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Supporting engagement in occupation for persons at the end stage of life

A scoping review

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Abstract

Introduction Supporting persons at the end stage of life with continued engagement in occupations is a service that occupational therapists are knowledgeable in and equipped to do. However, occupational therapy services continue to be underutilized. Further knowledge is needed in ways to support engagement in occupations at the end stage of life.

Aim The aim of study was to synthesize knowledge on how OTs can support engagement in occupations for persons at the end stage of life.

Method A scoping review methodology with a deductive approach was conducted and a semantic content analysis was done to divide the extracted data into meaning units, codes and lastly themes. The search included databases MEDLINE, PUBMED, PSYCINFO and CINAHL.

Results The review included 16 articles and 11 themes within the constructs of the CMOP-E models person, occupation, environment, spirituality.

Conclusions The results show that OTs can provide service and interventions within all constructs of the CMOP-E model, person, occupation, environment, and spirituality. However, OT services continue to be underutilized.

Significance This review provides insight into the full scope of OT services to advocate for within agencies and communities to broaden perspectives on what OTs can provide for the dying population.

Keywords: activities of daily living, dying, hospice care, occupational engagement, occupational therapy, palliative care

Introduction

The World Health Organization (WHO) [1] considers palliative care a human right need, and it is estimated that globally each year there are 56,8 million people in need of palliative care. In the literature, the terms “hospice care”, “end of life care”, “palliative care” have all been used interchangeably, which can be confusing and efforts have been made to standardize the terms [2, 3]. The primary goal for end-of-life care is to support, maintain or improve quality of life for clients and their families [4]. Hospice care is defined as end-of-life care when a person has been diagnosed with a terminal illness and no treatment is deemed feasible. Along with the patient’s doctor attests to believe that the patient only has six months or less to live. Hospice provides a multiprofessional team to support the patient in their home or a facility [5]. Palliative care is the service offered by a professional team consisting of many different healthcare professionals and offers care, assessments, and support to maintain quality of life for individuals suffering from terminal illness, as well as their caregivers [1]. Enrolling in palliative care still allows patients to seek out medical treatment options [5].

Who we are, what we do and in the specific context where the occupation takes place provides a sense of meaning and value to people’s lives [6, 7]. As we age, our physical and cognitive abilities change, and we might need support in our activities of daily living (ADL’s). Occupational therapists (OT) are educated in rehabilitative and compensative methods to support people in their daily activities and thus, support a person’s quality of life all the way to the end stage of life [8]. Occupational therapy can be defined as the therapeutic use of daily life occupations with the purpose to enable, maintain and enhance engagement in participation for individuals, groups or populations [9]. According to the American Occupational Therapy Association (AOTA), the purpose of an OT is to provide client-centered care to enable participation in meaningful activities [8]. Research is showing that continued engagement and being able to participate in occupations can help provide a “good death” experience for both

the client themselves and their loved ones [10]. Wilcock [11] described occupational engagement as objectively observable, and subjectively experienced outcomes going beyond performance on a mental and spiritual level [11]. According to research, from a patient perspective occupational patterns and roles are still important to maintain according to best capacity and ability for dying individuals [12]. Even if it takes some effort, continued engagement in valued occupation is prioritized [13].

State of the art

Research is showing that OT services within end-of-life care is underutilized, and OTs are mainly contacted for equipment prescription (such as beds, toilet and shower stools etc.) or home modifications, and do not have the resources or capacity to provide other services [12, 14-16]. Most research within the field is conducted in Western countries (e.g., Australia, Sweden, Canada) and is limited to qualitative studies and scoping reviews. No RCT studies or bigger cohort studies were found. The qualitative studies include patient, OT, and other healthcare professionals' perspective. Many of the studies from Australia are done by the same researchers, whereas studies from other western countries have different researchers. Because OT is considered a female dominated profession [17], most of the participants in the studies are women, which could skew the perspective of the whole study and other research in the field. Although more research is being done today within the field of occupational therapy and end stage of life care, there are still gaps in structured evidence on how OT's can support engagement in occupation for people at the end stage of life.

Theoretical framework

There are many models and frameworks used within the field of occupational therapy. One of them is the Canadian Model of Occupational Performance and Engagement (CMOP-E) model [18]. CMOP-E was chosen for this study because of the population of persons at the end stage of life who may have very limited occupational performance but a need for continued occupational engagement and participation [18, 19]. The CMOP-E model contains a unique concept of “spirituality”, a connectedness with a higher being and to what is meaningful in life [18], which is relevant to a person at the end stage of life due to heightened awareness of existential matters.

CMOP-E has three main constructs- Person, Environment and Occupation. Spirituality is considered the core and refers to the essence of who we are as human beings [18]. The spirituality component has its own place in the person domain but is naturally interrelated to the other two domains as well. Looking closer at the CMOP-E models main constructs, in the person domain *occupational performance* and *engagement* are the keywords containing of the cognitive, affective, and physical aspects of a person. The environment domain contains four components, cultural, institutional, physical, and social. In the occupation domain, the three components are selfcare, productivity and leisure.

Persons at the end stage of life experience a changing body with loss of different abilities that effects their ability but not their will to participate [19]. This has an effect on a person’s physical capability as well as psychosocial and spiritual self [1]. The level of importance, meaning and satisfaction an occupation holds to a person needs to be considered, which extends from the actual performance of an occupation into the broader concept of occupational engagement [18]. According to Morgan et al. [19] an ability to keep doing creates meaning to life, even in the face of bodily decline. Doing the familiar things and being engaged in meaningful occupation creates an ongoing connection to self, or a “voyage into self” where a person can connect the

past, present and future [20]. This scoping review study sought to gather information and structure the result of the search within the constructs of the CMOP-E model and may contribute with tools and information in ways to support engagement in occupation in end-of-life care for future OT's.

Aim

The aim of study was to synthesize knowledge on how OTs can support engagement in occupations for persons at the end stage of life.

Method

The research design chosen for this study is scoping review which includes a broader search of both evidence based and grey literature and is considered an appropriate method when scoping the area for future research within that field [21, 22]. Scoping reviews are synthesizing and summarizing knowledge to chart direction and has become increasingly popular both within established and emerging research fields [23]. Arksey and O'Malleys [22] framework of six steps, that was further enhanced by Levac et al. [21] was used as a methodological process as recommended by Colquhoun et al. [23]. This study is reported in line with the guidelines provided by Preferred Reporting Items for Systematic reviews and Meta analyses Extension for Scoping Reviews (PRISMScR) [24].

1. Identifying the research question

How can occupational therapists support engagement in occupation for persons at the end stage of life?

2. Identifying relevant articles

This step was done using the databases and search terms described below as well as inclusion and exclusion criteria of articles. Search term blocks are 1. “Occupational therapy or occupational therapist AND end of life care OR hospice care or dying AND engagement”, 2. “occupational therapy or occupational therapist AND end of life care or hospice or dying AND activities of daily living or activities.” Inclusion criteria was articles and grey literature published between 2003 and 2023, in English. Exclusion criteria was other reviews of the topic. The population and age spectrum were set to adults 18+ years of age. Data collection was done with support of the librarian through the databases MEDLINE, PUBMED, PSYCINFO and CINAHL because of their diverse inclusion of nursing and allied health related studies. Additional data collection was also done by looking through reference lists of chosen articles, as well as manual PRIMO search through Jönköping university’s online library (Table 1).

[Insert Table 1].

3. Study selection

The search produced a total of 755 articles that were initially screened by title and key search terms. 95 were selected based on title and abstract, 36 were chosen for full text screening. Database search produced 15 articles that answered the research question presented (Figure 1). Reference list search produced 15 articles, four were included in the study. Contact list produced seven articles, one was included.

[Insert Figure 1].

4. Charting the data

Data that answered the research question was extracted from the articles into a data charting form, as the base for the analysis. Tables and flow chart are used to structure the articles chosen

and provide information of the search, screening, and extraction process (Table 2). The author read through the selected articles multiple times and extracted data into charting format.

[Insert Table 2].

5. Collating, summarizing, and reporting results

The aim was to map ways of supporting engagement against CMOP-E constructs [18]. A deductive or theoretical approach was taken to analyze the data through the lens of the CMOP-E model four main constructs person, environment, occupation, spirituality (Figure 2).

[Insert Figure 2].

To reduce the risk of bias, the thematic framework by Braun and Clarke was used and a semantic content analysis was done to interpret the data [25]. Semantic approach to thematic content analysis is describing the “surface” or literal meaning of context. Data was first summarized into meaning units, then coded and lastly organized in themes according to the process presented by Braun and Clarke [25] (Table 3).

[Insert Table 3].

The descriptive information of the articles and how it answers the aim of the study can be found in Table 1. All studies were analyzed using the same process and steps. An example of the semantic content analysis can be seen in Table 3. Although spirituality is considered the core and essence of a person and connects throughout all the domains, it will be given its own domain for the purpose of structure and clarity. All studies and literature included one or many of the terms “end of life”, “life threatening illness”, “hospice or palliative care”. Since end of life, hospice and palliative care is used interchangeably in the literature, the author included studies that contained one or more of the terms.

6. Consultation

Final step was consulting consumers and/or stakeholders to provide them opportunities to add or suggest references and insight beyond the selected literature [21]. This step was performed after the author had done an independent database search and selected articles. For consultation, the main author/authors of articles selected were chosen as contacts and added to the contact list. They were all contacted via email and given a month to respond. After two weeks a reminder email was sent out. The aim and preliminary results of the study was presented, and the contacts were asked about further information about the subject that could contribute with important information to answer the research question and aim. The consultation produced seven articles from which one additional article was included in this review.

Ethical considerations

Ethical consideration regarding participants was not applicable to this scoping review since all the studies included already have been published and there was no interaction with participants for data collection. Regarding the risk of bias, to avoid search bias the author verified appropriate search terms with the librarian at Jönköping's University. Including different databases and search through reference lists minimizes database bias [26]. Contextual bias was observed through reflexivity about the author's own cultural, societal, racial, gender context in relation to the information found on research question and aim of the study. The risk of methodological positioning was observed to not favor any research method. The author did not receive funding, therefore funding bias is not relevant to this study [27]. Critical appraisal tools were not used, because of the challenges it would present in analyzing vast range of published and grey literature included [21].

Results

The results are presented within the constructs of the CMOP-E model, with subheadings themes that emerged from the semantic content analysis. The studies and literature included were primarily qualitative research [28-37], one quantitative [38], one mixed study [39], two research paper with no participants [40, 41], and two case studies including a total of nine case studies [42, 43], (see Table 1). The culture and country where the studies originated from varied. All literature and studies were published in western countries, although one study [32] was conducted in Singapore with the participants being older Chinese adults. The studies had the following countries of origin: USA [28, 37, 41, 42], Australia [29, 30, 39, 43], Canada [31, 36, 40], New Zealand [34, 35], UK [38]. One study from New Zealand had participants of varied ethnic backgrounds such as Māori, Tongan and Chinese [34]. The constructs and belonging themes will be presented as follows: person, occupation, environment, and spirituality. Eleven themes emerged: using client centeredness and goal prioritizing, grieving and coping strategies, comfort and safety interventions, enabling activities and independence, supporting activities of living, affairs in order, adapting the environment to enable participation, culture brings comfort and belonging, social belonging, barriers and benefits, creating connection is soothing for the spirit (see Figure 2).

There were seven studies that provided a patient/caregiver perspective on engagement in occupation [29, 30, 34, 36, 37, 42, 43] and seven from an occupational therapist perspective [28, 31-33, 35, 38, 39]. The patients were a mixture of home dwellers as well as living in nursing homes or palliative/hospice care units. Ways to support engagement in occupation for persons at the end stage of life are presented using CMOP-E constructs.

Person

Cognitive

Using client centeredness and goal prioritizing. Many of the studies highlighted the therapeutic relationship between the occupational therapist and the client. Creating a relationship and listening to the client's narrative was considered vital for any intervention to be successful [39]. To effectively make use of self, OTs communicated with the client on a regular basis about the clients' goals and what they prioritize, what is meaningful and provided them purpose [28, 33, 39, 40]. An OT must have a client centered care approach [28] and that can include the family and caregivers depending on the client's situation and cultural context [32, 34]. One study mentioned using a goal setting questionnaire for their clients [43]. OT's can also educate family and caregivers on transfer methods and the use of assistive technology/devices to optimize client safety, comfort, function and uphold clients' values, roles, and interests [29-31, 33, 38, 41, 42]. One study reported that support for client and caregivers in the form of teaching was done by 91% of the OTs interviewed (n=67) who worked with terminally ill patients [31].

Affective

Grieving and coping strategies. Interventions regarding the person domain in relation to *affective* areas were reported as follows: OT educating caregivers on self-management strategies after death of a loved one (bereavement) and how to adapt to new routines and habits [28, 38]. Supporting and educating clients and families on the importance of continued engagement in meaningful activities was also reported [40]. OT's may also have conversations about activities and feelings related to inability or ability to perform those, as well as existential issues [33]. OT's can support processing a client's personal intrinsic changes to decrease

anxiety [38, 41]. Some strategies reported were through breathing exercises, relaxation techniques, meditation [40].

Physical

Comfort and safety interventions. Within the person and *physical* domain, OT's provided education on seating, positioning and pressure care was also reported, as well as upper limb therapy training and shoulder protections strategies [38, 43]. Sleep hygiene, pain control, discharge assessments are other interventions mentioned [35, 38, 41] within the physical person domain. Informing client on energy preservation techniques or fatigue management [31, 34, 38, 41, 42] were also common interventions.

Occupation

Selfcare

Enabling activities and independence. Because of illness or bodily deterioration many of the valued occupations clients had, needed to be modified according to their ability to perform and energy level. The results show that maintaining functional abilities in *self-care* provides a sense of dignity and independence and is highly valued among clients at the end stage of life [31, 39, 42]. Supporting in activities of daily living (ADL) OT's used different approaches to occupation such as compensation, compromise, adaptive or preservation [41-43]. Seating assessments and graded return to occupations were some interventions mentioned [35, 38, 43]. Clients reported that feeling safe and comfortable had an impact on their activities [30] and for some resting was a meaningful occupation [32].

Leisure

Supporting activities of living. In the *leisure* part of the occupation domain, activities that were not energy intensive were prioritized. Creative occupations were mentioned in many studies because of the positive impact it had on clients [35, 37, 40]. Some of the creative occupations mentioned were woodwork, pottery, silk painting, soapmaking, gardening [33, 40]. Other low energy activities that clients engaged in were playing cards, needlework, knitting, food preparation and even origami [33, 34, 42]. One study gave an example of an OT working with a woman with motor neuron disease who before her disease had been very creative. She got engaged in craft activities, working together with the OT by blinking her choices of beads and colors for a necklace [35]. Another example of the meaningful creative activities provide for some of the clients, is leaving a legacy by writing letters to grandchildren, record videos, make scrapbooks or photo albums [35, 39, 42]. By engaging in knitting, one woman using adaptive equipment knitted scarfs for her whole family [35]. Appreciation of just taking a slow walk-in nature, watching TV with family members, talking to a friend on the phone or reading a book [36]. Another example of supporting the occupation of eating is when the OT helped a client with some swallowing techniques to enable the client to eat a favored meal together with the family [28]. OT's working with terminally ill people reported in one study that occupations such as transfers was 62% of interventions they supported in, while mobility was 49% and hygiene 40% [31]. Some clients were assisted by the OT to finish a "bucket list" activity, such as going to the beach one last time to feel sand between her toes [39], while another received practical help with timetable and pacing activities before a trip to the client's home country [35]. Completing these activities brought a sense of closure to the clients.

Productivity

Affairs in order. OTs reported facilitating discharge planning or day leaves for people through risk; environment; and physical capacity assessments [38]. This was done so clients could go home and clean out their homes, to make practical arrangements such as arranging for financial and legal affairs, funeral arrangements, power of attorney, organizing guardianship [30, 39]. Other OTs mentioned specific clients who took care of practical matters, such as selling the car so his wife wouldn't have to deal with it after his death [33].

Environment

Physical

Adapting the environment to enable participation. In the physical environment many studies mentioned that OT's can prescribe assistive equipment/devices or technology such as wheelchairs, walkers, adjustable beds, commode chairs, showers stools, raised toilet seats, grab rails, bed poles, bed triangles, ramps, home modifications among others [29, 30, 33, 35, 38, 39, 42, 43]. Clients reported feeling safer, more comfortable and maintaining independence while using assistive equipment. By modifying the environment, the OT enabled participation in valued activities such as providing a pressure cushion to a client to enable them to sit in the living room with the family instead of just lying in the bedroom [30]. Such an intervention enhanced social participation in the home environment. One of the studies reported that 90% (n= 67) of the OTs used environmental modifications such as positioning using cushions, mattresses. The same study also reported that 91% of the OTs supported occupations with therapeutic surfaces, 87% with technical aids and 27% made bathroom modifications [31]. Repositioning was also mentioned as an intervention to ease breathlessness which in turn enabled function and increased comfort [28, 38, 41, 42]. Having an adjustable bed enabled one woman to watch TV with her grandchildren who climbed up in bed with her [29]. Being able

to spend time outside was a valued occupation for some clients, or to do one last trip to a special place. The OT prescribed a wheelchair or a walker to assist getting outside [33, 34, 36, 39] and in one study, the OTs wanted to bring the activities closer to the client in the form of a trolley with games and provide facilities for creative arts [33].

Cultural

Culture bring comfort and belonging. Two studies had a cultural environment with different ethnic backgrounds [32, 34] and brought a different perspective on the social environment. In these two contexts, the OT was required to not only look at the engagement and independence of the client, but rather take a family perspective of interdependence. In one family, the OT could help the family with strategies to reorganize the kitchen or laundry room to help reduce time spent on cooking and cleaning for the client [34]. There may also be family roles within the culture that encourage the client to be depending on their family as a way for the family to show love. An example would be feeding the person even if they are capable of feeding themselves [32].

Social

Social belonging. Being part of group activities or belong to a social group was another important factor for clients, an OT can facilitate creative activity group in hospice care [37], a church group, support social interaction with family and friends at home [34]. It was common for clients to report prioritizing social relationships [36]. Being in the presence of others, even if passively just watching was considered engaging in a social context [32].

Institutional

Barriers and benefits. From an OT perspective lack of time and education, financial resources, organizational and administrative difficulties were mentioned as a barrier to establish a connection to the client and supporting their needs [33, 38, 40]. Late referrals to occupational therapy were mentioned as another institutional or organizational dilemma, since a late referral diminished the OTs ability to support the needs to their client [33]. Another limitation within the organization was that other healthcare professionals were not aware of the full scope of service OTs can offer besides equipment [31, 38].

From a client perspective, they were grateful that the OT could support them in leaving the institutional care environment to return home [31].

Spirituality

Essence of a person- connectedness

Creating connection is soothing for the spirit. From a client perspective enabled participating in a meaningful occupation such as a family gathering can contain a spiritual element [40]. One family performed their religious practice in the bedroom of the client [34]. Reflections and conversations together with the OT about existential issues, living and dying were mentioned [33, 36]. Being engaged in a favored occupation gave some clients a sense of achievement and feelings of being valued, a “rehab of the spirit” [35]. OT support took expression as helping a client to be in a context where they could read the Bible, sing, or pray [34]. Through creative activities clients also found a connection to their past, present and future [42].

Discussion

This aim of this scoping review was to synthesize knowledge on how OTs can support engagement in occupations for persons at the end stage of life. The results show that OTs can support persons at the end stage of life in all the constructs of the CMOP-E model, person, occupation, environment, and spirituality [18]. Engagement and occupational performance of a person is affected by all these domains. The constructs that held most of the interventions were the physical environment with interventions regarding equipment, as well as leisure occupations. Leisure activities, specifically creative activities sparked engagement and created meaning to clients. Clients who are at the end stage of life benefitted from being supported in their various leisure activities for their affective, social, and cognitive wellbeing. OTs reported wanting to support what is meaningful to their clients but felt restricted to equipment prescription and home modifications to alleviate the immediate and acute physical challenges their clients had. OTs often expressed that the care system did not have the resources or capacity to provide the full scope of OT services [14, 15, 33, 38, 40, 44]. Interestingly, other research is also showing that OTs do not feel they have sufficient training or education in end of life care [45], and might not be able to meet anticipated needs should they promote the full scope of OTs skillset [38]. This study identifies the gap between the service generally provided and that which OTs are equipped of providing their clients. Time constriction, lack of resources and education of both OTs and other healthcare professionals narrows the OT service down to equipment prescription instead of providing a broad repertoire of interventions and the full service of a holistic approach that OTs are known for [46]. Therefore, it is vital that OTs actively promote the profession and require further education at universities, conferences, in the community, and workplace. Further education for OTs within end-of-life care is just as important as educating other healthcare professionals of the full scope of interventions an OT can provide and inform organizations of cost-effective interventions other than equipment prescription. OT educational

programs could perhaps offer a wider range of internships working with different populations, such as persons at the end of life. The outcome of this study confirms previous research that persons at the end stage of life still want to participate and be active to the best of their capability [12, 19]. The results shows that despite terminal illness, there is an innate will to stay engaged in activities through experiencing social belonging, do creative activities, be independent, make practical arrangements and create connections [30, 31, 33-35, 37, 39, 40, 42]. For some people, being engaged in leisure activities might add more value and quality of life then being independent in occupations of selfcare. Using a client centered questionnaire is a way for the OT to assess what the client themselves perceive important and focus their energy on that occupation. Having limited time to build up a relationship between the OT and a client that is rapidly deteriorating provides very little opportunity for client centeredness. And yet client centeredness was considered the most important first step in many of the studies included [28, 33, 39, 40]. For a client at the end stage of life, having an OT support engagement in valuable activities would support quality of life, independence, and dignity to the occupational roles of a lifetime [12, 29]. Evidence suggest there is a cost effectiveness of neutral or lower cost for improved care in home care interventions for elderly [47]. OTs could provide many low-cost interventions for home dwelling people that would enhance engagement and perhaps increase quality of end of life. Many creative activities do not require a lot of material or money, only time as a resource. Cost-effective interventions might be more sustainable for society with hospice or palliative home care for end of life. Clients with a diagnosed terminal illness who participated in creative activities provided by the OT were in a nursery home. The participants thought the group activity provided them with a social context and opportunity to create something to leave behind to family and friends [37]. It was a way for the participants to leave a legacy, but also to focus on living instead of dying. More research is needed on if a home dwelling person at the end stage of life would be given those resources of social interaction and

leisure activities such as creative arts by an OT visiting from a home care agency, and if it is supporting or improving quality of life for the client.

Conclusion

The aim of this scoping review was to synthesize knowledge on how OTs can support engagement in occupations for persons at the end stage of life. The results show that OTs can provide service and interventions within all constructs of the CMOP-E model, person, occupation, environment, and spirituality. However, OT services continue to be underutilized, especially in the affective, spiritual, and social areas of the clients' lives.

Significance

This scoping review provides tools and information on OT interventions and ways of supporting engagement for persons at the end stage of life. It also provides insight into the full scope of OT services to advocate for within agencies and communities to broaden the general perspectives on what OTs can provide for the dying population and their loved ones. Future research should analyze cost effectiveness of people at the end stage of life living at home versus institution in combination with quality-of-life assessment receiving full scope of OT services.

Methodological considerations

To achieve trustworthiness there were core concepts such as dependability, credibility, transferability and confirmability to consider [48]. This study had some limitations that may have affected the results of the study. The author worked alone, which may affect the credibility and conformability of the study. A strength is that the author used multiple databases and reference lists for studies to gain current knowledge in the field, as well as reached out to other researchers. The author did practice reflexivity throughout the process to minimize the risk of bias. A strength in the dependability of the study is that the author used a clear structure of Arksey and O'Malley's [22] framework of six steps, further enhanced by Levac et al. [21], and the thematic framework by Braun and Clarke was used to interpret the data [25]. Further, the process was made transparent through tables and figures which strengthens the credibility and conformability of the study. The studies selected were all from western countries, which may limit the transferability of the study. Future research should focus on how engagement is supported from a global perspective, including underdeveloped countries in Africa, South America, Middle east and Asia.

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Table 1. Database search

| Database | Search terms | Search results | Articles eligible based on title or abstract | Articles included after reading full article |
|---|--|----------------|--|--|
| CINAHL | “Occupational therapy or occupational therapist AND end of life or hospice or dying AND engagement” | (n=22) | (n=6) | (n=2) |
| | “Occupational therapy or occupational therapist AND end of life care or hospice or dying AND activities of daily living or activities” | (n=80) | (n=18) | (n=4) |
| Medline | “Occupational therapy or occupational therapist AND end of life or hospice or dying AND engagement” | (n=44) | (n=8) | (n=1) |
| | “Occupational therapy or occupational therapist AND end of life care or hospice or dying AND activities of daily living or activities” | (n=205) | (n=18) | (n=1) |
| PsycInfo | “Occupational therapy or occupational therapist AND end of life or hospice or dying AND engagement” | (n=55) | (n=4) | (n=0) |
| | “Occupational therapy or occupational therapist AND end of life care or hospice or dying AND activities of daily living or activities” | (n=174) | (n=6) | (n=0) |
| PubMed | “Occupational therapy or occupational therapist AND end of life or hospice or dying AND engagement” | (n=136) | (n=16) | (n=3) |
| | “Occupational therapy or occupational therapist AND end of life care or hospice or dying AND activities of daily living or activities” | (n=29) | (n=10) | (n=0) |
| Manually searching reference list of included studies | | (n=15) | (n=9) | (n=4) |

Country of contact persons

| | | | |
|--------------|----------------|----------------|---------------|
| Sweden | 0 | 0 | 0 |
| Sweden | 0 | 0 | 0 |
| Sweden | 0 | 0 | 0 |
| Australia | 0 | 0 | 0 |
| Australia | 7 | 7 | 1 |
| New Zealand | 0 | 0 | 0 |
| New Zealand | 0 | 0 | 0 |
| Canada | 0 | 0 | 0 |
| Canada | 0 | 0 | 0 |
| Canada | 0 | 0 | 0 |
| Total | (n=762) | (n=102) | (n=16) |

Table 2. Articles included

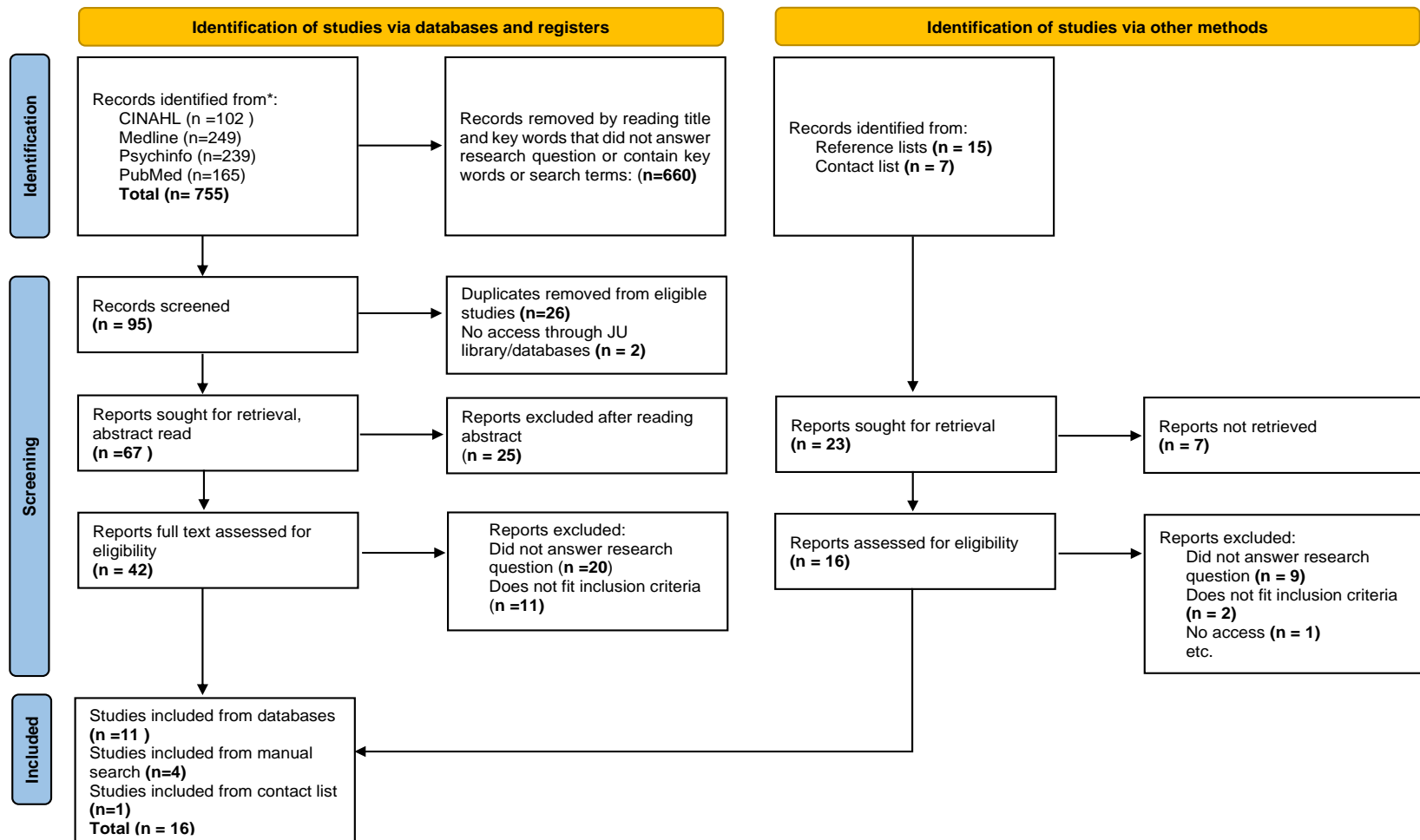
| First author- (Year) | Country | Aim | Research method/sample, age | Identified ways to support engagement in occupation for people at the end stage of life |
|--------------------------------|-----------------------|---|---|---|
| 1. Pizzi (2015) [30] | USA | Client-centered care at the end of life as that which enables engagement in meaningful occupation and promotes health and well-being until one dies | Qualitative 12 interviews with hospice professionals (OT, PT RN, social worker) age 30-53 Only 3 female OT's interviews included | Client-centered care is an important approach at the end of life. The use of creative occupations and family education. |
| 2 Morgan (2022) [31] | Australia | Factors influencing patients with advanced disease and caregivers' utilization of assistive equipment that enable this participation | Qualitative 14 participants diagnosed with a life-limiting illness 11 caregivers of a person with a life-limiting illness (n=23) | The complexities associated with the use of assistive equipment at the end of life. Using or declining assistive equipment to support patients values, roles and interests. |
| 3.Badger (2016) [32] | Australia | The lived experience of occupational therapy in palliative care for people with a life-threatening illness | Qualitative, phenomenological approach 8 participants diagnosed with a life limiting illness Male (n=2) Female (n=6) Age 18-85+ | Comfort and safety has an impact on activities |
| 4. Talbot-Coulombe (2022) [33] | Canada | Québec occupational therapists' practice in palliative and end-of-life care and barriers they encounter | Quantitative online survey 67 occupational therapists (97% female) | Optimized comfort and safety in meaningful occupations such as mobility, transfers, and hygiene. |
| 5. Lim (2023) [34] | Singapore (Australia) | Occupational therapists' perceptions of the occupations of terminally ill Chinese older adults and their caregivers | Qualitative method 11 participants All female occupational therapists | In family-centric societies facilitate interdependence instead of independence in activities of daily living. |
| 6. Tavemark (2019) [35] | Sweden | Occupational therapists' experiences of enabling activity for seriously ill and dying clients. | Qualitative 14 Occupational therapists Male (n=1) | Prioritizing and planning activities according to clients' preferences and capacities |

| | | | | |
|-------------------------|-------------|--|--|---|
| 7. Angelo (2014) [36] | New Zealand | Explore palliative caregiver occupations among Māori, Chinese and Tongan ethnicities | Female (n=13) Age 33-64 Qualitative 6 Informants (Age 38-67) who were caring for a dying family member, Male (n=3) Female (n=3) | Group activities and adapting the environment Ethnic influence in occupations of food preparation, spirituality and family gathering |
| 8. Martin (2018) [37] | New Zealand | Explore occupational therapy practice within the specialized palliative care area of hospice. | Qualitative research study 7 female occupational therapists | Maintaining function in activities of daily living and focusing on occupations with special meaning and importance to the client. |
| 9. Lala (2011) [38] | Canada | The embodied nature of occupation at end of life from the perspectives of Canadians 60 years of age or older who are diagnosed with a terminal illness | Qualitative 8 participants diagnosed with terminal illness Male (n=3) Female (n=5) Age 63-80 | Body changing and reflections on life and death. Meaningful last activities and relationships |
| 10. La Cour (2007) [39] | Sweden | Meanings that people with advanced cancer ascribe to engaging in creative activity in palliative occupational therapy | Qualitative 8 participants that received palliative care Age 41-74 | Engagement in creative activity as a coping tool to handle challenges in living with a disease |
| 11. Eva (2018) [40] | England | Map the scope of occupational therapy palliative care interventions across Europe | Quantitative cross-sectional survey 237 participants | The scope of what OT's services are within palliative care in Europe |
| 12. Hammill (2019) [41] | Australia | Occupational therapists' perceptions on clients' occupational engagement post-diagnosis of a life-limiting condition | Mixed method, Quantitative and Qualitative grounded theory method 144 occupational therapists Majority Female (90%) | Focusing on life and maintaining independence what clients do to practically prepare for death and find closure. |

| | | | | |
|---|-----------|--|---|--|
| 13 Sharma (2018) [42] | Canada | Meaningful creative occupations, spirituality, therapeutic use of self, and psychosocial interventions | Research paper No participants | The use of creative occupations and psychosocial interventions |
| 14. Hill (2011) [43] | USA | The role of the occupational therapy practitioner when providing services to clients with chronic or terminal health conditions who are at the end of life | Research paper | Using different approaches to support the client's and/or family's quality of end of life. |
| 15 American Occupational Therapy Association (AOTA) (2016) [44] | USA | How personally meaningful occupational participation can better support an acute model of palliative care practice | Case study (n=7) only 6 qualified for this study as one case was a child Female (n=4) Male (n=2) | Interventions to support the client's ability to maintain important roles and relationships and to engage in the occupations related to those roles. |
| 16. Ashworth (2014) [45] | Australia | The role of occupational therapists and occupational therapy assistants in providing services to clients who are living with chronic or terminal conditions and are at the end of life | Case study (n=3) Female (n=2) Male (n=1) | Achieving better patient QOL through utilization of goal setting and occupational participation in caregiver equipment training and interventions |

Table 3. Example of semantic content analysis

| Meaning units | Codes | Themes |
|--|---|--|
| <p>Leisure</p> <p>Activities that were not energy intensive were prioritized and creative occupations were mentioned in many studies because of the positive impact it had on clients</p> <p>Some of the creative and low energy occupations mentioned and appreciated were woodwork, pottery, silk painting, soapmaking, gardening, playing cards, needlework, knitting, food preparation and even origami</p> <p>Meaningful creative activities for some of the clients, is leaving a legacy by writing letters to grandchildren, record videos, make scrapbooks or photo albums, writing autobiographies</p> | <p>Low energy and creative activities had a positive impact on clients</p> <p>Different creative occupations to engage in</p> <p>Meaningful to find ways of leaving a legacy for family members</p> | <p>Supporting activities of living</p> |
| <p>Physical environment</p> <p>Some OT's saw modifying the environment as an overall goal</p> <p>OT's reported recommending, lending, testing and installing technical aids or therapeutic surfaces such as cushions, mattresses, overlays, hospital beds, grab bars, floor-to-ceiling poles, wheelchairs, walkers, and bath and toilet seats</p> <p>Independent mobility inside the house and outdoor outings were highly valued and often only achieved with the use of a wheelchair or a walker</p> | <p>Adapting the environment through a wide range of different equipment and home modification interventions</p> | <p>Adapting the environment to enable participation</p> |



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

Figure 1. Flow chart over scoping review process

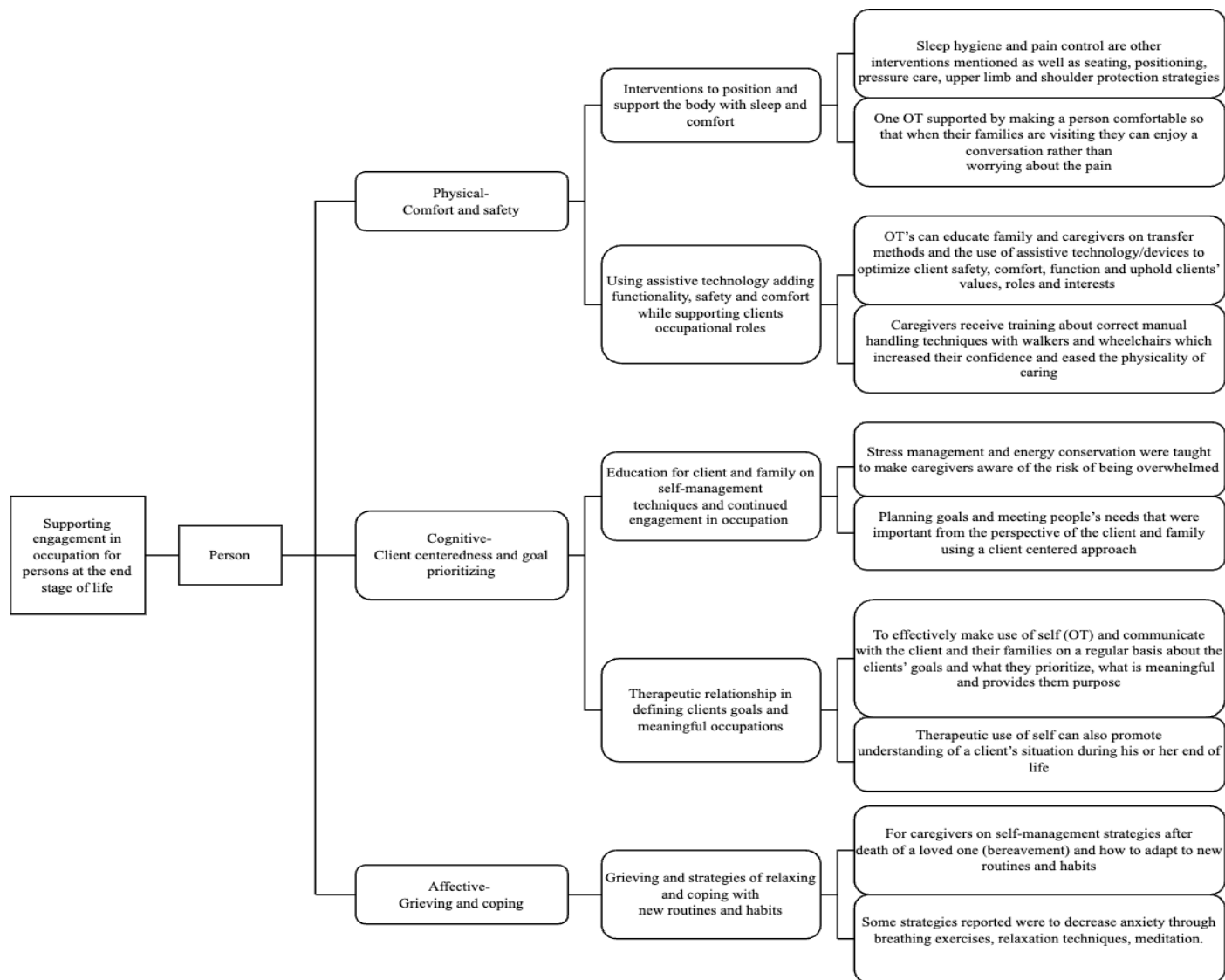


Figure 2. Person, theme construct overview