Received: 7 July 2023 | Accepted: 19 September 2023

DOI: 10.1111/1440-1630.12908

FEATURE ARTICLE

Australian Occupational Therapy Journal | WILEY

Occupational adaptation for adults living with advanced cancer: A phenomenological longitudinal study

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Funding information
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by an Australian Government Research Training Program (RTP) Scholarship (Julie Brose). Julie Brose's time is supported by the National Institute for Health and Care Research Applied Research Collaboration West (NIHR ARC West), UK.

Abstract

Introduction: People living with advanced cancer want to continue participating in their valued occupations amid cancer progression. However, increasing dependence and bodily deterioration challenge a person's ability to do so, thus requiring adaptation to how they engage in their occupations. Theoretical frameworks on the process of occupational adaptation often do not address the implications of progressive functional decline.

Methods: A longitudinal phenomenological design was used to understand the lived experience of occupational engagement for working-aged adults living with advanced cancer. A semi-structured interview series explored participants' experience of occupational engagement and how this changed over time. Data were analysed thematically and mapped against the Model of Human Occupation (MOHO).

Findings: Eight adults (40–64 years old) participated in 33 interviews over 19 months. Three themes were constructed from the data: ongoing adaptation through doing, the significance of volition in adaptation, and everyday life is contingent on my environment. Study findings demonstrate that the process of adaptation occurs through occupational engagement, is motivated by volition, and is affected by the environment. Volition and the environment play a more central role in occupational adaptation than occupational competency for the advanced cancer cohort.

Conclusion: Study findings further MOHO's theoretical conceptualisation of occupational adaptation by identifying the centrality of volition and the environment in the process of adaptation. For people living with advanced cancer, disease progression results in unremitting functional decline, thus rendering competency an unstable and untenable construct. Rather, this paper argues that occupational adaptation is facilitated by volition (i.e., the motivation behind the doing) and the environment, thus fostering a sense of identity and meaning at the end of life. Occupational therapists' awareness of the significance of volition and the environment can thus foster continued occupational engagement and meaning at the end of life for people living with advanced cancer.

KEYWORDS
cancer, environment, Model of Human Occupation, occupational adaptation, palliative care, palliative rehabilitation, volition

1 | INTRODUCTION

People living with advanced cancer often experience unremitting functional decline and change in their final year of life. This continual deterioration in independence due to cancer progression results in increasing difficulty with occupational engagement. The loss of ability to participate in meaningful activities due to advanced cancer can result in distress and suffering and is a primary reason why people choose medical assistance to end their life (Health Canada, 2022; Oregon Health Authority, 2022). For example, 'Intolerable suffering' was defined as the inability to participate in valued activities by 86.3% of people who chose medical assistance in dying in Canada (Health Canada, 2022). Although this demonstrates the importance of maintaining occupational participation, limited access to palliative care occupational therapists means that occupational engagement may not be adequately addressed in palliative care settings, where ongoing functional decline continues until death (Chow et al., 2022; Park Lala & Kinsella, 2011).

For those living with advanced cancer, engaging in valued occupations can maintain a person's sense of self and meaning (Hammill et al., 2019; Maersk et al., 2017). Occupational engagement is defined as a person's active or passive involvement in a subjectively meaningful occupation within their environmental context, made possible through their physical, emotional, and cognitive abilities (American Occupational Therapy Association, 2020; Black et al., 2019; Taylor, 2017; Wilcock, 1993). The Model of Human Occupation (MOHO) also describes occupational engagement within the context of the synergistic relationship between the individual's volition (values, interests, and self-efficacy), habituation (roles, routines, and habits), and performance capacity (subjective and objective physical, emotional, and cognitive abilities) (Taylor, 2017). As a person's function declines due to advanced cancer progression, adjustments must be made to facilitate continued occupational engagement. The role of occupational engagement and adaptation for people receiving palliative care services in recent research highlights the occupational therapist's role in adapting occupations to facilitate continued occupational engagement and optimise quality of life at the end of life (Brose et al., 2023; Chow et al., 2023; Dolgoy et al., 2021; Morgan et al., 2022; Peoples et al., 2017).

Key Points for Occupational Therapy

- Occupational adaptation occurs *through* occupational engagement for people living with advanced cancer.
- Volition plays a central role in the process of occupational adaptation in advanced cancer.
- A dynamic relationship exists between identity, volition, and the environment, building on MOHO's existing conceptualisation of occupational adaptation.

The concept of occupational adaptation has received increasing attention in occupational therapy research, particularly for people who are redefining a new normal following a health event such as an acquired brain injury or stroke and for specific diagnostic groups such as physical disabilities or attention deficit hyperactivity disorder (Cotton, 2012; Klinger, 2005; Paley Altit et al., 2019; Parsons & Stanley, 2008; Walder & Molineux, 2017; Williams & Murray, 2013). However, there is a paucity of research on occupational adaptation for people living with progressive and advanced cancer. Two recent studies on this topic explored the experience of occupational engagement for people living with advanced cancer, arguing that adaptation occurs *through* participating in occupations (Brose et al., 2023; Morgan et al., 2017). Occupational therapy theories have various descriptions of adaptation, from the Canadian Model of Client-Centred Enablement outlining adaptation as an occupational therapy skill to facilitate occupational engagement (Townsend et al., 2013) to the Occupational Adaptation Model which describes occupational adaptation as both an intervention strategy and an internal process of the service user (Schkade & Schultz, 1992; Schultz & Schkade, 1992). MOHO defines occupational adaptation as 'the development of a positive occupational identity, coupled with the experience of occupational competence over time within the context of one's environment' (de las Heras de Pablo et al., 2017, p. 116). Occupational competence is defined as the ability 'to sustain a pattern of occupational participation that reflects one's

occupational identity' (de las Heras de Pablo et al., 2017, p. 117). However, what is not known is how occupational adaptation occurs if neither functional stability nor occupational competence is possible due to ongoing, progressive deterioration. This paper builds on existing conceptual understanding of occupational adaptation by exploring the *process of occupational adaptation* amid increasing functional decline. As MOHO was the theoretical framework underpinning this study, this definition of occupational adaptation will be adopted.

Two additional MOHO concepts are relevant to this study given their impact on a person's experience of occupational engagement: volition and the environment. MOHO defines *volition* as the motivator behind occupational engagement based on a person's interests, values, and personal causation (feelings of capacity and self-efficacy). It is defined as 'a pattern of thoughts and feelings about oneself as an actor in one's world which occur as one anticipates, chooses, experiences, and interprets what one does' (Yamada et al., 2017, p. 14). More specifically, the volitional cycle describes the interaction between these three volitional components (interests, values, and personal causation) in how a person (1) anticipates and (2) chooses an occupation to participate in, then (3) experiences the occupation and (4) interprets this experience (Lee & Kielhofner, 2017). The *environment* is described in MOHO as a central component of the dynamic relationship between the person, their occupation, and their environment, where changes in one of the three areas affect the other (Fisher et al., 2017). The environment impacts a person's experience of the world due to its ability to hinder or facilitate occupational engagement. For example, the presence of a raised toilet seat can facilitate independence and dignity in personal hygiene (Badger et al., 2016). However, occupational adaptation theoretical frameworks do not routinely consider the significant role of volition or the environment for people experiencing progressive functional decline.

Despite the increasing focus on occupational adaptation within occupational therapy literature, limited research focusses on the *process* of occupational adaptation when functional stability is unattainable due to a progressive, life-limiting condition such as advanced cancer. In addition, longitudinal explorations of occupational adaptation are lacking. This study sought to understand the lived experience of occupational engagement and adaptation with continuing deterioration for working-aged adults with advanced cancer and how this changed over time. The paper argues that volition is more central than competence in the process of adaptation and that the environment is a vital component to this.

2 | METHODS

2.1 | Ethics

Ethics for the study was obtained through the Human Research Ethics Committee at Flinders University, Australia (SBREC 7858) and the Health Research Ethics Board of Alberta–Cancer Committee, Canada (HREBA. CC-17-0556).

2.2 | Study design

A pragmatic hermeneutic phenomenological design was employed for this longitudinal study as it privileges participant voices while acknowledging the interconnectivity of theory and clinical practice (Hartrick Doane & Varcoe, 2005; Saldaña, 2003; van Manen, 1990). This focus on lived experience gave insights into how working-aged adults adapted to changes in occupational participation, considering the influences of time, environment, bodily changes, and relationships (Carel, 2016; Kleinman, 2020; Toombs, 1987). MOHO was the primary theoretical framework chosen to underpin this study due to its unique emphasis on a person's lived experience, the value it places on volition as a motivator behind occupational engagement, and its exploration of the concept of occupational adaptation. Findings were mapped against MOHO theory and lived experience literature (Carel, 2016; Kleinman, 2020; Taylor, 2017; Toombs, 1987).

2.3 | Participants and recruitment

The study took place in communities outside a city in Western Canada. Purposive sampling was used to recruit participants by health-care professionals in a rural home care team if they met the study inclusion criteria: people living with advanced cancer, between 18 and 64 years old, residing in their own homes, having some difficulty with daily living tasks as per an Australian-Karnofsky Performance Scale (AKPS) score of 70 or below (Abernethy et al., 2005), and able to participate in interviews in the English language. Recruitment processes have been previously reported (Brose et al., 2023).

2.4 | Data collection

An experienced palliative care occupational therapist and qualitative researcher (J. B.) created the semi-structured interview guide, informed by current literature on the illness experience, advanced cancer, and MOHO (Table 1).

TABLE 1 Interview guide.

Sample questions	MOHO concept
1. How are you doing?	Subjective experience
2. Can you tell me a bit about yourself? (*first interview*)	Subjective experience
3. How has your week/month been? (since I saw you last? - *for follow-up interviews*)	Subjective experience
4. What does a typical day look like for you? (*including activities, roles/ responsibilities*)	Habituation Performance capacity Occupational identity
5. Out of the activities you mentioned, what is most important to you? (*and why?*)	Volition Occupational identity
6. Can you tell me how these everyday activities have changed for you in the past month? (*What was that like for you?*)	Occupational adaptation Social relationships Subjective experience
7. Out of the responsibilities you mentioned, what is most important to you (*why?*)	Volition
8. How have your roles or responsibilities changed in the past month? (*What was that like for you? Can you tell me a bit more about this?*)	Occupational adaptation Subjective experience
9. What is the biggest concern you have about these changes?	Volition Performance capacity Occupational identity
10. What do you think is causing these changes?	Personal causation Volition Habituation Environment Occupational adaptation
11. Is there anything that you would like to do but cannot do at the moment?	Volitional anticipation
12. What is the one thing you are most concerned about no longer being able to do? Tell me more about this.	Volition Personal causation Occupational identity
13. (If there is change): Has the way you manage your everyday activities/roles/ habits changed how you see yourself? If so, how?	Occupational adaptation Occupational identity
14. Is there anything you would like to discuss about your everyday activities that we have not talked about today?	Subjective experience

The topic guide was refined by two experienced qualitative researchers (D. M. and E. W.), one with significant palliative care occupational therapy experience. Open-ended questions enabled participants to discuss their experience of occupational engagement within the context of their home environment, consistent with the hermeneutic phenomenological study design. Participants were invited to reflect on any changes noted between interviews. Further discussion was facilitated through additional prompts.

Four to six weekly interview intervals tracked changes over time and explored the experience of occupational engagement and the process of occupational adaptation amid cancer progression. Participants' schedules determined exact timelines due to factors such as medical appointments, hospital stays, or social events.

2.5 | Data analysis and rigour

Colaizzi's (1978) thematic analysis method was adapted using Saldaña's (2003) longitudinal analysis to ensure the inductive analysis was consistent with the study's longitudinal phenomenological approach (Brose et al., 2023). NVivo facilitated data management, and iterative thematic analysis occurred throughout the interview series. Initial themes were coded by J. B. and refined with input from D. M. and E. W.

Rigour was enhanced through the longitudinal study design, member checking, reflexive journaling, researcher triangulation, and an audit trail (Liamputtong, 2013; Lincoln & Guba, 1986). Member checking of interviews occurred at subsequent interviews with surviving participants. All researchers were experienced palliative care occupational therapists and/or qualitative researchers working in clinical and/or academic roles.

3 | FINDINGS

This paper reports on one aspect of a larger study on occupational engagement for working-aged adults living with advanced cancer: *the process of occupational adaptation*. Study findings extend MOHO theory relating to occupational adaptation for people with advanced and progressive cancer. Other themes are reported elsewhere (Brose et al., 2023).

3.1 | Participants

Recruitment and data collection occurred over 19 months. Eight adults living with advanced cancer in

their own homes participated in the longitudinal study. All participants were between the ages of 40 and 61; additional demographic information is listed in Table 2.

All interviews were conducted by J. B. in the participants' home environment, except for one interview at the community health centre and one interview at a hospice, as per the participants' request. Only two interviews had family or friends present. All interviews were audio recorded apart from two interviews at participant request: one in the hospice and one following the deaths of family members. The 33 interviews ranged from 25 to 80 minutes and were transcribed verbatim, apart from the two interviews not recorded, where field notes were taken. Further details around reflexivity have been reported elsewhere (Brose et al., 2023). Data collection ceased at the time of death for all but two participants, where thematic saturation occurred following over 1 year of interviews (Fusch & Ness, 2015).

TABLE 2 Participant characteristics.

Characteristics	$n = 8$ n (%)
Gender	
Male	3 (37.5%)
Female	5 (62.5%)
Age	
40–49	3 (37.5%)
50–59	2 (25%)
60–64	3 (37.5%)
Diagnosis	
Advanced cancer	8 (100%)
Lives with spouse/partner	
Yes	6 (75%)
No	2 (25%)
Lives with children	
Yes	4 (50%)
No	4 (50%)
Lives with pets	
Yes	6 (75%)
No	2 (25%)
Number of interviews	
1	2 (25)
2–5	4 (50)
6–10	2 (25)

3.2 | Themes

Three themes constructed from the data describe the process of adaptation over time for working-aged adults living with advanced cancer:

1. You adapt and move forward: Ongoing adaptation through doing
2. The little things matter the most and motivate me: The significance of volition in adaptation
3. Everyday life is contingent on my environment

The lived experience of adaptation was evident in participant narratives who experienced progressive functional decline over time. Consistent with the study's hermeneutic phenomenological approach, participant voices are central and highlighted in the quotes included.

3.2.1 | You adapt and move forward: Ongoing adaptation through doing

Being independent means the world to me: The intentional pursuit of occupational engagement

All participants placed significant value on maintaining their independence with meaningful tasks. This provided a sense of normalcy and a sense of self at a time when their world was changing and their function continued to decline. They spoke about prioritising everyday occupations related to their regular routines, which meant foregoing certain tasks at times, such as receiving assistance with bathing, in order to have energy for occupations later in the day, such as meeting friends for coffee. Prioritising independence in valued occupations enabled them to maintain their pre-cancer sense of self, despite acknowledging the impact of their advanced cancer. At times, this meant pushing through symptoms in order to complete a task. For example, Melissa enjoyed meeting up with friends and spoke of experiencing pain sitting in a café for long periods of time. However, she described why pushing through the pain to socialise with friends was worth it, saying it was 'the amount of joy that I'm going to get from the situation, so meeting up with a friend that I really enjoy or that would be worth it' (Melissa, Interview 8).

The desire to be independent was often tied in with activities that were part of their everyday life. Lisa lived on her own and loved taking walks in the mountains or going to work. She explained that

> I feel better when I get out and do things, so that is why it is important to get out and walk or go to work or something because once I'm there and sort of get into it a little

> bit, I do feel better than I would I think than if I were just staying at home feeling crappy. I still feel crappy, but at least I'm out doing something. (Lisa, Interview 1)

This desire to live purposefully in their quest for ongoing participation in valued occupations was highlighted in their prioritisation of what was most important to them and their pursuit of developing strategies to facilitate continued engagement. 'I want to set achievements ahead and not just sit around and wait to die' (Peter, Interview 1).

I want to keep doing things, even when I am dying: The process of adaptation

All participants described how they intentionally pursued occupational engagement as their cancer progressed. They wanted to continue participating in their occupations, not simply be passive recipients of care. Tammy was previously very involved in her community and struggled when others tried to do things for her instead of allowing her to try to do as much as she could for herself. She said that 'when people say, "oh let me do that for you," I say, "no, I can do it myself." So what if this is the way I peel my orange? I can peel my own orange' (Tammy, Interview 9). All participants valued reciprocity in relationships, such as being a confidant and mentor to their young adult children and friends or helping with school transitions for children.

The working-aged adults with advanced cancer in this study described how occupational adaptation occurred *through* occupational engagement. They were not adapting to a new, stable 'normal'. Rather, it was a continual process of adaptation requiring multiple modifications over weeks and months as they adjusted to their increasing dependence. In order to continue engaging in their higher-prioritised occupations as function declined, these adults needed to adapt *how* they participated in their occupations. For example, Peter described his cancer progression as being 'about the freedom. I don't have that freedom anymore. So that's tough, that's really hard. I can't just jump in the car and go meet a friend' (Peter, Interview 1). To maintain his social network and role of friend, Peter adjusted and began hosting others at his house instead. 'A decrease in ability ... is tough, but you adapt. You've got to do what you've got to do' (Peter, Interview 3).

Adaptation often occurred through *doing* activities, as the participants learnt what they could or could no longer do, tried different strategies, or modified their environment or occupation to continue participating in the activity. Changing modes of engagement was evident throughout the interview series for all participants. Over the weeks and months, participants demonstrated different ways of task modification. This included altering one component of the task, substituting one task for another, or shifting from a more to a less active role in the activity. For example, Tammy described her desire to maintain her physical activity despite reduced functional abilities: 'I love the water, but I'm not swimming right now because I've lost the use of my upper body. But I walk' (Tammy, Interview 1). Thus, occupational adaptation enabled participants to maintain their sense of self through maintaining involvement in occupations pertaining to their values or interests by which they defined themselves. (Task modification is reported in more detail in Brose et al., 2023.)

3.2.2 | The little things matter the most and motivate me: The significance of volition in adaptation

My priorities are shaped by what is important to me: The significance of volition

Participants shared how living a 'normal' life was vitally important to them at this time of life; they described how they lived out their interests and values through what they did. These working-aged participants often prioritised their roles of parent, family member, friend, or worker. This was reflected in their desire to participate in occupations pertaining to their valued roles and interests, such as eating meals with their family or spending time with their young children, participating in recreational activities or remaining connected to their workplace. Peter described the value he placed on his role as a father for two young children, saying:

> It's those little things that matter the most. The sit down at the dinner table and being able to talk about the day. Before, it was just kind of eh, it's part of the day, but it means a lot now. (Peter, Interview 1)

Participants' values and interests shaped how they prioritised their occupations, thus helping them choose whether to participate in particular occupations and not others. Melissa, a mother of four, described how she prioritised valued occupations related to her family over other less meaningful activities, such as doing a puzzle:

> ... the cookie day, I spent all day making them, and I was in a ton of pain at the end of the day, but I was happy. I was like, that was worth it. The puzzle was not worth it. The cookies were worth it, yeah, I would do that again. My dad goes so crazy over

them that it makes me feel so good. He's like, 'these are my favourite.' He eats like 20 ... it brings joy to someone else, and I get to enjoy their joy, and they're tasty, whereas the puzzle is just like [shrugs] 'Okay. I did a puzzle.' (Melissa, Interview 5)

Faced with limited energy stores and declining mobility, Melissa made the intentional decision to participate in certain occupations (baking cookies) and not in others (doing puzzles).

3.2.3 | Everyday life is contingent on my environment

Physical barriers hinder my ability to participate

The physical environment significantly impacts the ability to engage in valued occupations. When participants experienced barriers in their environments, they were unable to do what was important to them. Similar to many houses in the area, Peter lived in a two-storey house. He could not go up the stairs due to a spinal cord compression requiring a wheelchair to be used; no stairlift was in place. He indicated that

> I haven't been up to my own bedroom for over a month as well, so not being able to utilise any of the rest of the house, it's not easy. ... One of the things I don't like is I don't sleep with my wife anymore because our bedroom is upstairs. She sleeps up there and I sleep down here. So not being able to be with the person that you love, that's difficult. It's hard. So that's another little thing that people don't really think about. It's that physical separation. Even though you're in the same place, you're not. That is really tough. (Peter, Interview 1)

Routine tasks were made difficult when environmental barriers occurred. The incompatibility between the environment and the person's abilities resulted in functional impairments. It was not just limiting *how* they engaged in a particular occupation but also *whether they could participate* in a task at all, as Peter described:

> It's been hell. It really does suck; I'm not going to lie. It's not even just being stuck in the house; it's literally being stuck on one level of the house. I have a man cave in the basement, and ... I can't even go down there and enjoy being relaxed in my own home. (Peter, Interview 1)

The impact of the environment also included seasonal challenges, such as wildfire smoke or snowy weather. Tammy described how wildfire smoke prevented her from going for walks in her mountainous community:

> The smoke [from wildfires] was chasing all the animals this way from [over the mountains], so we were getting extra bears and cougars. That is what is happening, the animals were coming this way because the smoke was so bad, so I wasn't going out by myself. I won't walk by myself. (Tammy, Interview 3)

Jessica similarly said it was 'very frustrating with the smoke and the heat ... it was horrible. It made for really long days. I felt my energy probably was worse, and my emotional energy, my depression of things. I was crying a lot' (Melissa, Interview 2).

Physical barriers such as snowy sidewalks restricted their ability to walk around their community when experiencing fatigue or mobility challenges. Melissa loved going for walks and struggled when the weather affected her ability to leave the house. She became hesitant to ambulate outdoors in the winter due to the higher falls risk on icy sidewalks, saying, 'I'm also nervous now in the winter because I have fallen a couple of times' (Interview 4).

Other participants described the impact of a long walk to the bus stop or the shops, as their fatigue levels precluded them from the distance they would have to walk (Lisa Interview 1, Jessica Interview 2). The impact of the inability to access the shops or public transportation was compounded by living in a rural community, where participants became increasingly reliant on others to drive them to the shops, get medication, or attend appointments. Jessica described her experience living on a rural property with limited public transportation, increasing her reliance on a car. Unfortunately, her vehicle broke down and she could no longer pick up her child from school, go to the grocery store, or meet friends for coffee:

> It impacts your sense of self. It really knocks you down and that's why with that car I really needed, I need to go to the bank and I need to get in my car and just be able to know that I can rely upon that car just to go down to the bank and do my little errands and not be impacted by that car. (Jessica, Interview 2)

Thus, the physical environment significantly impacted a person's ability to participate in occupations.

Reducing the impact of environmental barriers: Occupational adaptation and the environment

Despite the challenges imposed by environmental barriers, participants were able to continue engaging in valued occupations if these barriers were addressed. Peter had a stairlift and porch lift installed, and he was then able to tuck his children into bed at night or go outside and play with them at the local playground (Peter, Interview 3). He described how obtaining a power wheelchair:

> ... has made a big difference. ... I know that I've lost some of my independence and that's fine, it's going to happen, and there is not much you can do about that. But that being said, I've also been able to regain some of my independence, which has been fantastic, whether it be getting a glass down [from the cupboard] or rolling out to the porch lift and going outside, you know, out to the driveway and watching the kids paint with chalk or draw with chalk or do whatever they want to do, and be part of their lives and take it all in again, it has been great. (Peter, Interview 3)

Other minor modifications, such as having a chair placed in a particular location, can facilitate participation in social events. Melissa loved to dance, but her fatigue and reduced activity tolerance precluded her from dancing as she previously would have. Her friend set up a recliner chair:

> so I was lying back—it was amazing—and then when he wanted everyone to dance, he moved the La-Z-Boy into the middle of living room and laid it back and said 'okay, Melissa, you go in there, I'm going to turn on the disco ball, and everyone dance around you'. It was awesome, it was so amazing! ... It was fun! I just kind of moved my arms around. It was really good. That was a highlight for sure. It meant a lot. (Melissa, Interview 6)

Without this environmental modification, Melissa would have been unable to engage in dancing with her friends. Thus, the environment plays a significant role in facilitating or preventing occupational engagement. Adaptations to the physical environment can significantly impact a person's sense of self and connection with others.

4 | DISCUSSION

This study furthers MOHO's conceptualisations of occupational adaptation by identifying the significant role that volition and the environment play in the process of adaptation amid shifting experiences of competency and increasing dependence. These working-aged adults living with advanced cancer sought to intentionally participate in occupations pertaining to their interests and values, impacting their sense of self-efficacy. Thus, the value placed on engaging in particular occupations is unique to the individual.

Study findings showed that volition for this cohort was closely related to their valued roles of parent, spouse, friend, or worker, consistent with existing research on working-aged adults living with advanced cancer (Knox et al., 2017; Lundquist et al., 2019; Park et al., 2017). Participant narratives support the importance of volition, identified by MOHO theory as the motivator for occupational engagement (Lee & Kielhofner, 2017).

Importantly, findings demonstrate that volition plays a more central role in occupational adaptation than occupational competency for the advanced cancer cohort. For this cohort, the volitional cycle includes the impact of volition on occupational priorities, thus impacting their choice of which occupations to engage in, as outlined in Figure 1. This then reinforces or diminishes their sense of volition, which then impacts what their occupational priorities are.

Study findings also demonstrate the centrality of the environment, as it is inseparable from this dynamic relationship of volition, occupational priorities, choice, and eventual engagement. If environmental barriers remain unaddressed at any stage of the volitional cycle, then the person may be unable to participate in their chosen occupation.

This study affirmed the significance of continued occupational engagement to maintain a sense of self as

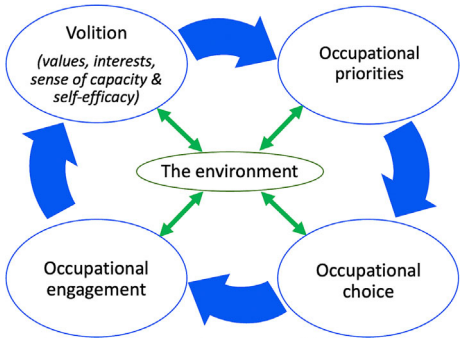

FIGURE 1 The volitional cycle: advanced cancer. *Source*: Brose (2021).

function declined and death approached, as supported by other literature (Hammill et al., 2019; Maersk et al., 2017). Participants intentionally chose activities consistent with their interests and values through which they defined themselves, therefore supporting personal causation (i.e., sense of self-efficacy and capacity). This volitional cycle reinforced their occupational identity and sense of normalcy during a time of constant change.

Given that advanced cancer progression results in fluctuating yet increasing dependency, *continuous occupational adaptation* is required in order to maintain participation in valued occupations. MOHO's conceptualisation of occupational adaptation includes a person's 'experience of occupational competence' (de las Heras de Pablo et al., 2017, p. 116). However, attaining occupational competency amid ongoing, progressive functional decline is unrealistic and unachievable. This study argues that a greater focus should be placed on the optimisation of volition and the volitional cycle when identifying factors impacting occupational adaptation, rather than occupational competence.

Advanced cancer progression results in an eventual decline in functional abilities over time and, therefore, reduced ability to participate in valued occupations (la Cour & Hansen, 2012; Morgan et al., 2017; Park Lala & Kinsella, 2011). Tracking occupational choices of participants during this longitudinal study identified three occupational paths that occurred following increasing difficulty with occupational engagement due to functional decline in advanced cancer. These three occupational paths are depicted in Figure 2: (1) intentional choice to no longer participate in an occupation (e.g., choosing to no longer do puzzles or go for walks), (2) external barriers preventing occupational engagement (e.g., climate or stairs eliminating the option to participate in an activity), or (3) intentional choice to continue engaging in the occupation through modifying the modes of engagement (e.g., modifying the environment, switching one task for another).

Due to the progressive nature of their cancer and resultant functional decline, occupational adaptation was an ongoing process. The compensatory strategies, occupational shifts or environmental modifications facilitated continued occupational engagement in daily life, albeit in modified form. Although established evidence shows that the 'little things' often become increasingly valuable when living with advanced cancer (Arantzamendi et al., 2020; García-Rueda et al., 2016; Morgan et al., 2017), limited attention has focussed on the role of adaptation to optimise the ability to participate in these seemingly minor successes or little things at end of life. For example, although Tammy's overall functional status and AKPS score had declined over the year-long interview series, she used compensatory strategies and environmental modifications in small tasks (e.g., modifying clothing to avoid using zippers to dress independently) to optimise her ability to participate in occupations (e.g., having friends over). These small wins are significant for people experiencing unremitting bodily deterioration as they foster a sense of self and normalcy amid, and despite, the rollercoaster journey of advanced cancer, and encourage further engagement in valued occupations. Findings demonstrate that occupational adaptation does not require adaptation to a new normal, as a stable normal is unattainable. Rather, occupational adaptation is a continual process that occurs within ongoing change and functional decline. As Peter said, 'you just find a way, and you do what you've got to do; you just adapt and overcome' (Interview 3).

4.1 | Limitations and future research

Limitations of this study are similar to other studies at end-of-life, including participant attrition due to disease

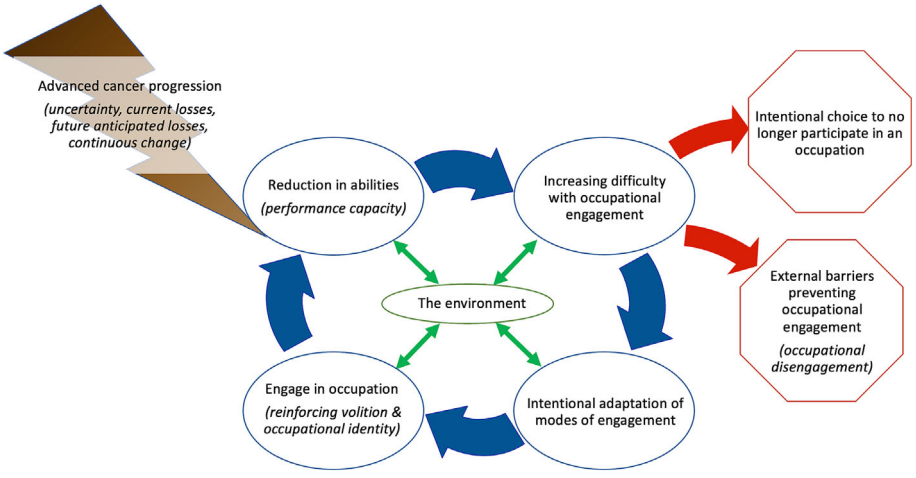

FIGURE 2 The process of occupational adaptation: advanced cancer. *Source*: Brose (2021).

progression and death and gatekeeping, which initially restricted recruitment (Bloomer et al., 2018; Steinhauser et al., 2006). Occupational patterns were limited to the specific geographical area and age group of participants. Generalisability is limited due to cultural and age-specific norms pertaining to what they deem meaningful, including the value of work, family, and independence.

Further longitudinal research is warranted to help us better understand the lived experience and process of occupational adaptation for a larger cohort of adults living with other progressive medical conditions in different geographical areas. Additional research on how occupational therapists assess and address volition and adaptation when working with people with palliative and end-of-life care needs would provide greater insight into their clinical reasoning processes and enhance the care provided.

4.2 | Implications for occupational therapy practice

Understanding the significance of occupational engagement and the link between engagement, volition, the environment and occupational adaptation can shape clinical practice when working with adults living with advanced cancer. Occupational therapists are encouraged to listen to the volition and occupational priorities of those they work with to identify meaningful interventions to facilitate continued occupational engagement within the contexts or environments in which they inhabit. Due to the nature of progressive functional decline in advanced cancer, ongoing reassessment should be considered to facilitate continued occupational engagement. MOHO can be used as a framework to understand a person's motivation behind occupational engagement (volition), their daily routines (habituation) and their abilities (performance capacity) within their environmental context.

5 | CONCLUSION

Study findings build on the MOHO concept of occupational adaptation for people with advanced cancer and identify the importance of facilitating volitional control when attaining occupational competency is unachievable. This study affirms that occupational adaptation is an ongoing process driven by a person's volition, occurring *through* occupational engagement for people experiencing the complex downward trajectory of advanced cancer. People intentionally choose to participate in valued occupations amid—and despite—increasing dependency due to cancer progression, as this can facilitate a sense of self and normalcy. The motivator for occupational adaptation is a person's volition (interests, values, and personal causation). Environmental factors often facilitate or prevent participation in occupations and must be considered. The environment also plays a central role in facilitating or preventing occupational engagement.

Greater consideration of occupational adaptation and its dynamic relationship with volition and the environment is required, particularly when the plateauing of competency is untenable. As a person's abilities decline due to cancer progression, occupational therapists need to address not only the individual's functional abilities but also the motivation behind their desire to participate in occupations. This can foster quality of life at the end of life, facilitating a sense of normalcy and meaning. A greater understanding of occupational adaptation can inform the theoretical frameworks that underpin occupational therapy practice, enabling person-centred care for people experiencing progressive and unremitting functional decline.

AUTHOR CONTRIBUTIONS

All authors meet the authorship criteria as outlined in the International Committee of Medical Journal Editors (ICJME) recommendations. The first author designed the study, conducted data collection and the first analysis of themes, with contributions from the second and third authors for study design and discussions on thematic analysis. The first author was responsible for drafting and writing the article; all authors contributed to its completion and approved the final published version of this article.

ACKNOWLEDGEMENTS

The authors thank the participants and their families for sharing their stories in the final year of their lives.

CONFLICT OF INTEREST STATEMENT

The authors declared no conflict of interest related to the research, authorship, and/or publication of this article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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REFERENCES

Abernethy, A. P., Shelby-James, T., Fazekas, B. S., Woods, D., & Currow, D. C. (2005). The Australia-modified Karnofsky Performance Status (AKPS) scale: A revised scale for contemporary palliative care clinical practice. *BMC Palliative Care*, *4*(1), 7. https://doi.org/10.1186/1472-684X-4-7

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, *74*(Suppl. 2), 7412410010. https://doi.org/10.5014/ajot.2020.74S2001

Arantzamendi, M., García-Rueda, N., Carvajal, A., & Robinson, C. A. (2020). People with advanced cancer: The process of living well with awareness of dying. *Journal of Qualitative Health Research*, *30*(8), 1143–1155. https://doi.org/10.1177/1049732318816298

Badger, S., Macleod, R., & Honey, A. (2016). "It's not about treatment, it's how to improve your life": The lived experience of occupational therapy in palliative care. *Palliative & Supportive Care*, *14*(3), 225–231. https://doi.org/10.1017/S1478951515000826

Black, M. H., Milbourn, B., Desjardins, K., Sylvester, V., Parrant, K., & Buchanan, A. (2019). Understanding the meaning and use of occupational engagement: Findings from a scoping review. *British Journal of Occupational Therapy*, *82*, 272–287. https://doi.org/10.1177/0308022618821580

Bloomer, M. J., Hutchinson, A. M., Brooks, L., & Botti, M. (2018). Dying persons' perspectives on, or experiences of, participating in research: An integrative review. *Palliative Medicine*, *32*(4), 851–860. https://doi.org/10.1177/0269216317744503

Brose, J. M. (2021). The intentional pursuit of everyday life while dying: A longitudinal exploration of occupational engagement for working-aged adults living with advanced cancer [PhD dissertation, Flinders University]. https://theses.flinders.edu.au/view/05838a65-7370-4ebb-9995-ea8bed678e5c/1

Brose, J. M., Willis, E., & Morgan, D. D. (2023). The intentional pursuit of everyday life while dying: A longitudinal qualitative study of working-aged adults living with advanced cancer. *Palliative Medicine*, *37*(8), 1210–1221. https://doi.org/10.1177/02692163231180911

Carel, H. (2016). *Phenomenology of illness*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199669653.001.0001

Chow, J. K., Pickens, N. D., Fletcher, T., Bowyer, P., & Thompson, M. (2022). Missed opportunities to ease suffering: An explanatory model of occupational therapy utilization in end-of-life care. *American Journal of Hospice & Palliative Medicine*, *40*, 10499091221143917. https://doi.org/10.1177/10499091221143917

Chow, J. K., Pickens, N. D., Fletcher, T., Thompson, M., & Bowyer, P. (2023). "You've got to do something": Developing occupational therapists' role in end-of-life care. *OTJR: Occupational Therapy Journal of Research*, *43*(1), 109–118. https://doi.org/10.1177/15394492221088239

Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 48–71). Oxford University Press.

Cotton, G. S. (2012). Occupational identity disruption after traumatic brain injury: An approach to occupational therapy evaluation and treatment. *Occupational Therapy in Health Care*, *26*(4), 270–282. https://doi.org/10.3109/07380577.2012.726759

la Cour, K., & Hansen, H. P. (2012). Aesthetic engagements: "Being" in everyday life with advanced cancer. *American Journal of Hospice & Palliative Medicine*, *29*(2), 126–133. https://doi.org/10.1177/1049909111413117

Dolgoy, N., Driga, A., & Brose, J. M. (2021). The essential role of occupational therapy to address functional needs of individuals living with advanced chronic cancers. *Seminars in Oncology Nursing*, *37*(4), 151172. https://doi.org/10.1016/j.soncn.2021.151172

Fisher, G., Parkinson, S., & Haglund, L. (2017). The environment and human occupation. In R. R. Taylor (Ed.), *Kielhofner's model of human occupation: Theory and application* (5th ed., pp. 91–106). Wolters Kluwer.

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, *20*(9), 1408–1416. https://doi.org/10.46743/2160-3715/2015.2281

García-Rueda, N., Carvajal Valcárcel, A., Saracíbar-Razquin, M., & Arantzamendi Solabarrieta, M. (2016). The experience of living with advanced-stage cancer: A thematic synthesis of the literature. *European Journal of Cancer Care*, *25*(4), 551–569. https://doi.org/10.1111/ecc.12523

Hammill, K., Bye, R., & Cook, C. (2019). Occupational engagement of people living with a life-limiting illness: Occupational therapists' perceptions. *Australian Occupational Therapy Journal*, *66*(2), 145–153. https://doi.org/10.1111/1440-1630.12557

Hartrick Doane, G., & Varcoe, C. (2005). Toward compassionate action: Pragmatism and the inseparability of theory/practice. *Advances in Nursing Science*, *28*(1), 81–90. https://doi.org/10.1097/00012272-200501000-00009

Health Canada. (2022). Third annual report on medical assistance in dying in Canada 2021. https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html

Kleinman, A. (2020). *The illness narratives: Suffering, healing, and the human condition*. Basic Books.

Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science*, *12*(1), 9–16. https://doi.org/10.1080/14427591.2005.9686543

Knox, M. K., Hales, S., Nissim, R., Jung, J., Lo, C., Zimmermann, C., & Rodin, G. (2017). Lost and stranded: The experience of younger adults with advanced cancer. *Supportive Care in Cancer*, *25*(2), 399–407. https://doi.org/10.1007/s00520-016-3415-8

de las Heras de Pablo, C.-G., Fan, C.-W., & Kielhofner, G. (2017). Dimensions of doing. In R. R. Taylor (Ed.), *Kielhofner's model of human occupation: Theory and application* (5th ed., pp. 107–122). Wolters Kluwer.

Lee, S. W., & Kielhofner, G. (2017). Volition. In R. R. Taylor (Ed.), *Kielhofner's model of human occupation: Theory and application* (5th ed., pp. 38–56). Wolters Kluwer.

Liamputtong, P. (2013). *Qualitative research methods*. Oxford University Press.

Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation*, *30*, 73–84. https://doi.org/10.1002/ev.1427

Lundquist, D. M., Berry, D., Boltz, M., Desanto-Madeya, S. A., & Grace, P. J. (2019). Wearing the mask of wellness: The experience of young women living with advanced breast cancer. *Oncology Nursing Forum*, *46*(3), 329–337. https://doi.org/10.1188/19.ONF.329-337

Maersk, J. L., Johannessen, H., & la Cour, K. (2017). Occupation as marker of self: Occupation in relation to self among people with advanced cancer. *Scandinavian Journal of Occupational Therapy*, *1-10*, 9–18. https://doi.org/10.1080/11038128.2017.1378366

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. State University of New York Press.

Morgan, D. D., Currow, D. C., Denehy, L., & Aranda, S. A. (2017). Living actively in the face of impending death: Constantly adjusting to bodily decline at the end-of-life. *BMJ Supportive & Palliative Care*, *7*(2), 179–188. https://doi.org/10.1136/bmjspcare-2014-000744

Morgan, D. D., Taylor, R. R., Ivy, M., George, S., Farrow, C., & Lee, V. (2022). Contemporary occupational priorities at the end of life mapped against model of human occupation constructs: A scoping review. *Australian Occupational Therapy Journal*, *69*(3), 341–373. https://doi.org/10.1111/1440-1630.12792

Oregon Health Authority. (2022). Oregon death with dignity act: 2021 data summary. https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

Paley Altit, T., Shor, R., & Maeir, A. (2019). Occupational identity, competence, and environments among adults with and without attention deficit hyperactivity disorder. *Occupational Therapy in Mental Health*, *35*(2), 205–215. https://doi.org/10.1080/0164212X.2019.1588833

Park, E. M., Check, D. K., Song, M.-K., Reeder-Hayes, K. E., Hanson, L. C., Yopp, J. M., Rosenstein, D. L., & Mayer, D. K. (2017). Parenting while living with advanced cancer: A qualitative study. *Palliative Medicine*, *31*(3), 231–238. https://doi.org/10.1177/0269216316661686

Park Lala, A., & Kinsella, E. A. (2011). A phenomenological inquiry into the embodied nature of occupation at end of life. *Canadian Journal of Occupational Therapy*, *78*(4), 246–254. https://doi.org/10.2182/cjot.2011.78.4.6

Parsons, L., & Stanley, M. (2008). The lived experience of occupational adaptation following acquired brain injury for people living in a rural area. *Australian Occupational Therapy Journal*, *55*(4), 231–238. https://doi.org/10.1111/j.1440-1630.2008.00753.x

Peoples, H., Nissen, N., Brandt, Å., & la Cour, K. (2017). Belonging and quality of life as perceived by people with advanced cancer who live at home. *Journal of Occupational Science*, *1-14*, 200–213. https://doi.org/10.1080/14427591.2017.1384932

Saldaña, J. (2003). *Longitudinal qualitative research: Analyzing change through time*. Rowman Altamira.

Schkade, J. K., & Schultz, S. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, Part 1. *American Journal of Occupational Therapy*, *46*(9), 829–837. https://doi.org/10.5014/ajot.46.9.829

Schultz, S., & Schkade, J. K. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, Part 2. *American Journal of Occupational Therapy*, *46*(10), 917–925. https://doi.org/10.5014/ajot.46.10.917

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., Lindquist, J. H., & Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative Medicine*, *20*(8), 745–754. https://doi.org/10.1177/0269216306073112

Taylor, R. R. (Ed.). (2017). *Kielhofner's model of human occupation: Theory and application* (5th ed.). Wolters Kluwer.

Toombs, S. K. (1987). The meaning of illness: A phenomenological approach to the patient-physician relationship. *Journal of Medicine and Philosophy*, *12*(3), 219–240. https://doi.org/10.1093/jmp/12.3.219

Townsend, E. A., Beagan, B., Kumas-Tan, Z., Versnel, J., Iwama, M., Landry, J., Stewart, D., & Brown, J. (2013). Enabling: Occupational therapy's core competency. In E. Townsend & H. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation* (pp. 87–133). CAOT Publications ACE.

Walder, K., & Molineux, M. (2017). Occupational adaptation and identity reconstruction: A grounded theory synthesis of qualitative studies exploring adults' experiences of adjustment to chronic disease, major illness or injury. *Journal of Occupational Science*, *24*(2), 225–243. https://doi.org/10.1080/14427591.2016.1269240

Wilcock, A. (1993). A theory of the human need for occupation. *Journal of Occupational Science*, *1*(1), 17–24. https://doi.org/10.1080/14427591.1993.9686375

Williams, S., & Murray, C. (2013). The lived experience of older adults' occupational adaptation following a stroke. *Australian Occupational Therapy Journal*, *60*(1), 39–47. https://doi.org/10.1111/1440-1630.12004

Yamada, T., Taylor, R. R., & Kielhofner, G. (2017). The person-specific concepts of human occupation. In R. R. Taylor (Ed.), *Kielhofner's model of human occupation: Theory and application* (5th ed., pp. 11–23). Wolters Kluwer.

How to cite this article: Brose, J. M., Willis, E., & Morgan, D. D. (2024). Occupational adaptation for adults living with advanced cancer: A phenomenological longitudinal study. *Australian Occupational Therapy Journal*, *71*(1), 52–63. https://doi.org/10.1111/1440-1630.12908