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International consensus on occupational therapy interventions for people with palliative care needs: A European Association for Palliative Care Group Concept Mapping study

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Abstract

Background: While evidence shows that occupational therapists can play a key role in the care of people with palliative care needs, more knowledge about effective occupational therapy interventions for this group is needed.

Aim: To identify, organise and prioritise intervention components considered to be effective within occupational therapy for people with palliative care needs from the perspective of occupational therapy clinicians, managers and researchers.

Design: Group Concept Mapping utilising a mixed methods participatory approach. Using a focus prompt, participants brainstormed, sorted, labelled and rated generated statements about effective occupational therapy intervention components. Multidimensional scaling analysis and cluster analysis were conducted.

Setting/Participants: Snowball recruitment was used to recruit participants. Participants included occupational therapists worldwide who were able to read and write in English and were working as clinicians, managers and/or researchers with occupational therapy interventions for people with palliative care needs.

Results: Seventy-two occupational therapists from 15 countries participated in the study representing Asia (n = 3, 20%), Europe (n = 8, 53%), Oceania (n = 2, 13%) and North America (n = 2, 13%). A total of 117 statements were identified and organised into five clusters: (1) being client-centred, (2) promoting occupational engagement to optimise quality of life, (3) involving the social and relational environment, (4) enabling occupations and (5) facilitating occupational adaptation.

Conclusions: Five clusters of core occupational therapy intervention components were considered to be effective when supporting people with palliative care needs. Research should use this knowledge to inform future occupational therapy interventions for this group of people.

Keywords

Occupational therapy, palliative care, quality of life, Group Concept Mapping

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What is already known about the topic?

- Occupational therapy plays a growing role in the care of people with palliative care needs.
- Although some research has mapped the scope of occupational therapy practice in palliative care and evaluated the efficacy of occupational therapy interventions, no research has achieved international consensus on occupational therapy intervention components considered to be effective for people with palliative care needs.

What this paper adds?

- An international consensus identified core occupational therapy intervention components that were considered effective for people with palliative care needs.
- These components include client-centred compensatory approaches that facilitate continuous adaptation to support occupational engagement and adjustment to deterioration.
- The involvement of the family to support quality of life underpins care.

Implications for practice, theory or policy?

- The results can be used to set a research agenda for future occupational therapy intervention studies in palliative care.
- Future studies may use the identified intervention components to inform the content of their interventions which subsequently can be evaluated in terms of feasibility, effect and cost effectiveness.

Background

Pursuing ongoing engagement in occupation[1–7] remains a priority for people with palliative care needs, irrespective of disease progression. The term *occupation* is used within the occupational therapy profession to describe meaningful and/or purposeful performance (i.e. doing) of tasks like dressing, eating, shopping, gardening, hiking and working.[8] Occupational engagement emerges when the doing is combined with an experience of value in that doing and is sometimes used interchangeably with participation.[9] The importance of occupational engagement is evidenced by the growing number of people being in the palliative phase of their disease choosing to end their life because the prospect or experience of losing their occupations is considered unbearable.[10,11] The main source of intolerable suffering as reported by those who chose medical assistance in dying[11] was identified as loss of the ability to engage in occupation. However, there are ways to mitigate this suffering, even as the disease progresses, and occupational therapists plays a key role in this.

The primary focus of occupational therapy for people with palliative care needs is to facilitate engagement in occupation.[7,12] However, while much research documents that occupational therapists may play a key role in the care of those with palliative care needs,[1,12–14] less attention has been devoted to establishing evidence for the effectiveness of occupational therapy interventions.[15–18] Thus, four intervention studies[15–18] found no clear effectiveness of occupational therapy interventions, which may in part be explained by the use of outcome measures focusing on functioning rather than improved or maintained occupational engagement.[19] More knowledge is therefore needed about effective occupational therapy interventions. When developing new interventions, current guideline recommends to draw on evidence and existing theory and involve different stakeholders, for example, occupational therapists working in palliative care with clinical and research expertise.[20]

The European Association for Palliative Care is membership organisation supporting clinicians and researchers promoting and developing palliative care, and they host several task force to achieve this aim. An Occupational Therapy Task Force in Palliative Care was established in 2019 and approved by the European Association for Palliative Care to set a research agenda for future occupational therapy intervention studies in palliative care. The first task in the group and the objective of the present study was to identify, organise and prioritise intervention components considered to be effective within occupational therapy interventions for people with palliative care needs from the perspective of occupational therapy clinicians, managers and researchers across Europe and internationally.

Methods

Study design and procedures

Group Concept Mapping was applied, which is a structured mixed-method participatory approach incorporating the perspectives of participants on a selected topic.[21–23] The following phases were included in the structured Group Concept Mapping process: (1) preparing , (2) generating the ideas (brainstorming), (3) structuring the statements (sorting and rating), (4) Group Concept Mapping analysis (data analysis) and (5) interpreting the

map (validation).[21] The brainstorming was conducted between December 6th 2021 and January 31st 2022, sorting and rating between February 24th and April 17th 2022. Finally, the validation meeting took place online June 9th 2022.

The process may involve face-to-face group sessions, online participation or both.[21] In the present study, brainstorming, sorting, labelling and rating were conducted individually online, whereas validation took place via an online group session on Zoom. Brainstorming, sorting, labelling, rating and generating a cluster rating map were performed using the Concept System® Groupwisdom™ software: Concept Systems, Inc. Copyright 2004–2020; all rights reserved (hereafter: Groupwisdom™).

Preparing. Before initiating the data collection, a focus prompt was formulated and piloted by a researcher, a clinician and a manager, all with a background as occupational therapists. The final version was: '*In my experience, an effective intervention component within occupational therapy interventions for people with palliative care needs is. . .*'

Generation of ideas (brainstorming). Potential participants received an email with a link to the brainstorm task in the Groupwisdom™ software. They were instructed to brainstorm as many brief responses as possible to the focus prompt. They were reminded to keep each sentence/idea short so that it contained only one meaning (for instance 'taking place in the person's home environment'). The brainstorming phase ran for 3 weeks. A reminder was sent to the Occupational Therapy Task Force network and the Facebook groups 3 days before the deadline regarding completion of the brainstorming phase. A broad list of ideas was generated from participants' responses. Identical ideas were identified independently by two of the authors, both occupational therapists and experienced with the group concept mapping methodology. Identical ideas were removed after consensus was reached. If needed, the language was edited to ensure readability.

Structuring the statements (sorting and rating). Again, potential participants received an email with information about the sorting and rating tasks along with a link to Groupwisdom™. First, participants were asked to sort all ideas generated during the brainstorm into groups of ideas and to label each group. This was an individual task that was performed according to individual preferences. Next, the participants rated the importance of each idea on a four-point ordinal scale from 'Not at all important' (score = 1) to 'Very important' (score = 4).

Group Concept Mapping analysis (data analysis). Based on phases two and three, Groupwisdom™ software was used to generate a Cluster Rating Map that showed how the ideas were grouped by cluster analysis with average cluster ratings overlaid. For further information, see the section on data analysis.

Interpreting the map (Validating). The Cluster Rating Map was presented to the participants at an online validation meeting. The first author, skilled in the Group Concept Mapping methodology and not member of the Occupational Therapy Task Force network, facilitated the validation process. Participants were engaged in group discussions to revise and interpret the map, including the number and contents of derived clusters and the labels. For further information, see the section on data analysis.

Participants

Potential participants were qualified occupational therapists, working as clinicians or managers and experienced in providing occupational therapy interventions. Also, researchers conducting studies of occupational therapy interventions for adults with palliative care needs in various settings (hospitals, community-based rehabilitation centres, palliative care units, etc.) were included. The participants were required to read and write in English and be willing to participate in at least one of three activities: brainstorming, sorting and rating and/or validation of data.

Recruitment

Potential participants for the online brainstorming, sorting and rating tasks were reached through the Occupational Therapy Task Force network and through relevant Facebook groups; they were invited to participate in the study and informed about the purpose of the study, the focus prompt, inclusion criteria and the process. Snowball sampling was used to extend the recruitment scope. Invitations were sent out for the brainstorming and sorting and rating activities, respectively. A reminder was also sent out. Participants who accepted the invitations to participate in the brainstorming and/or sorting and rating tasks received an email containing a link to an online questionnaire in SurveyXact. Here, they were asked to provide informed consent and informed about their right to withdraw at any stage without consequence.

Participants for the validation meeting were also recruited among members of the Occupational Therapy Task Force network and in a manner that ensured representativity in terms of current position (clinician, manager and researcher) and nationality. No compensation for participation was granted.

Data collection

After consent was provided, participants contributing to the brainstorming and/or sorting and rating tasks provided

demographic information (age, gender, job position, country of workplace, employment setting and diagnostic groups in these settings, and years spent working with people with palliative care needs). In the email, the participants also received a link to the specific task (brainstorm or sorting/rating) in Groupwisdom™.

The numbers of participants were recorded for each stage of the Group Concept Mapping process.

Data analyses

Participant characteristics. Age and years working with people with palliative care needs were reported using median and interquartile range because data showed absence of normal distribution. Remaining demographic data were presented in numbers and percentages. Analyses of participant characteristics were performed using STATA version 17.[24]

Data from the group concept mapping process. Groupwisdom™ software was used to perform data analyses based on the ideas derived from the brainstorming. Analyses were conducted in several steps. First, ideas gathered were consolidated; if needed, identical ideas were removed and ideas were revised to clarify the meaning. The remaining ideas were then imported into Groupwisdom™ in preparation for phases three and four.

Data from single participants in phase three were included in the cluster analysis if more than 75% of the ideas were sorted and if less than five ideas remained unrated. Based on the sorting and rating of ideas in phase three, multidimensional scaling analysis and cluster analysis were performed where related ideas were grouped into clusters of occupational therapy intervention components.[21] During this process, cluster solutions with 5–10 clusters were generated using the Groupwisdom™ software. The cluster solution with the number of clusters that matched the data best (i.e. represented sufficient details on the topic) was applied, creating the Cluster Rating Map (phase four). Within the multidimensional scaling analysis, the stress value is a statistic used to indicate 'goodness of fit'. A low stress value (<0.39) was used to determine congruence between the raw data and processed data.[21] Based on the labels provided by the participants in phase three, cluster labels (i.e. potential names for each cluster) were suggested by the Groupwisdom™ software. Besides illustrating the labelled clusters in relation to each other, the importance of ideas included in each cluster was also depicted by the number of layers in each cluster, based on median values for importance ratings for each idea in the cluster. Data analyses were conducted by the first and last author, both occupational therapists and experienced with the group concept mapping methodology. The Cluster Rating Map was refined and validated in Phase 5. Participants analysed the clusters and the included ideas to determine if the ideas were placed in the cluster that best matched the meaning of the ideas, and discussed to obtain consensus.

Results

Participant demographics and Group Concept Mapping data will be presented in the following sections.

Demographic data

In the brainstorm phase, 72 of the invited participants responded to the questionnaire in SurveyXact. Of these, 45 entered and 29 participants contributed with ideas online using the Groupwisdom™ software. In the sorting and rating phase, 62 participants completed the questionnaire in SurveyXact. Of these, 51 initiated the sorting and rating phase. Finally, six participants took part in the validation meeting to interpret the cluster rating map. They had all been involved in previous phases of the Group Concept Mapping process. Participants from 15 countries, representing Asia ($n = 3$, 20%), Europe ($n = 8$, 53%), Oceania ($n = 2$, 13%) and North America ($n = 2$, 13%), were involved across the phases of the Group Concept Mapping process (see details in Table 1).

Group Concept Mapping data

A total of 103 ideas were generated. After splitting ideas with more than one meaning and removing redundant (i.e. identical) ideas, 117 unique statements were included for sorting and rating. Minor linguistic revisions were made to clarify the meaning. Based on the predefined criteria, sorting of statements was approved for 24 participants (median number of sorted statements = 117, range: 88–117), and the rating of statements was approved for 18 participants (median number of rated statements = 117, range: 114–117). Thus, only 24 participants completed the sorting and 18 completed the rating. These participants sorted the statements into between 6 and 22 groups (median = 9). Twenty-seven (43.5%) participants left between 55 and 117 statements unsorted (median = 116). When asked to rate the importance of the statements, 33 (53%) participants left between 79 and 117 statements unrated (median = 117).

The multidimensional scaling analysis involved eight iterations and revealed a stress value of 0.27, that is, results were interpretable. In the analysis, solutions with five to nine clusters were applied. The cluster solution with eight clusters, generated by the CS® Groupwisdom™ software, was chosen for further examination at the validation meeting. The eight clusters, each containing between 9 and 20 statements, are presented in a cluster rating map (Figure 1).

Table 1. Demographic data of participants.

	Generating ideas	Structuring statements	Interpreting map
	(*N* = 72)	(*N* = 62)	(*N* = 6)
Age (years), median (IQR)	41 (32.5–48.5)	40.5 (32–53)	NA
Women, *n* (%)	68 (94)	58 (94)	6 (100)
Current position, *n* (%)			
Clinician	52 (72)	50 (81)	2 (33)
Manager	3 (4)	1 (2)	1 (17)
Researcher	10 (14)	7 (11)	3 (50)
Researcher and clinician	4 (6)	3 (5)	0 (0)
Other	3 (4)	1 (2)	0 (0)
Country of workplace, *n* (%)			
Australia	8 (11)	11 (18)	1 (17)
Canada	1 (1)	1 (2)	0 (0)
Denmark	7 (10)	9 (15)	1 (17)
Germany	0 (0)	3 (5)	0 (0)
Ireland	10 (14)	4 (6)	1 (17)
Japan	2 (3)	3 (5)	1 (17)
Malaysia	2 (3)	0 (0)	0 (0)
New Zealand	0 (0)	2 (3)	0 (0)
Norway	2 (3)	4 (6)	0 (0)
Scotland	0 (0)	1 (2)	0 (0)
Singapore	5 (7)	1 (2)	0 (0)
Spain	15 (21)	1 (2)	0 (0)
Sweden	6 (8)	8 (13)	1 (17)
United Kingdom	7 (10)	11 (18)	0 (0)
USA	7 (10)	3 (5)	1 (17)
Employment setting, *n* (%)			
Hospital	24 (33)	16 (26)	1 (17)
Community	21 (29)	14 (23)	0 (0)
Palliative institution	19 (26)	25 (40)	2 (33)
University	6 (8)	4 (6)	3 (50)
Other	2 (3)	3 (5)	0 (0)
Diagnostic groups in the setting, *n* (%)			
AIDS	9 (3)	5 (2)	NA
Amyotrophic lateral sclerosis	5 (2)	3 (1)	NA
Cancer	58 (21)	60 (22)	NA
Cardiovascular diseases	31 (11)	40 (15)	NA
Chronic respiratory diseases	35 (13)	44 (16)	NA
Dementia	37 (13)	31 (11)	NA
Diabetes	18 (6)	18 (7)	NA
Parkinson's diseases	37 (13)	32 (12)	NA
Multiple sclerosis	28 (10)	28 (10)	NA
Neurological diseases	8 (3)	8 (3)	NA
Other	11 (4)	5 (2)	NA
Years working with people with palliative care needs, median (IQR)*	9 (4–15)	9 (5–17)	NA

IQR: interquartile range.
*One missing.

At the validation meeting, consensus was reached about the location of the majority (*n* = 89, 77%) of the statements, and only 27 statements were moved between clusters. The eight clusters were collapsed into five; all statements from clusters 3 and 5 were moved to clusters 1, 2 or 4; and clusters 7 and 8 were collapsed and relabelled. As presented in Table 2, each cluster in the revised map now contained between 14 and 28 statements (Table 2 and Appendix 1). Furthermore, the participants suggested changes to the remaining five labels based on the contents

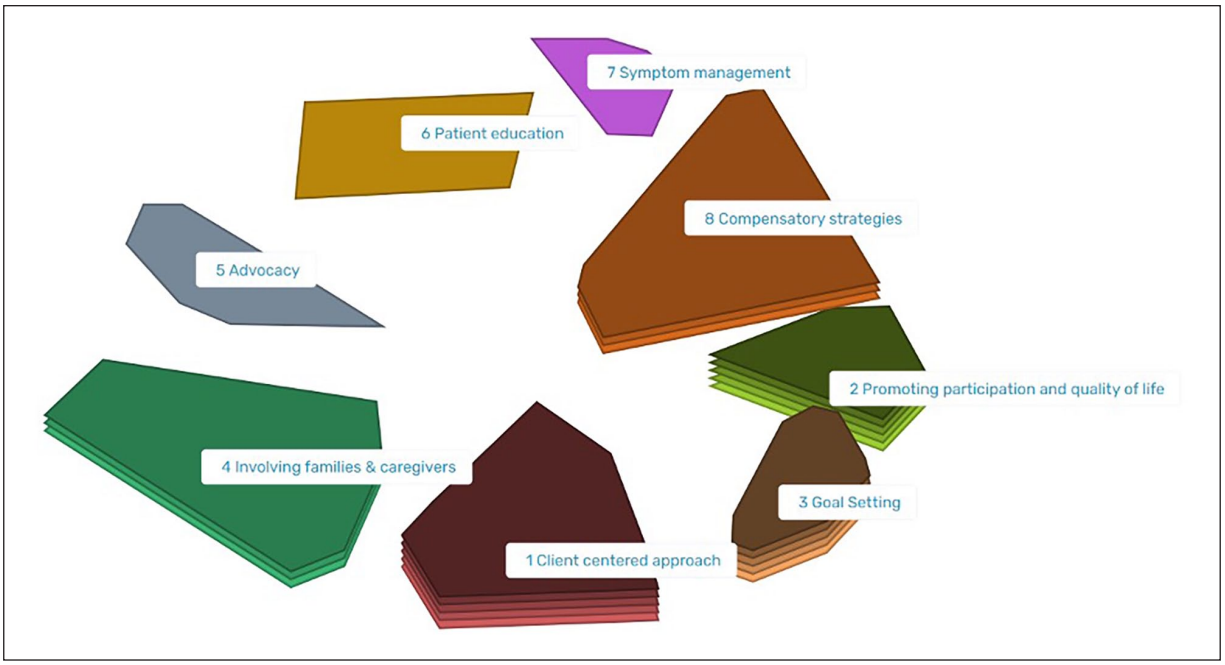

Figure 1. Shows the cluster rating map with eight clusters. Proximity of clusters on the map indicates how related they are. The height of a cluster signifies its relative importance, with higher clusters (i.e. the number of layers) containing statements being rated more important.

of each cluster. This process resulted in five renamed key concept clusters (Table 2).

Most statements were rated as important ($n = 79$, 67.5%) or very important ($n = 33$, 28.2%). These ratings were also reflected by a cluster median value of 4 in cluster 1, and 3 in the remaining four clusters (Table 2). The final five clusters and all the included statements are presented in Appendix 1.

Discussion

Main findings

This is the first study to achieve international consensus on occupational therapy intervention components considered to be effective for people with palliative care needs. Five clusters of intervention components were identified: (1) being client-centred, (2) promoting occupational engagement to optimise quality of life, (3) involving the social and relational environment, (4) enabling occupations and (5) facilitating occupational adaptation.

What this study adds

The five clusters of intervention components demonstrate that focusing on enabling occupation underpins all palliative care occupational therapy interventions considered to be effective. Enabling occupation is process where occupational therapists are working with people to enhance their ability to engage in occupation or modify the occupation or the environment to better support their engagement in occupation. Evidence supports the importance of engagement in occupation for people with palliative care needs[7,25] and how such engagement contributes to improving their quality of life.[26,27] Evidence also shows that people with palliative care needs experience decreasing ability to engage in occupations over time, often for sustained periods.[28] It was therefore not surprising to uncover the importance of supporting people with palliative care needs to adapt to their progressive loss of ability. The clusters 1, 3, 4 and 5 advocate an adaptive approach where occupational therapists apply different kinds of strategies to compensate for loss in ability to engage in occupation. Engagement in occupation at the end of life has been found to support adaptation to deterioration.[29] The occupational therapists participating in the validation meeting named the fifth cluster of intervention components 'facilitating occupational adaptation'. Adapting occupation is common terminology in occupational therapy when describing how people overcome challenges with occupation.[30] However, there seems to exist much debate about the term in research where several definitions exist and further refinement in terms of how it is defined and understood therefore needs to be done.[30]

Being client-centred (cluster 1) was considered particularly important (see Table 2). The client-centred approach typically used by occupational therapists is employed both to identify the client's most important occupations and to inform the continual adaptation of intervention content to meet the client's needs.[31] The

Table 2. Description of the final five clusters.

Cluster	Cluster median*	Summary of content
No. of ideas (%)	(min.-max.)	
1. Being client-centred *n* = 28 (24)	4 (3–4)	Being client-centred means identifying what is meaningful for people with palliative care needs and what their goals are. This is done by taking the time to listen to and understand what the most important aspects for them are. This also means that occupational therapy interventions are individualised, flexible and adaptive in order to meet the needs of people with palliative care needs because their function deteriorates over time.
2. Promoting occupational engagement to optimise quality of life *n* = 24 (21)	3.25 (2–4)	An important part of occupational therapy interventions is promoting occupations that contribute to the quality of life of people with palliative care needs for the time they have remaining. This could for instance include to help the individual engage in occupations at home to remain as independent as possible, or to help them find occupations that give them quality of life.
3. Involving the social, physical and relational environment *n* = 28 (24)	3 (2–4)	Effective occupational therapy interventions involve the social and relational environment including caregivers, families and friends, for example, openly discussing death with family, friends or other medical professionals. Family and friends can also be involved to help identify and enable important occupations. Another aspect of occupational therapy interventions is adapting the physical environment to enable people with palliative care needs achieve their preferred place of care and death.
4. Enabling occupation *n* = 23 (20)	3 (2–3)	The primary aim of occupational therapy interventions is to enable people's occupations. One of the most disabling factors for people with palliative care needs is the impact of anxiety, breathlessness, fatigue and pain. occupational therapy interventions therefore target these symptoms to enable their occupations. This could be by providing knowledge of the symptoms and the disease, and educating people with palliative care needs in energy-saving techniques and other kinds of self-help interventions that reduce the impact of their symptoms.
5. Facilitating occupational adaptation *n* = 14 (12)	3 (3–3.5)	Adaptation is an effective aspect of occupational therapy interventions and involves providing assistive technology, graduating occupations and pacing techniques, facilitating resting positions and breaks during the day, and prioritising occupations according to energy levels.

*The cluster median is calculated based on median values of ratings of importance for each statement within each cluster. Min. and max. represent the lowest and highest median value, respectively, for ideas within a cluster.

present study shows that occupational therapists involve the clients by listening and communicating and enabling choices and control. Other evidence suggests that employing a client-centred approach when caring for people at the end of life is vital for promoting quality of life, health and well-being.[7,32,33]

While the first cluster of intervention components describes how occupational therapists employ a client-centred approach when collaborating and interacting with their clients, other clusters (4 and 5) identify concrete types of adaptive intervention components to optimise engagement in occupation, for example, assistive technology and strategies to reduce the impact of symptoms on occupation. Assistive technologies are often used by people with palliative care needs and have been shown to enable occupation.[31,34] Although a key aim of palliative care is to alleviate symptoms, including anxiety, breathlessness, fatigue and pain, evidence suggests that some of these symptoms may have less influence on people's occupations over time.[35] Nonetheless, occupational therapy interventions support people as they move between 'wellness' (asserting control over symptoms) and illness (uncontrollable symptoms and deteriorating function), facilitating a sense of wellness in the midst of deterioration.[30,36–38]

The five clusters of occupational therapy intervention components identified illustrate that effective interventions involve a dynamic interaction between the person, the task (e.g. cooking, playing football, gardening) and their environment. This is supported by occupational therapy theories and models that argue that interventions must target one or more of these elements to enable occupation.[39,40] For instance, occupational therapy may introduce changes in the person's habits and routines by teaching energy-saving techniques and implementing time to rest. Alternatively, the intervention may be focused on adapting the tasks, for example, sitting or taking breaks while cooking, or replacing football with less strenuous games. Interventions addressing the environment may focus on securing a safe home and providing assistive technology allowing health professionals to deliver the needed care and enabling home death, as many in palliative care request.[41,42] Occupational therapy may therefore help people with palliative care needs achieve their preferred place of care and death or facilitate engagement in

occupations such as finalising financial and legal affairs and funeral preparations.[43]

A survey by the previous EAPC Task Force (2011–2016)[12] mapped the scope of European occupational therapy practice within palliative care. They found that occupational therapists often prescribe assistive technology for daily living; evaluate functioning; instruct in positioning, posture and comfort; and provide strategies to enable occupation. Our research builds upon and extends this study by adding an internationally derived consensus on core clusters of components of occupational therapy interventions for people with palliative care needs. Occupational therapy interventions are often complex and involve a combination of multiple components. Future research may examine the effectiveness of specific components identified in the present study in more detail to inform future intervention studies.[20,44]

Strengths and limitations

Employing the rigorous Group Concept Mapping methodology in this study is considered a strength. The Group Concept Mapping implies a structured approach combining qualitative data generation (i.e. ideas on a specific topic) and statistical analyses to support the structuring of data. As the Groupwisdom™ software offers online participation in the brainstorming, sorting and rating phases, we were able to include participants representing 15 countries around the world, which can be considered a strength. Although this representation of countries, it was not possible to provide demographic information of the participants who completed each phase of the GCM process. At the time of the study, we were not able to collect demographic information using the GroupWisdom software due to EU's General Data Protection Regulation requiring a server placed within EU. Instead, we asked potential participants to provide informed consent and demographic information via a link to SurveyXact. A pitfall of this strategy, however, was that it prohibited us from matching demographic information with the single participant's contribution to the GCM process. Furthermore, a high number of participants used the Groupwisdom™ software but did not sufficiently contribute to the process of structuring statements. While this may be considered a limitation of the study, the number of participants completing the sorting (n = 24) and rating (n = 18) tasks remained sufficient to conduct the statistical analyses and generate a valid cluster map, as reflected by the low stress value. Also, the number of participants completing these tasks is in line with Group Concept Mapping literature, which suggests that 10 individuals generally are considered a minimum for performing a valid statistical analysis.[21]

Conclusion

The present study identified five clusters of core occupational therapy intervention components considered to be effective when supporting people with palliative care needs: (1) being client-centred, (2) promoting occupational engagement to optimise quality of life, (3) involving the social and relational environment, (4) enabling occupations and (5) facilitating occupational adaptation. Future research may use this knowledge to inform and evaluate occupational therapy interventions for people with palliative care needs.

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Author contributions

MSP conceived the original idea of the project and obtained funding. EEW and MSP contributed to the design of the study. All authors participated in the interpretation of the data, revised the manuscript critically for important intellectual content and approved the final version.

Data sharing

No original data can be released.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethics

According to Danish legislation, ethical approval as well as approval from the Danish Data Protection Agency was not required, as no subjects were exposed to medical interventions and/or devices, and no sensitive data were collected.

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References

1. Eriksson L, Öster I and Lindberg M. The meaning of occupation for patients in palliative care when in hospital. *Palliat Support Care* 2016; 14(5): 541–552.
2. Haug SH, Danbolt LJ, Kvigne K, et al. How older people with incurable cancer experience daily living: a qualitative study from Norway. *Palliat Support Care* 2015; 13(4): 1037–1048.
3. Loughran K, Rice S and Robinson L. Living with incurable cancer: what are the rehabilitation needs in a palliative setting? *Disabil Rehabil* 2019; 41(7): 770–778.
4. McTiernan K and O'Connell M. An interpretative phenomenological analysis exploring the lived experience of

individuals dying from terminal cancer in Ireland. *Palliat Support Care* 2015; 13(3): 641–651.
5. Morgan DD, Currow DC, Denehy L, et al. Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life. *BMJ Support Palliat Care* 2017; 7(2): 179–188.
6. Peoples H, Nissen N, Brandt, et al. Perceptions of quality of life by people with advanced cancer who live at home. *Br J Occup Ther* 2021; 84(11): 723–730.
7. von Post H and Wagman P. What is important to patients in palliative care? A scoping review of the patient's perspective. *Scand J Occup Ther* 2017; 26(1): 1–8.
8. World Federation of Occupational Therapy. About occupational therapy, WFOT. 2012 [74124100101-741241001087]. https://wfot.org/about/about-occupational-therapy#:~:text=Definition%20%22Occupation%22,and%20are%20expected%20to%20do (accessed 23 November 2023)
9. Fisher AG and Materella A (eds). *Powerful practice: a model for authentic occupational therapy*. 1st ed. Fort Collins, CO: Center for Innovative OT Solutions, Inc, 2019.
10. Blanke C, LeBlanc M, Hershman D, et al. Characterizing 18 years of the Death with Dignity Act in Oregon. *JAMA Oncol* 2017; 3(10): 1403–1406.
11. Health Canada. *Second annual report on medical assistance in dying in Canada 2020*. Ottawa, ON: Health Canada, 2021.
12. Eva G and Morgan D. Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey. *Palliat Med* 2018; 32(5): 960–968.
13. Kasven Gonzalez N, Souverain R and Miale S. Improving quality of life through rehabilitation in palliative care: case report. *Palliat Support Care* 2010; 8(3): 359–369.
14. Svidén GA, Tham K and Borell L. Involvement in everyday life for people with a life threatening illness. *Palliat Support Care* 2010; 8(3): 345–352.
15. Lee WT, Chan HF and Wong E. Improvement of feeding independence in end-stage cancer patients under palliative care–a prospective, uncontrolled study. *Support Care Cancer* 2005; 13(12): 1051–1056.
16. Miller J and Hopkinson C. A retrospective audit exploring the use of relaxation as an intervention in oncology and palliative care. *Eur J Cancer Care* 2008; 17(5): 488–491.
17. Sakaguchi S and Okamura H. Effectiveness of collage activity based on a life review in elderly cancer patients: a preliminary study. *Palliat Support Care* 2015; 13(2): 285–293.
18. Pilegaard MS, la Cour K, Gregersen Oestergaard L, et al. The 'Cancer Home-Life Intervention': a randomised controlled trial evaluating the efficacy of an occupational therapy-based intervention in people with advanced cancer. *Palliat Med* 2018; 32(4): 744–756.
19. Chow JK and Pickens ND. Measuring the efficacy of occupational therapy in end-of-life care: a scoping review. *Am J Occup Ther* 2020; 74(1): 74012050201–740120502014.
20. O'Cathain A, Croot L, Duncan E, et al. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open* 2019; 9(8): e029954.
21. Kane M and Trochim W. *Concept mapping for planning and evaluation*. Thousand Oaks, CA: Sage Publications, 2007. https://methods.sagepub.com/book/concept-mapping-for-planning-and-evaluation (accessed 23 November 2023)
22. Trochim WMK. An introduction to concept mapping for planning and evaluation. *Eval Program Plann* 1989; 12(1): 1–16.
23. Trochim W and Kane M. Concept mapping: an introduction to structured conceptualization in health care. *Int J Qual Health Care* 2005; 17(3): 187–191.
24. StataCorp. *Stata Statistical Software: release 17*. College Station, TX: Stata Corp, LLC, 2021.
25. Morgan DD, Taylor RR, Ivy M, et al. Contemporary occupational priorities at the end of life mapped against model of human occupation constructs: a scoping review. *Aust Occup Ther J* 2022; 69: 341–373.
26. Brekke MF, la Cour K, Brandt, et al. The association between ADL ability and quality of life among people with advanced cancer. *Occup Ther Int* 2019; 2019: 2629673.
27. Peoples H, Nissen N, Brandt, et al. Belonging and quality of life as perceived by people with advanced cancer who live at home. *J Occup Sci* 2018; 25(2): 200–213.
28. Morgan DD, Tieman JJ, Allingham SF, et al. The trajectory of functional decline over the last 4 months of life in a palliative care population: A prospective, consecutive cohort study. *Palliat Med* 2019; 33(6): 693–703.
29. la Cour K, Josephsson S, Tishelman C, et al. Experiences of engagement in creative activity at a palliative care facility. *Palliat Support Care* 2007; 5(3): 241–250.
30. Walder K, Molineux M, Bissett M, et al. Occupational adaptation – analyzing the maturity and understanding of the concept through concept analysis. *Scand J Occup Ther* 2021; 28(1): 26–40.
31. la Cour K, Gregersen Oestergaard L, Brandt Å, et al. Process evaluation of the cancer home-Life Intervention: What can we learn from it for future intervention studies? *Palliat Med* 2020; 34(10): 1425–1435.
32. Badger S, Macleod R and Honey A. It's not about treatment, it's how to improve your life": the lived experience of occupational therapy in palliative care. *Palliat Support Care* 2016; 14(3): 225–231.
33. Pizzi MA. Promoting health and well-being at the end of life through client-centered care. *Scand J Occup Ther* 2015; 22(6): 442–449.
34. Pilegaard MS, la Cour K, Baldursdóttir F, et al. Assistive devices among people living at home with advanced cancer: use, non-use and who have unmet needs for assistive devices? *Eur J Cancer Care* 2022; 31(4): e13572.
35. Sampedro Pilegaard M, la Cour K, Brandt Å, et al. Impact of pain, fatigue and dyspnoea on occupational performance in people with advanced cancer: A longitudinal study. *Scand J Occup Ther* 2020; 27(7): 507–516.
36. la Cour K, Johannessen H and Josephsson S. Activity and meaning making in the everyday lives of people with advanced cancer. *Palliat Support Care* 2009; 7(4): 469–479.
37. Lindqvist O, Widmark A and Rasmussen BH. Reclaiming wellness–living with bodily problems, as narrated by men with advanced prostate cancer. *Cancer Nurs* 2006; 29(4): 327–337.
38. Morgan DD. *The ordinary becomes the extraordinary: the occupation of living whilst dying*. Parkville, VIC: University of Melbourne, 2012.

39. Nielsen KT, la Cour K, Christensen JR, et al. Lessons learned about occupation-focused and occupation-based interventions: a synthesis using group concept mapping methodology. *Scand J Occup Ther* 2020; 27(7): 481–492.
40. Taylor R (ed.). *Kielhofner's model of human occupation: theory and application*. 5th ed. Philadelphia, PA: Wolters Kluwer, 2017.
41. Ali M, Capel M, Jones G, et al. The importance of identifying preferred place of death. *BMJ Support Palliat Care* 2019; 9(1): 84–91.
42. Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12: 7.
43. Hammill K, Bye R and Cook C. Occupational engagement of people living with a life-limiting illness: occupational therapists' perceptions. *Aust Occup Ther J* 2019; 66(2): 145–153.
44. Skivington K, Matthews L, Simpson SA, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ* 2021; 374: n2061.

Appendix 1. Ideas sorted into final five clusters.

Cluster	Ideas #		Ratings of importance (median)
1. Being client-centred ($n = 28$)	1	An effective intervention component involves the practitioner remaining flexible in attitude	4
	2	An effective intervention component involves the practitioner remaining flexible in application of practice	4
	4	Considering OT needs regarding what is affected	3
	8	An important intervention component is the ability to listen – to 'be' with the patient and others involved in the person's care	4
	9	There are often 'less obvious'/subtle needs that need to be brought into the conversation to identify the person's goals	3
	10	Adapting and evolving as the patient deteriorates	3
	16	The ability to adjust the goals of OT interventions bit by bit to suit the patient's individual condition, even as the patient's function gradually declines	3
	20	Exploring the needs that the patient verbalises, as well as potential needs that are not, regarding activities of daily living, tasks, physical functioning and ways of life	3.5
	21	A needs-based approach	3
	24	Asking what the most important thing for them is	4
	27	Understanding that there's no 'one size fits all' OT intervention, and each case is going to be different	4
	41	Using a client-centred approach to identify meaningful tasks for palliative care patients	4
	42	Working with patients and their families to achieve realistic goals	3
	44	Ensuring you are patient-centred	4
	47	OTs in palliative care need to think/work outside the box. You need to tailor the interventions to every patient	4
	51	Having enough time with the patient is key	4
	52	Ensuring that rehabilitation goals are not at the expense of functional, quality of life and meaningful experiences	3
	54	Listening is an important part of working in palliative care	4
	56	Always being patient-centred	4
	57	Providing a holistic needs approach	4
	68	Outlining available care for patients	3
	72	Recognising that intervention planning requires flexibility to adapt to disease progression, and changing function and priorities	4
	74	Taking the time to understand what is meaningful for the person	4
	75	Setting goals with the patient to re-engage in meaningful activities	3
	84	Using client interviews to find out what occupations are important to them and their families	3
	100	As OTs, enabling choice and control for the patient in their everyday activities	4
	108	As clinicians, listening to all the patients' goals and prioritising them with the patient not on my or the medical team's needs	3
	113	Life stories, conversations about roles and identity through life	3

(Continued)

Appendix 1. (Continued)

Cluster	Ideas #		Ratings of importance (median)
2. Promoting occupational engagement to optimise quality of life (n = 24)	13	By assessing and observing activities of daily living and communication, we can notice changes in patients even without blood tests	3
	15	The ability to focus on the moments of fun and interests of ordinary life	4
	17	Evaluating the patient focusing on the activity	3
	30	Enabling and empowering patients to engage in the activities in which they want to be involved	4
	40	Focusing on meaningful activities to enhance quality of life	4
	45	Occupational storytelling, occupational story making and occupational story ending	3
	48	Patients in palliative care tend to forget about activities that are important to them and that give them quality of life. OTs have an important role in helping them prioritise and find activities that give them quality of life	4
	49	Assisting a patient with their goals and activities by providing interventions/strategies for them and their carers to maintain their independence and safety at home	3
	50	OT's focus on activity analysis can help the patient identify meaningful elements of their roles and focus on continuing them rather than trying to continue all activities out of habit when energy/tolerance is limited	3
	61	Meaningful activities	4
	63	Helping the individual remain as independent as possible	3
	64	Helping the individual maintain good quality of life	4
	79	Supporting the individual in prioritising occupations to continue everyday life at home	3
	80	Focusing on enabling occupational engagement	4
	81	Specific, measurable, achievable, realistic and timely goals	2
	91	Topics such as identity, roles and meaningful activities at the end of life	3.5
	93	Adapting and graduating meaningful activities, so the patient can still perform their daily living	4
	96	Clarifying and enabling the client's choice on significant ADL	4
	101	As an OT, using my unique perspective on occupations, function and a person's occupational performance components such as physical, motor, psychological, spiritual and environment to maximise the individual's engagement in daily occupations	3
	106	Being encouraging	3
	107	Ensuring that I am enabling my client to live until they die, and experience purposeful occupations that have meaning for them	4
	109	Considering the blend between what the person would like to do and their capacity to carry out that activity	3
	110	Person focused on their important activity	4
	114	Clarification of what joyful activities are for the palliative patient	3
3. Involving the social and relational environment (n = 28)	3	Considering the person through a palliative care lens, what can realistically be achieved	3
	5	Considering the environment	3
	6	Considering social needs	3.5
	7	Considering funding	2
	11	Being one that addresses the needs and goals of the patient and their family	3
	12	Concern for the history of patients and their families	3
	19	Suggesting changes to welfare equipment and the environment to suit the patient's abilities (physical and cognitive), behavioural characteristics and preferences	3
	28	Helping achieve preferred place of care	4
	29	Helping achieve preferred place of death	4
	35	Helping people achieve their preferred place of care through environmental adaptation	3
	36	Helping people achieve their preferred place of death through environmental adaptation	3.5

(Continued)

Appendix 1. (Continued)

Cluster	Ideas #		Ratings of importance (median)
	37	Guarantee of third generation rights	2
	43	Involving family and/or main caregivers in the treatment	3
	55	Openly discussing death with family, friends or other medical professionals	3
	58	Being spiritually connected	3
	59	Caregiver involvement	3.5
	60	Context dependence	3
	67	Asking patients what type of OT palliative care they think they need in the context of pre-existing and current family roles	3
	69	Facilitating people and their family caregivers in making decisions about care	3
	76	Enabling meaningful relationships and a sense of belonging	4
	90	Being a good listener to client and family/carers	4
	98	Importance of roles and relationships	3
	102	Recognising that in palliative care, what may be more important is the process rather than the outcome	4
	103	Preparing someone for death, grieving the life that they had, loss of roles, habits, occupations	3
	104	As an occupational therapist, considering the big picture for the patient and family, ensuring that I can bring the expertise of the OT to the job but also other members of the multidisciplinary team if that would contribute to a successful outcome	4
	105	Working with both the person and their family to achieve important goals at the end of life	4
	111	Covering the relatives' need for help and support	3
	112	Enabling the exchange of experiences with people in the same position	2
4. Enabling occupation (*n* = 23)	23	Education around disease progression	3
	25	Helping to understand fatigue	3
	32	Education of patients, family and home carer in matters like ergonomics	3
	33	Fatigue management	3
	34	Breathlessness management	3
	38	An important part of non-pharmacological symptom management	3
	46	Helping coping/rehabilitation after chemotherapy	3
	53	Symptom management interventions are initiated/reviewed at home and not just in in-patient setting	3
	62	Empowering individuals to self-manage symptoms that impact on their daily activities	3.5
	66	Energy conservation education	3
	77	Symptom management education related to advancing illness - breathlessness, fatigue, pain and anxiety	3
	82	Body image interventions	2
	83	Providing techniques on how to manage symptoms	3
	85	Use OT interventions including breathless management to reduce the amount of medication a client needs	3
	86	Use OT interventions including anxiety management to reduce the amount of medication a client needs	3
	87	Use OT interventions including fatigue management to reduce the amount of medication a client needs	3
	88	Use OT interventions including mindfulness to reduce the amount of medication a client needs	3
	89	Use OT interventions including equipment provision to reduce the amount of medication a client needs	3
	92	Introducing and guiding the patients in how to manage energy-saving techniques to perform and participate in their daily living	3

(Continued)

Appendix 1. (Continued)

Cluster	Ideas #		Ratings of importance (median)
	95	Helping with managing their changing emotions (usually fluctuate)	3
	97	Helping with managing their changing emotions (usually fluctuates)	3
	115	Stress reduction, for example, nature, yoga, meditation, music, etc.	3
	117	Energy management; energy-saving techniques	3
5. Facilitating occupational adaptation (*n* = 14)	14	Being able to bridge the aspects of symptom control with those of physical activity and activities of daily living (being aware of both, not just one or the other)	3
	18	Helping the patient to manage their own activities without worsening symptoms such as fatigue	3
	22	Pacing techniques to allow engagement in activities important to them	3
	26	Prioritising activities according to energy levels	3
	31	Enabling and empowering patients to be in the places they want to be	3
	39	Being proactive about helping people manage functional loss	3
	65	Assistive technology/assistive devices to facilitate independence	3
	70	Graduation of activities	3
	71	Covering the need for assistive devices that enable meaningful activities	3
	73	Guiding and implementing assistive devices to perform meaningful daily living	3
	78	Understanding how symptoms limit engagement in occupations	3
	94	Managing changing emotions and redirecting to joyful activities	3
	99	As clinicians, using our knowledge of disease progression, including symptoms, to support the patient as their disease progresses to balance (reduce) the impact of illness and disability to support meaningful occupational engagement	3.5
	116	Assessment of resting positions that enable breaks during the day	3