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'This is the peer reviewed version of the following article: Morgan, D. D., Currow, D. C., Denehy, L., & Aranda, S. A. (2015). Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life. *BMJ supportive & palliative care*, bmjspcare-2014. doi:10.1136/bmjspcare-2014-000744

which has been published in final form at

DOI:

<http://dx.doi.org/10.1136/bmjspcare-2014-000744>

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TITLE PAGE

Living actively in the face of impending death: Constantly adjusting to bodily decline at the end-of-life.

BMJ Support Palliat Care doi:10.1136/bmjspcare-2014-000744

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Key words:

Cancer, phenomenology, embodiment, participation, functional ability

Word count:

Abstract: 248

ABSTRACT

Context: People with advanced cancer experience bodily change resulting in debilitating functional decline. Although inability to participate in everyday activities (occupation) contributes to profound suffering, limited research has examined the relationship between altered bodily experience (embodiment) and functional ability.

Objectives: The purpose of this study was to better understand the lived experience of functional decline for people with advanced cancer living at home.

Methods: In-depth interviews were conducted with ten community dwelling people with advanced cancer about their bodily experiences of functional decline. This study employed a pragmatic qualitative approach, informed by hermeneutic phenomenology.

Results: People described living with rapidly disintegrating bodies and how this affected their ability to participate in everyday activities. Analysis identified themes which were evaluated against conceptual frameworks of 'occupation' and 'embodiment.' People experienced a shifting sense of self. They had to continuously reinterpret changing bodies. Previously automatic movements became disjointed and effortful. Simple actions like standing or getting out of bed required increasing concentration. Relentless bodily breakdown disrupted peoples' relationship with time, hindering their ability, but not their desire, to participate in everyday activities. Contending with this deterioration is the work of adaptation to functional decline at the end-of-life.

Conclusion: This study highlights the role active participation in everyday activities plays in mediating adjustment to functional decline. These findings challenge us to look beyond palliation of physical symptoms and psycho-spiritual care as ends in themselves. Symptom control and palliation should be viewed as mechanisms to optimise active participation in essential and valued activities.

INTRODUCTION

People with advanced cancer experience bodily deterioration resulting in debilitating functional decline.[1] Breakdown in body function contributes to increased dependence in everyday activity (occupation) and patient loss of dignity [2] and results in significant carer burden.[3] In the context of advanced disease, this breakdown is associated with subsequent social withdrawal contributing to a loss of self, a loss mediated by uncontrollable and often unbounded bodies.[4] However, adaptation to physical deterioration during illness has been found to be mediated by a reunification of self and body.[5] Embodiment is characterised by

an interconnectedness of body and self.[6-7] Our bodies are our way of being-in-the-world, [7] of knowing our world.[8-9] They enable us to engage in occupations such as self-care, leisure or work, within social, environmental and temporal settings.[8] Autobiographical accounts of illness experience starkly portray the multidimensional nature of being unwell, highlighting relationship between body and ability required to engage in everyday activities.[10-11]

Advances in disease modifying therapies increasingly give rise to extended survival, with prolonged periods of functional decline. Existing palliative care research about embodiment highlights existential suffering associated with altered bodily experience and the abject nature of a deteriorating body.[12-14] Altered embodiment may be manifested as heightened awareness of body habitus (e.g. tight skin, shortness of breath, uncontrolled dribbling), often described objectively by clinicians as symptoms. Rarely has patient subjective experience of bodily changes and their impact on functional ability been examined through the lens of altered embodiment *and* active participation in everyday activities (occupation).[15] Although emerging research examines the generative potential of occupational experiences at the end-of-life [16-17] and the occupation of dying,[18-19] the subjective experience of occupational performance is under-researched.[8] Importantly, a systematic review examining embodied experience at the end-of-life highlights an imperative for generating empirical and theoretical knowledge about this experience to better inform supportive interventions.[20]

The experience of functional decline is universal for people with a palliative diagnosis,[21] impinging upon every aspect of daily life. People are progressively confronted with an increasingly unfamiliar and confusing body. Irrespective of how disabled a person's body may be, using one's body is our key interface with living and the world.[8] While the health professional defines disease and symptoms that manifest it, the person defines the illness, the impact of physical symptoms and how they experience this in an embodied and functional context.[22-23] Embodied experiences of physically active living whilst dying are underrepresented in palliative care and occupational therapy literature. Better understanding patient experience of predictable bodily deterioration and subsequent impact on everyday function (occupation) is vital to informing assessments and interventions employed by health professionals to optimise function at the end-of-life. This study sought to understand the lived

experience of functional decline at the end-of-life by mapping it against conceptual frameworks of embodiment and occupation.

METHODS

Study design was informed by hermeneutic phenomenology as defined by van Manen (1990), [24] and both descriptive (phenomenological) and interpretive (hermeneutic). An interpretive paradigm privileges participants’ voices, providing insights into qualities of everyday experience not elicited from objective measures.[8] Interview schedule development (DM) and subsequent interpretation of findings (DM) was guided by conceptual frameworks of ‘embodiment’ and ‘occupation’ and relevant literature (Table 1) [25-26] and critically reviewed by experienced researchers (SA, DC, LD).

Table 1. Example of theoretical background of interview schedule

Interview questions <i>Examples of probes</i>	Theory
BODY/FUNCTIONAL CHANGES	
Tell me a bit about how you manage day to day things <i>What has that been like for you?</i> <i>What is it like to have legs like pillars?</i>	Model of Human Occupation Embodiment
If I followed you through a typical day, what would I see you doing? <i>How do you feel about these changes?</i> <i>How are you coping?</i> <i>What does this feel like?</i>	Model of Human Occupation Embodiment & Model of Human Occupation
OCCUPATIONAL OR EVERYDAY PRIORITIES	
What would you like to be able to do that you can’t now? <i>What’s that like for you now it’s changed?</i>	Model of Human Occupation Embodiment
What are you most concerned about not being able to do? <i>What’s that like to not have confidence in your leg?</i> <i>How do you feel about not being able to breathe in the shower?</i>	Model of Human Occupation Embodiment
Of all the challenges you’ve described, which is the most challenging to you? <i>What’s being tired like for you?</i> <i>How do you cope with those changes?</i>	Model of Human Occupation Embodiment

Interview questions aimed to elicit opinions, and emotional and sensory responses to embodied experiences of functional decline, a characteristic not always attended to by patients or clinicians.[26] Data analysis was informed by Colaizzi's seven step process (Table 2).[27] While descriptive in nature, this provided a clear, concise structure for rigorous analysis.

Table 2. Colaizzi's data analysis steps

<ol style="list-style-type: none">1. Repeated reading of participant descriptions.2. Extracting significant statements: Identification of significant words, phrases and statements related to embodiment, occupation and experience of functional decline.3. Formulating meanings: Examination of statements for ineffable or unspoken meanings, noting contextual influences. Formulated meanings must relate directly to the text, taking care not to confer inappropriate inferences or meanings.4. Clustering themes: Organisation of formulated meanings into clusters of subthemes and themes. Themes provided comprehensive answers to the research question.5. Writing exhaustive descriptions: Integration of all aggregate ideas from the clustered themes into a comprehensive summary.6. Identification of the fundamental structure: Compilation of the exhaustive descriptions into a condensed, more refined version.7. Validation: One page summaries of interviews sent to participants for review

Purposive sampling [28] captured the experience of functional decline. Participants were community dwelling, with advanced cancer, and an Australian Karnofsky Performance Status Scale (AKPS) score between 50 – 70.[29] These parameters were selected because people with these scores are not yet bedbound, but highly likely to experience a range of functional difficulties.[30] Those with uncontrolled physical symptoms, cognitive deficits or admitted for terminal care were excluded. Ethics approval was received from The University of Melbourne Human Research and Ethics Committee. All participants provided written, informed consent.

Procedures

Ten of the thirty-four potential participants joined the study. Recruitment procedures are outlined in Figure 1 and participant demographics described in Table 3.

Table 3. Participant demographic information

Gender	7 male
Age	Median: 72 yrs (range 52 – 95) Mean: 70.5 yrs
Marital status	Married/defacto: 8 Divorced/widowed: 2 (one of whom lives alone)
AKPS status	Median: 60 (range 50 – 70)

Data collection methods included in-depth interviews (DM), review of participant medical records and DM’s reflective journal. Semi-structured interviews were conducted with 7 men and 3 women in their own homes (DM). Ages ranged from 51 to 95 years. One participant lived alone. Carers were able to remain present during the interview.

Semi structured interviews, lasting from 39 to 77 minutes, were audio recorded, transcribed verbatim in de-identified format and stored as electronic and hard copies. A one page summary of each interview was posted to participants to verify accuracy of initial data interpretation. Early transcription and analyses were conducted to capture the nature of each interview. One participant was interviewed twice as her functional level improved significantly post-surgery. She wanted clarification around pseudonym use for her husband. Another made minor changes to her one page summary. Remaining participants indicated summaries reflected their interviews (n=6) or declined to respond due to deteriorating health (n=2).

Data analysis

Data analysis was informed by Colaizzi’s (1978) methods and inductive by nature. Concepts, themes and subthemes were developed from prolonged engagement with data.[28] Data was collected from a number of sources (participants, some family members, written histories). Trustworthiness was enhanced by an audit trail and one page summaries as described above. The researcher’s role and beliefs were made explicit through reflexive journaling, enhancing rigour.

Thematic analysis aimed to identify themes built from empirical data. Themes were developed by DM and critically reviewed by SA, DC and LD representing the disciplines of occupational therapy, nursing, medicine and physiotherapy. DM’s training as an occupational therapist inclined her to focus on opportunities and minimise distress, restricting early analysis. Initial theme development highlighted the positive, however, this bias was identified through the reflexive journal, observations of the other authors and literature.[31] Subsequent analysis was modified to capture both participant struggle and achievement. Application of conceptual frameworks to data highlighted aspects of findings that corroborated existing theory, and identified areas insufficiently addressed by existing frameworks. The Model of Human Occupation (MOHO) [6] is an established conceptual and empirically tested conceptual framework that informs and guides occupational therapy research and clinical practice. MOHO was selected as it incorporates the concept of lived body and the individual’s experience of altered embodiment in everyday occupations. The decision to limit to ten interviews was based on thematic saturation from this participant group. This research complies with qualitative research guidelines.[32]

RESULTS

Participants’ experiences were situated within the paradigms of embodiment and occupation. The first three themes were grouped into the domain of experience (Inhabiting a disintegrating body; Disrupted function, Disrupted time; Shifting sense of self). The fourth theme moved beyond these immediate experiences to the work of adaptation (Contending with deterioration: the work of adaptation). Themes and subthemes are presented in Table 4.

Table 4. The experience and meaning of functional decline at the end-of-life

Inhabiting a disintegrating body	Disrupted function, disrupted time	A shifting sense of self	Contending with deterioration: The work of occupational adaption
Subtheme <i>Living with my body</i>	Subtheme <i>Disrupted function</i>	Subtheme <i>An innate desire to do</i>	Subtheme <i>Re-evaluating who I am and the expectations I have of myself and everyday life (Occupational identity)</i>
Constructs An unfamiliar body A vulnerable body:	Constructs It just exhausts me I was able to...but now I	Constructs The desire for purposeful doing	Constructs Reframing expectations and appraisal of one’s abilities

something is wrong A disintegrating body An intrusive body An unreliable and unpredictable body	just can't	Less of this and more of that	and opportunities
	Subtheme <i>Disrupted time</i> <i>Constructs</i> A paradoxical relationship with time Altered routines- a different normal	Subtheme <i>A yearning to be</i> <i>Constructs</i> Being who I am	Subtheme <i>Strategies to manage bodily changes</i> <i>(Occupational competence)</i> <i>Constructs</i> Thinking about moving before doing New ways of doing
		Subtheme <i>The shifting relationship between doing and being</i> <i>Constructs</i> Doing enables me to continue to be Inability to do hinders my ability to be Inability to do means everything falls on my family	Subtheme <i>Drawing support from others to manage physical and functional changes</i> <i>Constructs</i> Receiving assistance is characterised by deep ambivalence Interactions with health clinicians may hinder or aid the work of contending How do others manage?

The interrelationship between the four themes is depicted in Figure 2, The occupation of living at the end-of-life. The first three themes, although presented discretely, overlap as lived experience in which corporeal, temporal and relational aspects of experience coexist.[24] Each theme, or experience, may move from foreground to background depending on body symptoms, and impact on functional ability or environmental (e.g. physical, social) surrounds. All three lie situated within the fourth theme, “Contending with deterioration: the work of adaptation.” “Contending with deterioration” was an active process that required participants to re-evaluate expectations of themselves and how they participated in everyday life. Contending was essential to facilitating adjustment to functional decline. Key participant experiences of altered embodiment, its impact on function and occupational priorities are described in Table 5.

Table 5. Ways in which experiences of altered embodiment impacts function and occupational priorities

<i>Experience of altered embodiment and impact on function</i>	<i>Occupational priorities</i>
A painful, tired, unpredictable body sets limits on how and when I move, feel vulnerable, challenge to figure out ways to adapt to changeable pain	Keep going, not give in, keep eating, keep getting out of bed, keep trying to do things, sort out my affairs, spend time with my [spouse] and adult children
Legs become unreliable, weaker, shoot out, decreased confidence in legs, increasingly fatigued, changing speed of movement to accommodate unreliability of legs	Be able to get up from bed, chair and toilet. Do the everyday normal things even if it takes longer than before, stay at home for as long as possible, activities with friends
Intrusive pain and fatigue dictate daily routines, important to test out bodily limits, decreased bodily control akin to premature ageing - self contempt, fear	Most important thing is to do the form guide every Friday, keeping mentally active as well as doing what I can for myself, be this getting dressed, cooking, spending time with my [spouse]
Body tells me I am dying, see new tumours appear on limbs daily, fearful to eat because of unpredictable severe pain spasms, "living skeleton" - weak, exhausted	Balance between doing what I can for myself and receiving assistance but distressed about being a burden, teach my [spouse] practical things he/she will need to do when he/she is alone
Oozing pressure sore, dangerous body at risk of disintegrating because of dehiscent skin flap, unreliable achy legs that feel like jelly, tired, painful body	Watching my children play sport, going for coffee, learn something new within physical abilities (e.g. painting), spend time with others in similar situation
Shortness of breath and leg weakness, unreliable legs make me fearful, anxious to the point of panic attacks, ageing prematurely.	Reading because it is achievable but not what I want to do with my day, work on my cars, everything is important to keep doing, independence with toileting is non-negotiable
Although I talk to my legs I can't make them do what I tell them. Grinding, intrusive pain restricts movement, I constantly have to work to maintain mobility/function	Modified gardening activities, projects I had no time to do when I was working, house cleaning, return to work in some capacity, go on a holiday, do what I want when I want
My legs feel like pillars of sponge attached to my feet, legs are unfamiliar and strange, restrictive body, have to learn to reinterpret it when close to others	Sharing tasks with partner around home (cooking, cleaning), connecting with my music and friends, garden, find new activities to replace lost ones
Pain niggles can escalate quickly without warning, no strength in hands and legs, think before moving to avoid reflex reaching which causes much pain	Keep moving, keep walking, be doing something but unclear about what this might be, darn socks that my [spouse] gives me, watch television
Legs have no oomph, horrendous lethargy, hole where ear should be, swollen tongue and constant dribbling, weakness makes everything take so much longer	Moving and watching others move is equally important, share tasks at home to minimise burden on my [spouse], reciprocity important, find new purposeful, less physical activities to do

Theme 1. Inhabiting a disintegrating body

All participants experienced relentless progressive bodily deterioration and breakdown. Each individual's response to functional decline was unique, influenced by the meaning attached to each experience. Invariably, an unfamiliar, unwell body was confronting and confusing. Baffled by unfamiliar sensations in his legs, Oliver (71 yrs) felt compelled to move them in unusual ways,

"Well just that I want to put them up in the air and when I put them up in the air...they hurt just as much. It's just weird."

Participants' bodies were an inescapable reminder they were unwell and deteriorating rapidly. A lucid mind, cognisant of deterioration, only served to heighten their experience of vulnerability. Participants lived in bodies that were literally disintegrating, crumbling, leaking and wearing down. Sharon (59 yrs) knew the vacuum assisted closure dressing for her Grade IV pressure sore (from skin through to bone) was preventing further bodily disintegration, literally removing her disintegrating body

"While I've got the pump on it's maintaining..., skin's not breaking down any more... sucking out all that old stuff underneath."

Some experienced their bodies as objects of disgust, abhorrent to others, particularly when bodily fluids could not be contained. Physical sensations associated with deterioration were intrusive. These bodily changes became more intrusive when participants were unable to exert control over them. Charlie (77 yrs) noted,

"...if I move forward a little bit at the wrong angle, it whacks you ...Like I can reach down there...but if I try to bend over down there...No way!"

Participants experienced their unreliable and unpredictable bodies as embarrassing, frustrating, even terrifying when breathing became impossible after only a short walk. Unreliable legs caused Bob (69 yrs) to fall twice, which he attributed to,

"...just lack of muscle tone, my legs just give way, the body short of the waist, there's just bugger all there to hold me up."

Participants' altered bodily experience was confusing and disorienting. A disintegrating body felt dangerous.

Theme 2. Disrupted function, disrupted time

Participants experienced inexorable fatigue and any activity took more time. Exhaustion overwhelmed in every sense - physically, emotionally and cognitively. When fatigue became all-consuming, participants simply abandoned whatever they were doing. Complex activities such as leisure pursuits were often abandoned first.

"...the car out there, just can't get to it, it's been sittin' out there for a month...by the time I get there I feel really lethargic." (John, 71 yrs)

Available energy was often channelled into personal care needs. This was deeply frustrating.

Simply moving from sitting to standing required tremendous physical and mental concentration. Even component parts of activities ceased to be achievable.

"I said, 'If you [daughter] hadn't of been here I'd be stuck here' [toilet]... Just couldn't lever myself up...my knees sort of wouldn't bend...a week from being in hospital in bed." (Glenys, 72 yrs)

Participants required increasing assistance for all activities, evoking feelings of frustration and guilt. They expressed a constant underlying worry and anxiety about coping with rapidly increasing dependency.

Experience of time was irrevocably changed and paradoxical as it dragged by incredibly slowly but also flew by. All participants were conscious of how little time they had left to live. Loss of familiar and purposeful routines caused by inactivity was demoralising. Time lost meaning.

"...you lose track of time...because you're used to doing things on certain days and because you can no longer do them! ...a day is just getting up, doing what you have to do, going to sleep, getting up...there's not a lot of purpose." (Charlie, 77rs)

Bodies *and* time slowed down. Routines often depended on health professionals and other carers who made up the deficit for these bodily changes, resulting in lost capacity to plan and prioritise their own time use.

Theme 3. Shifting sense of self

Despite a disintegrating body, participants' desire to actively engage in everyday life remained undiminished. While yearning to be active remained a potent force, sense of self

was irrevocably altered. Nonetheless, participants were adamant they didn't want to sit languishing. The individual determined what was important to keep doing.

"...the everyday things... I'd just like to keep on doing what I did do, it doesn't matter if I can't do it as fast or as much but just keep doing the things that I have all my life."

(Glenys, 72 yrs)

Essentials around personal hygiene and ability to stand and walk were priorities for some. Opportunity to do enjoyable activities like gardening or completing the horse racing betting odds in the newspaper took priority for others.

Some participants expressed a desire to learn new physically achievable activities, as their ability to engage in familiar occupations declined. Participating in activities *with* others was experienced as retaining connection with people and *living*. Desire for participation was evidenced by ongoing engagement in occupations, even as function declined. Participants engaged increasingly in more sedentary activities like reading and computer games. Occupational participation also changed form, such as listening to music instead of playing an instrument. Importantly, active participation was not reliant on optimal physical activity. Ability to participate, even in a less physical manner, was fundamental in maintaining a sense of self.

Although participants deeply appreciated practical assistance received from carers, ability to contribute to others' wellbeing remained paramount. This could involve preparing a partner for life alone, or helping out around the house. Retaining responsibility was highly valued. Inability or withdrawal of opportunity to contribute to others' well being was experienced as degrading, extinguishing a sense of worth. At ninety-five, Albert struggled with his wife's efforts to protect him from overexertion.

"Alice has taken over; she won't let me do anything so I've got to do it behind her back then she blasts me. That's the only thing...I still like responsibility." (Albert, 95 yrs)

A disintegrating body restricted participants' abilities to participate in social outings such as family events, which was deeply frustrating. Fear of being a continuing burden to others was very distressing. Participants continually reappraised how they saw themselves and how

they fitted into their environments in the face of progressive and relentless deterioration. They experienced a constantly shifting sense of self.

Theme 4. Contending with deterioration: the work of adaptation

Illness poses a significant threat to occupational (everyday activities) adaptation. Participants had to reframe self expectations as they appraised self (occupational identity) and abilities (occupational competence). Occupations once considered inconsequential or automatic; such as putting on a sock, were perceived by some as a major achievement. Integrity of occupational identity was compromised when participants were unable to adjust expectations down, reappraising who they were in light of these changes. Continued engagement in everyday occupations required participants to develop strategies to manage disrupted embodiment. Interpretation of bodily changes required time.

Participants pushed themselves to establish functional limits. They had to consciously think about *how* they moved before they did and develop new ways of moving. Forward planning was required for activities previously performed unconsciously. Several described a battle between self and body. Self tried to force the body to move. Occasionally *self* won, but more often the *body* was the victor, demanding rest. Participants changed how they moved as their bodies ceased to function in familiar ways. Movement became disjointed, not fluid and smooth, punctuated by stops and starts.

"I can't just jump up..., I've got to wiggle up to the edge and then push myself up... I can't just jump up...out of the chair anymore."(Sharon, 59 yrs)

Participants continually reframed expectations of what was achievable. They paced themselves, resting more frequently. As they became familiar with unceasing bodily deterioration, they learned how to work with this uncertainty. Contingency became the certainty. New, creative ways of moving were required in order to engage in everyday activities. Participants were more likely to accept assistive equipment as bodies deteriorated. The need to test physical capacity, "*learning the limitations*" (Bob), was powerful. Participants preferred to try and do things independently before asking for assistance. When assistance was required, it evoked marked ambivalence. Participants

deeply appreciated help but experienced equally strong opposing responses of frustration, guilt and self-doubt when help was offered.

Interactions with health clinicians hindered or helped the work of contending with relentless functional decline. Honest communication about prognosis and provision of flexible options for care helped participants plan their future. Conversely, unskilled clinicians and fragmented care, characterised by poor communication, led to insufficient support, frustration and isolation. Several participants wanted to share experiences and coping strategies with others in similar situations.

DISCUSSION

Two aspects of end-of-life illness experience are underrepresented in palliative care and occupational therapy literature – embodiment (how we experience our bodies) and occupation (everyday activities) at the end-of-life. This study examined the experience of embodied functional decline and its impact on occupation. An in-depth understanding of the end-of-life illness experience is essential to inform clinical assessment and interventions that address people's needs.

To précis the four themes, people with advanced cancer experience physical changes, resulting in disrupted embodiment, progressive functional decline and an altered relationship with time. Sense of self is challenged in the face of inexorable deterioration and shortened life, as ability to engage in essential and valued occupations becomes increasingly difficult, often impossible. The work of contending with a shifting sense of self, a disintegrating body, disrupted function, and altered relationship with time is not simply an inevitable consequence of functional decline, rather pivotal in facilitating adjustment to these changes. This is mediated in several ways. Engagement in everyday occupations provides opportunity to develop a mutually enabling relationship between body and self.[17, 33-34] This study lends support to emerging evidence that the work of contending with deterioration through testing out limits and potential of changing bodies maintains and, for some, improves functional ability of people with advanced disease.[35-38]

Importantly, adjustment to progressive occupational loss and disrupted embodiment for those with advanced cancer occurs *through* struggling to participate in everyday occupations. Contending with deterioration is not just about restoration of function, instead about trying and failing; continually testing ever decreasing physical abilities to establish what *is* possible.[12, 16-17] While existential contemplation about loss is an inherent part of this process, the work of contending with deterioration cannot occur without *active* physical participation. Occupational adaptation [8] or contending, as defined by this study, is the outworking of a person’s occupational competence, influenced by their sense of self or occupational identity.

A person does not cease to be who they are because of a diagnosis of advanced cancer.[18, 39] *Doing* enables us to be who we are in the present, helping us become who we have the capacity to be.[40] Conversely, inability to participate, albeit in limited ways, contributes to profound suffering.[41] These findings lend support to Christiansen’s (1999)[42] proposition that identity (sense of self) is linked to occupational participation (*doing*). Doing creates meaning in life. Grappling with these continuous changes enables people to establish continuity with past, present and future, holding on to an evolving sense of self. Seemingly small expressions of participation like potting plants instead of rigorous gardening become profoundly important.

Participants reframed what constituted achievement in their everyday life. Little achievements became vitally important. The ordinariness of achievements concealed their heightened significance. Participants found ongoing connection with living, meaning and purpose *through* engagement in meaningful occupation, albeit in ever declining ways.[15,40,43] Clinical and research implications are outlined in Table 6.

Table 6. Implications for clinical practice and future research

Clinical implications	Research Implications
The drive to actively participate in everyday activities is strong, even in the face of functional decline. Study participants spontaneously employed strategies to continue living as actively as they could for as long as possible. Although they wanted	Areas warranting further research include - How to better inform understanding of patient experience of altered embodiment and its impact on optimising function. MOHO offers a range of rigorously developed

guidance about how to do this, little was forthcoming from health clinicians.

The work of contending with functional decline is confronting and difficult but *critical* for mediating occupational adaptation at the end-of-life. Key factors to enabling participation are

- Ask the patient what is important to *them* to be doing now
- Facilitate access to the experience of disrupted embodiment by helping patients articulate how their body feels and how this affects their functional ability.

It is vital to distinguish between *palliative* and *terminal* states when considering optimising function at the end-of-life. Participants in this group were not imminently terminal (i.e. last days to hours) although some died within weeks of interview. Active participation in everyday activities at the end-of-life is of *paramount* importance to people.

assessment tools that capture lived experience perspectives.[6] However, there is limited research into the use of these tools for those with a palliative diagnosis.

- Further investigation into interventions that will optimise function and enhance participation in valued and essential activities at the end-of-life
- Examination of current practice barriers that hinder rehabilitation to optimise function at the end-of-life

Limitations

A qualitative interpretive paradigm was chosen in order to elicit participants' experience of altered embodiment and its relationship with occupation. This approach does not seek to generate findings that are directly transferable to other populations. Single interviews limit observations to that precise point in time and cannot capture longitudinal changes. They also limit the sense of comfort and intimacy that can be developed between researcher and participant, restricting opportunity to explore more sensitive topics.

All participants were Anglo European with more men. All but one person had carers. It is likely that different cohorts (e.g. people living alone, different diagnostic groups) could yield different results. Understanding experiences of those who declined to participate may have revealed additional insights into this lived experience.

CONCLUSIONS

This study's key significance lies in the identification of the critical importance of active participation in everyday occupations in the face of functional decline, enabled by effective symptom palliation and psycho-spiritual care. It highlights the integral role of active participation not only in attenuating suffering, but in mediating adaptation to bodily

changes and functional decline at the end-of-life. Study findings support and add empirical data to the conceptual frameworks of occupation and embodiment. Findings emphasise the dynamic interplay between lived body and occupation for those with advanced cancer.

This study draws attention to the active living undertaken by people in the midst of dying. Meaning ascribed to every day occupations is heightened as ability to participate diminishes. However, the significance of these activities often remains obscured by their ordinariness. As clinicians and researchers, we must challenge nihilistic attitudes that view functional decline as inevitable and ignore opportunities to optimise function at the end-of-life. Physical and existential adjustment to loss of function is mediated *through* participation. Opportunities to participate must be provided to optimise function in valued and essential occupations, as determined by the individual. This research speaks to the extraordinary nature of the ordinary and the complexity of living until you die. The empirically developed framework of occupation (MOHO) provides a foundation for future examination of participation in everyday occupations at the end-of-life.

Acknowledgements

This work was funded by a National Health and Medical Research Council Palliative Care PhD Training scholarship awarded to D.D.M. The authors acknowledge the 10 participants for their involvement in these interviews and their contribution to the future care of others.

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Competing Interests: None declared.

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