1753–1760. doi:10.1177/1049732315617444.
- [18] Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13(1):117. doi:10.1186/1471-2288-13-117.
- [19] Hall WA, Long B, Bermbach N, et al. Qualitative teamwork issues and strategies: coordination through mutual adjustment. *Qual Health Res*. 2005;15(3):394–410. doi:10.1177/1049732304272015.
- [20] Creswell J. editor. *Qualitative inquiry & research design: choosing among five approaches*. Thousand Oaks (CA): Sage Publications; 2007.
- [21] Lorenz LS, Charrette AL, O'Neil-Pirozzi TM, et al. Healthy body, healthy mind: a mixed methods study of outcomes, barriers and supports for exercise by people who have chronic moderate-to-severe acquired brain injury. *Disabil Health J*. 2018;11(1):70–78. doi:10.1016/j.dhjo.2017.08.005.
- [22] Picorelli AM, Pereira LS, Pereira DS, et al. Adherence to exercise programs for older people is influenced by program characteristics and personal factors: a systematic review. *J Physiother*. 2014;60(3):151–156. doi:10.1016/j.jphys.2014.06.012.