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# 'Is my journey destination home?' Exploring the experiences of older adults who undertake a transition care programme: a qualitative study

Jo-Aine Hang<sup>1\*</sup> , Jacqueline Francis-Coad<sup>1</sup> , Portia Ho<sup>2</sup>, Nicholas Waldron<sup>1,3</sup>, Kate Purslowe<sup>4</sup> and Anne-Marie Hill<sup>1</sup>

<sup>1</sup>Curtin School of Allied Health, Curtin University, Perth, Western Australia, Australia, <sup>2</sup>Rocky Bay, Mosman Park, Western Australia, Australia, <sup>3</sup>Department of Aged Care and Rehabilitation, Armadale Kelmscott Memorial Hospital, East Metropolitan Health Service, Armadale, Western Australia, Australia and <sup>4</sup>Amana Living Inc., Perth, Western Australia, Australia

\*Corresponding author. Email: [jo-aine.hang@postgrad.curtin.edu.au](mailto:jo-aine.hang@postgrad.curtin.edu.au)

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## Abstract

Transition care programmes (TCP) provide older adults with goal-oriented rehabilitation after hospitalisation. However, limited research has focused on understanding older adults' experiences when undertaking TCP. Using a phenomenological approach, we explored the lived experience of older adults undertaking a TCP at a transition care facility in Australia. A purposive sample ( $N = 33$  participants: 16 older adults, four family members and 13 staff) was recruited. Semi-structured interviews were undertaken at three time-points during admission and inductive thematic analysis was utilised. Older adults reflected on their TCP experiences through an emotional lens through which they deliberated, 'is my destination home?' Fear of losing independence and uncertainty about their discharge destination strongly influenced older adults' perspectives regarding their TCP experience. Emotional responses, both positive and negative, were influenced by expectations prior to admission, level of family support and staff behaviour. Staff and family concurred that many older adults were confused about their admission to the facility and initially were unprepared to engage in the rehabilitation provided. Older adults experienced TCP as a time of great uncertainty and feared the unknown when discharged from hospital to transition care. They expressed grief at the loss of existing life roles and anxiety about the possibility of being unable to return home. Health professionals need to inform and tailor rehabilitation for older adults to better support this transient time of life.

**Keywords:** aged; continuity of patient care; intermediate care; qualitative research

## Introduction

Rehabilitation programmes for older adults who are discharged from hospital now include short-term goal-orientated programmes to facilitate successful transition

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from hospital to home, such as 'transition care' (TC) and intermediate care (IC) (Young *et al.*, 2015; Australian Government Department of Health, 2019; Sezgin *et al.*, 2020). Transition care programmes (TCP) aim to maximise older adults' independence and improve the likelihood of discharge home so they can return to independent living in the community, prevent hospital readmissions and, where appropriate, provide rehabilitation prior to the older adult entering residential care.

A recent review of TCP (both community and facility-based settings in the United Kingdom (UK)) suggested that programmes improved older adults' functional ability and reduced hospital admissions, but found limited evidence about whether these programmes reduced institutionalisation and improved quality of life (Sezgin *et al.*, 2020). Rehabilitation principles identify that it is important for patients to be actively engaged in their rehabilitation. Establishing two-way communication with patients to understand their perspective and take their preferences into account can assist to create collaborative and effective rehabilitation (Lequerica *et al.*, 2008; Bernhardsson *et al.*, 2019). Older adults are more likely to engage in rehabilitation if it is meaningful to them and they understand its benefits, as the level of functional recovery they achieve can significantly impact their discharge destination (Jette *et al.*, 2003; Lequerica *et al.*, 2008).

Limited research has explored older adults' experiences when undertaking TCP. Qualitative research in the United States of America (USA) suggests that lack of clear information and understanding of the services offered, previous negative experiences, rushed decision making and not knowing where to get assistance may mean older adults and their families feel unwilling or unprepared to undertake TCP (Topaz *et al.*, 2015; Sefcik *et al.*, 2017). A study in two IC units in Denmark explored the experiences of older adults who were admitted to IC prior to being prepared for discharge home (Martinsen *et al.*, 2015). These older adults generally reported positive experiences including feeling that staff interactions were supportive and the IC environment was enabling (Martinsen *et al.*, 2015). However, a national review of IC services in the UK identified that aspects of some older adults' experiences were less than adequate, including their involvement in goal planning and decision making (Young *et al.*, 2015). Older adults' experience of health-care services was thus identified as an area for improvement (Young *et al.*, 2015). Understanding older adults' perspectives has the potential to increase the effectiveness of the rehabilitation provided and consequently improve outcomes.

The objective of the study was to explore the lived experience of older adults undertaking a TCP at a TC facility in Western Australia. Findings from the study aimed to inform the design and development of patient education materials that could assist older adults and their families preparing to undertake and navigate TC.

## Methods

### *Ethical considerations*

Ethical approvals were obtained from the Human Research Ethics Committee of an Australian university (Curtin University) and from the aged care organisation (Amana Living Inc.) providing the TCP. All participants either provided written, informed consent or written informed consent was provided by the next-of-kin or legal guardian for participants who did not have the capacity to provide consent.

### **Design**

The study took a descriptive phenomenological approach to explore and understand the lived experiences of older adults undertaking a TCP (Liamputpong, 2013; Matua and Van Der Wal, 2015). Descriptive phenomenology emphasises gaining knowledge through direct exploration of a person's experiences and focuses on describing the first-hand experience being investigated. Participants were interviewed at three time-points to capture a rich understanding of their TCP experiences, exploring their rehabilitation journey at admission through recovery phases and when preparing for eventual discharge. Bracketing is an important component in this approach so that the researcher's pre-understandings are put aside to provide an analysis that faithfully describes, and raises awareness of, the everyday experience of the participants (Matua and Van Der Wal, 2015). Adopting this approach allowed researchers to gain a rich and true understanding of older adults' experiences of TCP (Liamputpong, 2013; Matua and Van Der Wal, 2015). Hence phenomenology is useful for clinical researchers to gain knowledge of the participant's experiences in a health context, as these experiences can guide and inform clinical practice.

### **Participants and setting**

A purposive sample of participants (older adults ( $N = 16$ ) and family members ( $N = 4$ ) nominated by older adults) were recruited within a week of admission at a TC facility in Western Australia from March to September 2020. Recruitment strategies included advertisement flyers being disseminated at the TC facility and the referring hospital with potential participants being invited to contact the researcher either via email or telephone. Inclusion criteria for older adults were being aged 60 years and above, able to communicate and undertake an interview without the need of an interpreter, and either providing written, informed consent or having a family member or legal guardian able to provide written, informed consent (for older adults with a Mini-Mental State Examination (MMSE) score less than 23/30) (Folstein *et al.*, 1975). All older adults admitted to the facility were screened on admission using MMSE. For any older adults who expressed an interest in taking part in the study but who had scored less than 23/30, the researcher approached their next of kin to have a joint discussion regarding the study and for the family member, with the agreement of the older adult, to provide written, informed consent. Older adults who were admitted to the facility for respite care or who were not actively participating in the rehabilitation programme or were there for less than two weeks were excluded. Inclusion criteria for family members were being aged 18 years and above, able to provide written consent, and able to understand and communicate in English throughout the interview without the need of an interpreter.

Staff ( $N = 11$ ) working at the TC facility and two off-site health professionals who had experience referring older adults into TCP from hospital were also invited to participate. Inclusion criteria for TCP staff and off-site hospital health professionals were being aged 18 years and above, working at the designated TC facility for a minimum of three months or had experience of referring older adults to TCP, and able to provide written consent. Sampling family and health professionals' experiences in TCP as well as the older adults assisted the researchers in gaining

rich and in-depth information from multiple perspectives (Patton, 2002; Liamputpong, 2013).

### **Data collection procedure**

#### *Interview*

Semi-structured face-to-face interviews were conducted in a quiet, private room at the TC facility with the individual participant and the primary researcher (JAH). Some interviews were also conducted through individual telephone calls due to COVID-19 restriction of access to the facility between March and June 2020. All older adults completed three interviews. Nine older adults completed all three interviews face-to-face, while seven older adults completed some interviews online or via telephone. In this sub-group of participants, one completed all three interviews online, while the remaining six had at least one face-to-face interview with others online or via telephone. The therapy assistants at the facility set up either an online video call or telephone call making sure the older adult was seated comfortably in a quiet room with a drink and call bell within reach, before leaving them to talk with the researcher (JAH). Each interview lasted approximately 30–45 minutes and was audio-recorded on an external recording device. The researcher (JAH) made journal notes during the interview, including observations of the participant's body language, gestures and non-verbal expressions. Older adults were interviewed at three time-points (initial, mid-way and one week prior to discharge) during their admission and family members were interviewed at two time-points (at admission and one week prior to discharge). TC staff were interviewed twice (approximately eight weeks apart) and off-site health professionals were interviewed once. The full interview schedule for all participants is presented in Table S1 in the online supplementary material.

#### *Topic guide*

The semi-structured interview guide contained open-ended, non-directive questions and was piloted to explicitly ascertain any sensitive content or topics of potential bias for removal. The researchers made minor adjustments to the interview guide after piloting, to make the questions clearer and easier to understand. Guiding questions and interview procedure were constructed to explore in depth participants' understanding and awareness of TCP, their expectations about undertaking TCP and their thoughts and feelings throughout the TCP journey. The interview guides are presented in Tables S2–S5 in the online supplementary material.

The nature of qualitative enquiry itself makes it subject to the influence of a researcher's prior assumptions and experiences (Liamputpong, 2013; Creswell, 2014). Reflexivity was undertaken by the primary researcher (JAH), a female physiotherapist with five years of gerontological experience in both clinical and research settings. Although the researcher had an awareness of TC settings through her experience as a physiotherapist, she had not worked at the participating TC facility and thus had no prior relationship with the participants. The researcher kept a journal enabling her to remain engaged in critical self-awareness throughout the research process. Employing the concept of bracketing assisted the researcher to set aside her pre-conceived beliefs and biases to uncover the essence of the

phenomenon being studied and retain the authenticity of the participants' lived experience (Liamputpong, 2013; Creswell, 2014). An audit trail was constructed to demonstrate dependability, by clearly detailing all aspects of the research process. Member checking was conducted with two to three participants after each round of interviews to strengthen the credibility of the study. The combination of these processes aimed to enhance the trustworthiness of the findings (Liamputpong, 2013; Creswell, 2014).

### **Data analysis**

Each interview audio was listened to multiple times and was transcribed verbatim by the primary researcher (JAH) to familiarise herself with the data. This assisted in gaining an accurate understanding of participants' experiences and added credibility to the results (Liamputpong, 2013). The software package QSR NVivo 12 for Windows (NVivo qualitative data analysis software, version 12, 2021, QSR International, Melbourne) was utilised to manage the data and to explore codes and patterns across the dataset. The consolidated criteria for reporting qualitative research (COREQ) guidelines were adhered to when designing and conducting the study and reporting the findings (Tong *et al.*, 2007). This aimed to improve research rigour and ensure comprehensiveness and credibility of the interviews while promoting transparency in reporting among researchers (Tong *et al.*, 2007).

Thematic analysis using an inductive approach generated themes from the 'bottom up' and identified patterns which are linked to the data collected (Braun and Clarke, 2013). Three researchers coded and examined the data independently for each interview group with the primary researcher (JAH) coding all interviews, a second researcher (PH) coding family members' interviews, with a third researcher (JFC) coding staff, older adults and off-site health professionals' interviews. The researchers conferred back and forth through the data coding as a method of triangulation that aimed to strengthen the analysis. Keywords were identified from the data and codes were grouped into categories. Two researchers (JAH, JFC) continuously explored new categories and examined patterns in the interview data with the aim of gaining a rich description that included all perspectives. Data collection ceased upon saturation as confirmed through consensus by all three researchers having reviewed the data to ascertain that sufficient information had been obtained, with no new identified codes or themes emerging (Liamputpong, 2013).

The researchers developed candidate themes and examined whether all the data pertaining to the codes were able to be allocated into these themes. The first researcher (JAH) compared her initial findings with the two other researchers (JFC, PH) and a fourth researcher (AMH) who was an experienced senior researcher in gerontology reviewed the candidate themes (Creswell, 2014). Themes were then examined and refined to ensure each theme represented the data collected to create an initial thematic map to assist in conceptualising the findings. The thematic map was further refined by all researchers to ensure it reflected the overall findings of the data collected. Finally, accuracy of findings was assessed using the study objective, with researchers identifying an overarching theme; this assisted in answering the research question:

- What is the lived experience of older adults undertaking facility-based TCP?

## Results

There were 33 participants (16 older adults, four family members, 11 TC staff and two hospital health professionals) who completed the interviews. All participants provided written, informed consent, other than one participant who had an MMSE score of 22/30. This participant provided informed consent alongside their next of kin who provided written, informed consent. Two TC staff did not complete the second interview as both resigned from the TC facility during the study period. The mean age of the older adults was 80.6 years (standard deviation = 9.48), half were female (N = 8, 50%) and the predominant admission diagnosis was orthopaedic (N = 13, 81.3%). The majority of TC staff (N = 9, 81.2%) had worked in TC for more than 30 months. Characteristics of the study sample are presented in Table S6 in the online supplementary material.

### ***Overarching theme: 'Is my journey destination home?'***

Older adults in this study described their transition experience from hospital, through TCP and subsequently to home or permanent residential aged care (RAC). The overarching theme identified the TCP experience as a journey with the central query being, 'Is my journey destination home?' This journey was influenced by multiple factors including older adults' understanding about the context and nature of TCP, their expectations about what TCP entailed, their physical and mental ability to engage with and complete the rehabilitation programme, and mastery of skillsets to regain functional independence. The behaviour of TC staff towards them and support, or absence of support, from family members added another layer of complexity that contributed to the older adult's journey being charged with emotional 'highs and lows'. This wave of emotions, which the older adults ascribed to their positive and negative experiences, provided a lens (emotional) through which to view their journeys (Wurm *et al.*, 2010; de Jong *et al.*, 2019). One 82-year-old lady (patient (P)05) reflected on her distress then disappointment and finally acceptance of her placement:

I was a bit distressed at first ... when they sent me here, I felt as though well at least I should be keeping up with what they started me on in the hospital ... but it didn't occur, so I was a bit upset about that ... I've got over it.

Many older adults were filled with uncertainty as to why they were transferred to a TC facility and whether or not they would be going home. This was perceived as a negative experience as exemplified by a 78-year-old lady (P02), who shook her head tearfully saying, 'I don't know where I am going.' Hospital health professionals (health professional (HP)02) also acknowledged the older adults' uncertainty, describing transferring to TC as:

Fear of the unknown ... they don't know what that place looks like ... it's another disruption, another move, it's not home.

A few older adults understood why they were participating in TCP but still perceived the opportunity as a negative, due to the inability to participate in their community

and loss of their life role. This was re-iterated by an 86-year-old lady (P03) who was grieving the loss of providing care for her sick husband:

It [TCP experience] is ... somewhat painful in many ways and a lot of time you feel sad ... I lost [caring for] my husband ... he is with his daughters.

Prevailing uncertainty through the journey led to feelings of insecurity, as illustrated by a 91-year-old gentleman (P07): 'I don't know what the details are for discharge. I need to see the social worker.' However, the determination to return home was overwhelming for some, as exemplified by an 86-year-old lady (P03) who, on discussing her discharge plan, stated 'still going home. I don't want to share a room with another person for the rest of my life. It is just not the same'.

Overall, older adults' experiences in TCP were filled with emotional 'highs and lows', predominantly negative emotions as they were uncertain of their discharge destination and recovery while grieving for the loss of independence and life role in the community.

### ***Understanding regarding TCP***

Older adults' understanding of TCP was constructed from the information they received in the hospital setting, their family members' understanding and their personal experiences of prior rehabilitation. One 85-year-old lady (P14) demonstrated her well-informed understanding, stating: 'Transition care is a half-way house, you get the extra intervention to get you more mobile.' However, most older adults had a lack of understanding as to what TCP entailed at admission, 'I didn't know quite what it [TCP] would be', stated an 80-year-old gentleman (P04). Older adults' level of understanding as to why they were transferred to TC and what the programme entailed influenced their willingness to participate in rehabilitation. TC staff felt this stemmed from the hospital setting:

Quite often what they're [older adults] told in hospital is not what TCP actually is [and] that's a problem. (60-year-old female TC staff (TS)05)

Some older adults had a preconceived understanding that they were going to a TC facility just to be looked after and they would not be doing much activity; one 85-year-old gentleman (P04) commented, 'I thought before coming here it [TC] was like a holiday camp!' This was augmented by a hospital health professional who perceived the purpose of TCP was only to assist with maintenance of the older adults' functional abilities, not necessarily to improve their function adding:

So really it's just for maintenance so they don't get worse because that is the whole point right? ... because it is not a rehab ward. (Female, HP01)

Towards the end of the programme, some older adults felt more confident and at ease as they gained some understanding of the purpose of TCP, relaying that it provided them with an opportunity to plan for returning home safely:

I feel confident enough that I will manage on my own, but to have her [my daughter] there for the first two weeks will be reassuring. (82-year-old lady, P05)

Older adults' understanding regarding what TCP entailed influenced their TCP experience and their willingness to participate in the rehabilitation at admission. Participants and their families lacked understanding about what TCP entailed prior to their TCP admission.

### **Expectations about TCP**

Preconceived ideas of what TCP involved shaped older adults' expectations on admission to TCP. This was acknowledged by TC staff who were aware of older adults' misconceptions:

Initially when people come here, they walk in and they look and they think this is a nursing home and think I don't want to be in a nursing home. (48-year-old female, TS10)

Most TC staff acknowledged that older adults' uncertainty on admission was evidenced by preconceived ideas as to why they had been admitted to TCP rather than returning directly home:

Sometimes some clients don't have any idea what's going on, why they're here from hospital instead of going straight home. (39-year-old male, TS12)

Many older adults were expecting to return home directly from hospital and it was a real shock when they found themselves in TC for further rehabilitation. A 63-year-old gentleman (P12), after being admitted for a few days, expressed his frustration and grief saying, 'I am fed up with this place, I am supposed to be home by now.' One 76-year-old lady (P13) questioned, 'Who knows what to expect?' when expressing her uncertainty regarding TCP from the lack of information provided. There were further expressions of anger and frustration when expectations were unmet; examples included not receiving an individualised exercise programme, not having a variety of activities suited to personal needs or short lengths of stay. This was supported by TC staff:

I try and tell them [clients who prefer one-to-one exercise] that it's hard for us to give them the same length of involvement or engagement as they would get in a group ... because it's not time efficient ... it's not possible. (58-year-old female, TS02)

Although many older adults readjusted their expectations, during the second interviews some still felt aggrieved with the loss of freedom and autonomy to undertake their usual activities:

I haven't been able to get out in the garden yet ... they don't allow me to go out on my own in case I fall over. (77-year-old gentleman, P01)

Some family members also stated that their experiences did not match their expectations of the TC service, with a 68-year-old male (family (F)04) adding:

We didn't really know what we were in for ... we didn't know that it's not possible to have somebody with him [family member] 24/7.

Older adults and family members' unmet expectations stemmed from the pre-conceived ideas of what TCP was which resulted in their initial experience in TCP being less positive.

### **Goals**

Team goal setting (including the older adult) in TCP is important to allow TC staff to partner with older adults and work towards realistic achievable goals. When older adults were asked if they had set any goals with TC staff at admission, many were unable to remember whether they had been asked; an 80-year-old gentleman (P04) commented, 'They did [establish goals] in hospital but not sure if they have done it here.' This uncertainty may have been partly due to confusion following a sudden transfer to a new environment and the large number of processes and assessments happening at admission. This was refuted by TC staff who were very clear that goals were established from admission:

A lot of people come with a discharge goal pathway that's been determined through the family conference and the TCP co-ordinator ... we re-established that [goal] with the person and with the family and that evolves over time. (60-year-old female, TS05)

However, most older adults did not have a goal that specifically related to their rehabilitation in TCP. When asked about their goals, they described a discharge goal which was overwhelmingly to return home. This was exemplified by an 86-year-old lady (P14) who stated: 'My son said I need to go to an intermediate place before going home ... the goal I want to achieve.' In the initial research interview, the majority of older adults stated their goal was to return home. This was exemplified by a 77-year-old gentleman (P01) who stated: 'My main goal is to get home ... motivation is to be home again.' Older adults did not perceive that they had participated in a team discussion on how to achieve their long-term goal (*i.e.* return home) within the first few days of arriving in the TC facility.

### **Functional ability**

Understanding their physical limitations at admission, such as immobilisation due to a fracture healing, influenced older adults' perceptions of the TC journey as physical limitations impacted on functional ability and, consequently, independence. Some older adults experienced low mood and they were less willing to engage in rehabilitation if they felt their functional ability was not improving:

I am frustrated about not getting anywhere ... I want to get down to the next stage. (86-year-old lady, P03)

Other participants who were experiencing functional decline on admission to TCP, especially where this presented as a decrease in their physical ability, felt motivated and excited as they saw improvement in their physical ability to perform a task, commenting:

I have exercises that I have to do every day ... and the way I'm going, I feel I have improved a lot. (91-year-old gentleman, P10)

Older adults with mental health conditions, such as depression or anxiety, had more difficulty engaging in rehabilitation which, in turn, impacted their functional recovery: 'When I am feeling very down, I don't feel like doing anything', reflected a 64-year-old lady (P09). Older adults' physical and mental health conditions impacted on whether they experienced a positive or negative journey in TCP.

### **Mastery**

Mastery of skills in TCP, such as walking independently and safely, strongly influenced older adults' TC experience. Skill mastery was impacted by several factors. The structure of the programme influenced the time available for supervised practice and subsequent repetition of skills, which is necessary for motor learning. Older adults' abilities to overcome impairments, in conjunction with their mental, emotional and social wellbeing, enabled progression of skills; an 82-year-old lady (P05) shared her thoughts, adding:

I'm getting myself as active mentally and physically as possible, and I think that's really helped get me to where I am today, which is ready to go home.

Having support, encouragement and opportunity to practise functional tasks, such as showering and dressing, was important in empowering older adults to master a skill:

Here staff are making a change [for older adults] ... for instance, initially I struggled to have a shower ... but now I feel more confident to shower with staff beside me. (91-year-old gentleman, P10)

In contrast, older adults felt disheartened and disempowered when they were held back from practising a skill:

They don't trust us to do it ourselves, virtually helping me with showering ... I was required to work harder in hospital ... I could almost do everything in hospital. (80-year-old gentleman, P04)

Older adults felt more empowered when provided with opportunities to practise relevant skills throughout their journey in TCP prior to discharge from a TC facility.

### **Programme**

Although the TCP is goal-oriented, programme components such as exercise or cognitive activity groups were not tailored for each older adult, leading one

76-year-old lady (P13) to state: 'Activities are alright ... we do the same exercises everyday it is a bit too much ... don't need to do the same things everyday.' Some found the programme activities uninteresting, 'a bit boring ... Still doing exercises' (78-year-old gentleman, P08) and another 85-year-old gentleman (P06) commented: 'Not terribly interested in bingo ... I got my marbles. I don't need that type of stimulation.' Limited therapy services on the weekend were mentioned by both older adults and staff as a disappointment, with potential rehabilitation time wasted. During the 2020 COVID-19 restrictions (March to May), older adults in TCP were offered individual therapy sessions, which were perceived overall as a positive enhancement of the programme. Older adults' readiness and willingness to engage in the programme was important to ensure a positive experience in TCP, as embodied by a 91-year-old gentleman (P10), 'You got to be prepared to do what they ask you to do', and for some the level of activity provided was sufficient:

You don't have much time to do anything else, there's always something to do.  
(91-year-old gentleman, P10)

Although the TC facility provided daily group exercises and activities during weekdays, most older adults preferred exercises and activities that were tailored to their needs.

### **Staff behaviour**

Staff behaviour towards older adults either enhanced or worsened their experience in TCP. Positive staff behaviours, such as listening and empathising, clear communication and building rapport helped older adults to settle, adapt to the TCP routine and trust the staff. This empowered older adults to engage in the programme and have a more positive experience. One 64-year-old lady (P09) commented:

They [staff] have been very helpful trying to find a place for me, having my wound looked after, easy to communicate ... staff spending more time with you and more activities here ... If you are upset, they give you a bit of space.

Conversely, negative staff behaviours, such as not responding to the call bell in a timely manner, made family anxious and increased their sense of distrust, as a 68-year-old male (F04) commented:

We pretty much immediately knew that there were going to be some issues because they had insufficient staff to have a quick response to alarms that go off ... he's had two falls, both of which could have been avoided.

Overall, most older adults experienced positive staff behaviour throughout their stay in TCP.

### **Family support**

Family support appeared to influence whether older adults experienced a positive journey in TCP, with one 88-year-old gentleman (P10) expressing, 'a lot of family

support from my boys and wife ... they motivated me to get better to go home'. Conversely, some older adults had a negative experience when family members doubted their commitment to the programme. An 85-year-old lady (P03) stated, 'my daughter thinks I am not taking this [TCP] serious enough after my fall'. Family support also contributed to whether older adults were able to return to their former community life or less-favourable living arrangements:

I discussed with my daughter [regarding 24-hour care] and she said I can do it [return home]. (76-year-old lady, P13)

Others felt frustrated and disappointed when their family members were unsupportive of their goal to return home, pushing RAC placement against their will:

My family wants me to be in a nursing home, but I want to be in my own home.  
(86-year-old lady, P14)

Having supportive family members who actively listened to them and acted in their best interest appeared to enable older adults to experience a positive journey through TCP even when their planned discharge was admission to a care home:

Wherever I go, I will be happy. All my children are getting it [RAC] for me.  
(91-year-old gentleman, P07)

Overall, family support impacted on how the older adults perceived their TCP journey and influenced whether an older adult was able return home to the community.

## Discussion

Older adults perceived their transition journey through TCP as a positive or negative emotional experience primarily influenced by their planned or tentative discharge destination. Factors that influenced their experience and subsequent emotional responses were their understanding of TCP, their expectations, functional ability, mastery of skills, goals, family support and staff behaviour. Some older adults feared the unknown and felt insecure because they were unsure of what TCP entailed and were anxious about whether they would be able to return home *versus* requiring admission to RAC. Similarly, studies in Australia and the USA have reported high levels of uncertainty and ambivalence amongst older adults admitted to TCP when the expected discharge destination is unclear (Sefcik *et al.*, 2017; Cations *et al.*, 2020). Our findings contrast with a cohort admitted to an IC programme in Denmark who reported a largely positive experience. However, this group of older adults had clear pre-planned goals to be discharged home (Martinsen *et al.*, 2015), which may have positively influenced their expectation of TCP in achieving their desired outcome.

Older adults' emotional responses impacted their motivation to participate in rehabilitation, with positive responses being associated with increased motivation. This finding was similar to older adults who were more motivated to participate in inpatient rehabilitation if they wanted to return home (van Seben *et al.*, 2019).

Our study found older adults grieved and felt frustrated at their loss of independence when they were unable to perform personal activities of daily living independently in TC and were unable to get back to their roles in the community. Adjusting to a 'new normal' functional level while being overwhelmed with changes to their health has been associated with older adults feeling underprepared for what lies ahead when transitioning from hospital to a new environment (Grimmer *et al.*, 2004; Sefcik *et al.*, 2017; Liebzeit *et al.*, 2020). Lack of preparatory information about TC, having pre-conceived ideas and unmet expectations expressed by older adults were confirmed by family members, TC staff and hospital clinicians, which strongly suggested that more preparation is required prior to TC admission (Sefcik *et al.*, 2016; Gadbois *et al.*, 2017). This concurs with previous findings that the lack of clinicians' knowledge of what TCP entails (Burke *et al.*, 2017), older adults not being given the opportunity to ask questions (Allen *et al.*, 2017), miscommunication at hospital discharge (Giosa *et al.*, 2014) and family members not being involved in decision making (Reid and Hulme, 2008) lead to older adults experiencing negative emotions and feeling underprepared to undertake TCP. Family member support also strongly influenced whether older adults experienced TCP positively and contributed to them being able to discharge home. Older adults undertaking rehabilitation in inpatient rehabilitation facilities in the USA were also more likely to return home if their family members were supportive and had the capacity and resources to care for them at home (Lutz *et al.*, 2017).

The older adults in our study had functional deficits related to mobility and self-care, therefore skill mastery was important in regaining functional independence. However, most participants were not able to enunciate rehabilitation-specific goals. Not having clear rehabilitation goals resulted in some older adults having unrealistic expectations regarding the skill mastery required to achieve discharge home. This finding was similar to previous findings where health professionals in an inpatient rehabilitation setting reported their patients were unable to provide a goal that they wanted to achieve and often had unrealistic goals (van Seben *et al.*, 2019). Even though TC staff reported mutual goals were set during the family conference in the hospital setting and with the TC co-ordinator and staff, most older adults had no recollection of these discussions. This could be due to older adults being overwhelmed with meeting so many different people and receiving large volumes of information, particularly at TC admission. This may indicate that staff need to discuss goals at subsequent sessions following the TC admission process. A national survey in the UK reported that older adults reported that they felt their experiences were less than adequate because they were not sufficiently involved in goal setting and decision making and that discharge planning was not discussed (Young *et al.*, 2015).

### **Strength and limitations**

A key strength of the study is that to the authors' knowledge, it is the first to explore the lived experience of older adults undertaking a facility-based TCP. The validity of the study was enhanced by triangulating perspectives of the older adults' TCP journey with two supporting sources (family members and TC staff) (Creswell, 2014).

Additionally, interviews were conducted by an experienced physiotherapist who was not part of the TCP organisation, which may have allowed participants to feel more confident to set aside socially desirable responses and provide a negative response if desired. This also aimed to address ethical considerations in working with older adults, to ensure their opinions were respected as being in private and in confidence, in addition to comments being de-identified and presented as a whole. Participants were frailer, older adults who had just been through hospital admissions and sometimes serious illnesses, hence researchers provided extended time for the participants to decide whether they would like to enrol in the study. All participants were also encouraged and given the opportunity to discuss the research with family members or friends, so that they could reflect and feel confident about deciding whether or not to participate. Participants were offered care prior to all interviews, to address any requirements for drinks, comfort and other physical needs. Family members who participated were also reminded that their comments would not be provided directly to the facility, but would be combined and presented as part of a de-identified report.

Due to the nature of the COVID-19 pandemic, some interviews were conducted either using online or telephone calls which limited the researcher's observation of participants' body language, gestures and emotions portrayed during the interview. Four participants met the researcher for the first time through an online call, which may have resulted in reduced rapport and made observation of verbal cues challenging, and only one participant had all three calls online. The findings were generated from one facility and hence cannot be generalised to other TC settings. Our findings may be helpful for other settings that undertake facility-based rehabilitation programmes. Further research to explore and understand how to involve older adults in their own discharge planning when they are unwell is important, especially when critical changes in life roles and living situations are planned. Extensive research has examined older adults' discharge from the hospital system (Leppin *et al.*, 2014; Gonçalves-Bradley *et al.*, 2016; Greysen *et al.*, 2017). However rapidly changing services that now encourage care at home and the growing ageing population suggest we need to deepen our understanding of the problems older adults encounter in the TC system.

## Conclusion

Older adults discharged from hospital to a TC facility for rehabilitation experienced their journey as one of great uncertainty. Some older adults experienced additional anxiety about whether they would be able to return home. Physical, mental and emotional wellbeing, such as grief and anxiety about their situation, impacted their motivation and ability to engage in the rehabilitation provided. Clear goals, understanding the purpose of TCP, being able to manage expectations and having family support improved the older adults' experience. Health professionals and family may require more resources and training to emotionally support older adults at the time of transition from hospital to TCP, as it was frequently experienced as overwhelming and a time of great turmoil. Future research would benefit by looking at how to best address the transition between hospital, home or alternative permanent care to enhance the experience for older adults.

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#### Author contributions.

JAH led the drafting of the manuscript. AMH, JAH and JFC led the research design and assisted with monitoring the research. AMH and JAH led the research with support from JFC and NW. JAH conducted the interviews and KP led management of the research at the facility. NW contributed to recruitment of hospital staff and provided expert clinical input to the research design and interview guides. PH contributed to statistical analysis. All authors provided critical evaluation and approval of the final submitted manuscript. JAH undertook this research project as part of her doctoral studies under the guidance of AMH, JFC and NW.

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**Conflict of interest.** KP is employed by the organisation Amana Living Inc. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

**Ethical standards.** This research study was reviewed and approved by Curtin University Human Research Ethics Committee and Amana Living Clinical Governance.

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