

Occupational Therapy Practice in Palliative and End-of-Life Care in Québec

La pratique des ergothérapeutes en soins palliatifs et de fin de vie au Québec

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Abstract

Background. There is an emerging evidence base about the scope of occupational therapy in palliative and end-of-life care, but little is known about this practice in Québec or barriers impeding it. **Purpose.** To describe Québec occupational therapists' practice in palliative and end-of-life care and barriers they encounter. **Method.** Using the Québec regulatory board members list, we invited occupational therapists working in palliative and end-of-life care to answer an online survey comprising 24 closed- and 5 open-ended questions. We analyzed data using descriptive statistics and content analysis. **Findings.** The 67 survey participants mainly optimized comfort and safety in meaningful occupations such as mobility, transfers, and hygiene. Barriers to their practice included organizational obstacles and unfamiliarity with their role. **Implications.** Findings highlight the need to improve education and awareness among occupational therapists and other healthcare professionals about the scope of what occupational therapists can do in palliative and end-of-life care.

Résumé

Description. Des données émergent sur la pratique des ergothérapeutes en soins palliatifs et de fin de vie (SPFV), mais au Québec, celle-ci est peu documentée. **But.** Dresser un portrait de la pratique des ergothérapeutes du Québec en SPFV, et des obstacles rencontrés. **Méthodologie.** À partir de la liste des membres de l'ordre professionnel, les ergothérapeutes travaillant en SPFV ont été invités à répondre à un sondage en ligne comprenant 24 questions fermées et 5 questions ouvertes. Les données ont été soumises à des analyses descriptives et de contenu. **Résultats.** Les 67 participants interviennent principalement pour optimiser le confort et la sécurité dans les déplacements, les transferts et l'hygiène. Plusieurs obstacles entravent leur pratique, notamment des obstacles organisationnels et une méconnaissance de leur rôle. **Conséquences.** Les résultats soulignent la nécessité d'améliorer la formation et la connaissance des ergothérapeutes et des autres professionnels de la santé sur l'étendue possible de la pratique ergothérapeutique en SPFV.

Introduction

By fostering participation in meaningful occupations, occupational therapists improve the quality of life of their clients receiving palliative and end-of-life care (American Occupational Therapy Association [AOTA], 2016;

Canadian Association of Occupational Therapists [CAOT], 2017). They can also implement strategies to reduce pain and discomfort and recommend adaptations to the environment (Eva & Morgan, 2018; Montagnini et al., 2020). Recent research points to other ways occupational therapists could

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provide palliative and end-of-life care, such as helping clients to have an optimal death experience or assisting caregivers in meeting their own occupational needs (Hammill et al., 2019; Pickens & Long, 2016). In theory, occupational therapists have an important and unique role to play within palliative and end-of-life care teams. In practice, however, this role is often unknown or not clear to occupational therapists themselves (Ashworth, 2014; Hammill et al., 2014) and to other healthcare professionals (Knecht-Sabres et al., 2019).

Three recent studies explored current occupational therapy practice in palliative and end-of-life care in Australia (Hammill et al., 2017), New Zealand (Martin & Herkt, 2018), and 21 countries in Europe (Eva & Morgan, 2018). There are considerable differences between countries in the practice of occupational therapists who work with clients with terminal illnesses. For example, the proportion of therapists working in palliative care full time varies from 72% in the United Kingdom (UK) to 52% in Australia and 24% in European countries other than the UK. Furthermore, occupational therapy interventions appear to focus mostly on equipment provision (Eva & Morgan, 2018; Martin & Herkt, 2018). However, in the UK, occupational therapists frequently intervene to address fatigue, breathlessness, and anxiety management (Eva & Morgan, 2018). Despite this somewhat broader scope of practice, 65% of the UK's and 63% of other European countries' occupational therapists believe they are not used to their full potential. Knecht-Sabres et al. (2019) suggest that this underutilization of occupational therapists in palliative and end-of-life care may be the result of a lack of understanding of their role by occupational therapists themselves as well as by other healthcare professionals. Systemic barriers such as fiscal restrictions (Tavemark et al., 2019) may also have a major impact. Therefore, there is a widespread, even global, need to clarify and promote occupational therapists' role in palliative and end-of-life care.

Over the past few decades, palliative and end-of-life care has been the subject of discussions and changes at the global, national, and provincial levels. These discussions have been motivated by inequity in access to palliative and end-of-life care. In 2014, the adoption of resolution 67.19 by the World Health Assembly aimed to optimize pain management and education of healthcare professionals as well as integrate services across all organizational levels, from community to specialized care (World Health Assembly, 2014). At the provincial level, the Government of Québec issued a development plan for the years 2015–2020. Among its priorities, this plan aimed to ensure equitable access to palliative and end-of-life care, regardless of the diagnosis or setting where services were delivered (Gouvernement du Québec, 2015). Thus, professionals from various practice settings and professions, including occupational therapists, are increasingly required to be aware of and provide quality palliative and end-of-life care. Interdisciplinary teams are needed to ensure the quality of services to this vulnerable population (Health Canada, 2018). CAOT believes that occupational therapists play an important role with palliative and end-of-life clients and advocates for these professionals

to be an integral part of interdisciplinary teams (Canadian Association of Occupational Therapists [CAOT], 2017). Despite its growing relevance, the practice of Québec occupational therapists in palliative and end-of-life care has not been documented, nor have the barriers they face. This knowledge could be used to develop future guidelines as well as highlight the actual and potential contribution of occupational therapists to palliative and end-of-life care. Thus, the aim of this study was to provide a preliminary description of current occupational therapy practice in palliative and end-of-life care in Québec and identify significant barriers.

Methods

Data were gathered through an online survey posted on LimeSurvey. This platform distributes surveys only to the target population and ensures security of the data, which are accessible only to investigators with a password. The survey was part of a larger study investigating the educational needs of occupational therapists working with terminally ill clients in Québec. As we had to collect all training information accessible to the target population, for feasibility reasons the study was limited to Québec. The Research Ethics Board of the CIUSSS de l'Estrie-CHUS approved this study in March 2018 (ref. #2018-2752). To ensure informed consent, all relevant information pertaining to the study (objectives, length of the survey, risks and benefits, research team members, etc.) was included in the email invitation and also on the screen page of the online survey. There were no incentives to participate.

Sampling and Recruitment

To be eligible, potential participants had to be occupational therapists licensed to practice in the province of Québec who worked at least one day per month with terminally ill clients. According to the *Ordre des ergothérapeutes du Québec* (OEQ; Québec occupational therapists regulatory board), 718 occupational therapists met these inclusion criteria, and 627 had authorized the OEQ to use their email address to contact them for research purposes. They received an email invitation from the OEQ to take part in the survey, followed by a reminder one week later. The invitations included an electronic link to the survey. Everyone who received the electronic link could access the survey; no password was required. To increase participation, the electronic link was also made available to a private group of occupational therapists on Facebook (approximately 5,500 members at the time). The French-only survey was available from May 7 to May 28, 2018. To be licensed by a professional board in Québec, individuals must have sufficient knowledge of the French language to practise the profession (Éditeur Officiel du Québec, 2019).

Survey Questionnaire

The survey was designed by the authors based on a review of the literature and occupational therapy practice processes

(Townsend & Polatajko, 2013). It was reviewed by two experts in palliative and end-of-life care and pretested by five final-year occupational therapy students who were doing or had completed an internship in this practice setting. Based on their feedback, questions were added or clarified. The usability and technical functionality of the electronic survey were also tested at the same time. The questionnaire for the larger study comprised five sections. Section 1 contained questions about the practice context (e.g., proportion of work time spent in palliative and end-of-life care) while section 2 explored the process (e.g., type of evaluation and intervention). Section 3 addressed perceived competence and satisfaction with current practice and education (e.g., perceived competence to meet clients' needs), while barriers to participants' practice as well as education on palliative and end-of-life care were investigated in section 4 (e.g., open-ended questions regarding barriers to practice). Finally, section 5 collected sociodemographic data (e.g., age and gender). The survey questionnaire included a total of 24 close-ended questions, including six with Likert-type scales, and five open-ended questions. Responses to section 3, which included all Likert-type scale questions, and three open-ended questions in section 4, will be the topic of a subsequent paper.

Data Analysis

First, to describe respondent characteristics and the frequency of each evaluation and intervention method, quantitative data were summarized using descriptive statistics obtained with IBM SPSS, version 25. The percentage of respondents who used an evaluation or intervention method "always" or "often" was calculated. No outliers were detected, and since few data were missing (<1.5% per question), they were ignored in the final calculations. Second, qualitative data obtained from two open-ended questions were analyzed using deductive content analysis (Elo & Kyngäs, 2008) and Microsoft Word. For the first open-ended question asking how respondents achieved their overall goals, an unconstrained matrix based on the literature review and the Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2013) was developed by the authors. The matrix comprised five categories corresponding to the overall goals (optimize comfort and safety, etc.). The first author extracted the open-ended responses to this first question and put them in their corresponding categories. Then, for the categorized data, she developed descriptions (e.g., increase comfort and safety in transfers, mobility, feeding, sleep, hygiene or other significant occupation) and created subcategories for evaluation (such as assessing the risk of falls and wounds) and intervention (such as positioning in bed, chair, or wheelchair). Using the same data as well as data from the second open-ended question concerning what barriers were encountered, a second content analysis was done. Specifically, the first author extracted the open-ended responses and put them in the three categories (reasons for referral, specific goals, and barriers) established following the first content analysis. Within each category, data were identified and coded. For example, the following

quote from Participant 32: "Assessing equipment needs, promoting wound prevention and teaching care techniques" generated three codes: technical aid, skin care, and education. The first author then aggregated all similar codes into subcategories (i.e., under reasons for referral: evaluation, intervention, and systematic follow-up; under specific goals: person, occupation, and environment; and under barriers: organizational barriers and lack of knowledge). Then, using Microsoft Word's search function, she counted the frequency of each code related to the subcategories, reasons for referral and specific goals. The frequency of codes related to barriers was not reported because there were too few such codes. The third author verified 20% of all the codes assigned. Disagreements were discussed until reaching consensus. Results of the qualitative analysis are presented narratively. They are supported by examples of participants' answers (translated from French to English) that are representative of each category. Finally, when interpreting the results, qualitative (categories and subcategories) and quantitative (frequency of codes) results were combined to increase our understanding of occupational therapists' current practice and barriers.

Responses Rates

According to the OEQ members list, there were 627 potential participants; 79 accessed the first screen page and agreed to participate while 67 completed the survey. Thus, the overall view rate was 13%, and the completion rate was 85% of views (Eysenbach, 2004).

Findings

Respondent Characteristics

Most respondents were female (97%) and worked in homecare (64%; see Table 1). Their mean age was 38.5 years (range: 24–60 years). Half (52%) spent between two and five days per month with terminally ill clients, including time spent on administrative tasks (e.g., writing notes). The majority (64%) had practised in palliative and end-of-life care for <10 years. Of the 18 respondents with more than 21 years of experience as occupational therapists, only four (6%) had worked exclusively with palliative and end-of-life care clients. The health condition encountered most often was cancer (74%). Most clients were older adults (74%; SD: 17.2). Fifty-two of the respondents did not work with children. The 15 who did devote <25% of their time to this population, all in the context of home care.

Description of Palliative and End-of-Life Practice

This section describes occupational therapists' practice processes from referral to intervention. This description is based on combined qualitative and quantitative data. Table 2 reports the results of the first content analysis. Table 3 reports quantitative data from the closed-ended questions, and the frequency of emergence of the codes from the second content analysis.

Table 1.
Characteristics of Respondents (n = 67).

	Mean \pm SD or count (%) ¹
Age (years)	38.5 \pm 9.0
Gender (female)*	64 (97.0)
Years of experience as an occupational therapist*	10 (15.2)
5 or less	14 (21.2)
6 to 10	24 (36.4)
11 to 20	14 (21.2)
21 to 30	4 (6.1)
31 or more	
Average number of days per month working in palliative and end-of-life care	9 (13.4)
One day	35 (52.2)
Between 2 and 5 days	12 (17.9)
Between 6 and 14 days	11 (16.4)
15 days or more	
Years working in palliative and end-of-life care	
5 or less	27 (40.3)
6 to 10	16 (23.9)
11 to 20	20 (29.9)
21 or more	4 (6.0)
Primary practice setting	
Hospice	1 (1.5)
Long-term care	9 (13.4)
Hospital	12 (17.9)
Homecare	43 (64.2)
Other	2 (3.0)
Main health condition encountered most often*	
Dementia	11 (16.7)
Cancer	49 (74.2)
Other	6 (9.0)
Proportion of practice devoted to each population*	1.1 \pm 3.5
Pediatric	23.9 \pm 14.9
Adult	73.8 \pm 17.2
Older adult	

¹Data reported as mean \pm standard deviation or frequency with percentage in parentheses, derived from valid cases.

*Data missing for one respondent.

Three subcategories of reasons for referral were identified: evaluation, intervention and systematic client follow-up. Respondents noted that referrals were often for wound prevention and treatment, technical aid (e.g., electric bed at home) and positioning (Table 3). Only one participant, who worked in a hospital with elderly clients, did not receive consultation referrals but systematically evaluated all clients at admission. One aim for all respondents with terminally ill clients was to optimize comfort and safety. Some respondents also mentioned that their overall goal was to adapt activities, modify the environment, maintain functional abilities, and support caregivers (Table 2). To achieve these overall goals, respondents reported focusing their practice on 14 specific goals that could be classified based on the person (2 goals), occupation (10 goals), and environment (2 goals). For the person, interventions were mostly related to wound prevention and treatment (45%).

Concerning occupation, transfers (62%), mobility (49%), and hygiene (40%) were identified as specific goals respondents often addressed, as well as the bathroom (27%) for the environment (Table 3).

More than 80% of respondents always or often used the following evaluation methods: consultation of the client's file, interview(s) with the person or family members, clinical observations, and role-playing (Table 3). Questionnaires and assessment tools, standardized or not, were not often used with clients with a life-limiting illness. When questioned about how they achieved their overall goal, respondents added that evaluations focused on the risk of falls and wounds, need for restraint measures, and selecting the right equipment (Table 2).

Most occupational therapists frequently recommended or tried technical aids (87%) or therapeutic surfaces (91%), as well as positioning (90%) and teaching (91%). Only 8% of participants intervened to improve capacity with clients in palliative and end-of-life care (Table 3). When asked to specify their intervention methods, respondents 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 (Table 2). Teaching was done with clients, members of care teams, and caregivers, and focused mainly on three aspects: techniques, prevention, and concepts. Techniques included how to assist people with a terminal illness in personal care occupations, such as mobility and transfers. More specifically, some occupational therapists mentioned teaching safe mobility techniques, the correct use of assistive devices, or how to adapt an activity (Table 2). As for prevention, occupational therapists' instructions addressed the principles of fall and wound prevention. Stress management and energy conservation were also taught to make caregivers aware of the risk of being overwhelmed. Concerning concepts, occupational therapists taught optimal pain control, the different stages of the client's terminal illness, the stages of autonomy loss, available services, and the philosophy underlying end-of-life care (Table 2).

Barriers to Practice

Occupational therapists identified various barriers to their practice that can be divided into two main subcategories: organizational barriers and lack of knowledge about occupational therapists' role in palliative and end-of-life care. Organizational barriers included professional and administrative expectations, lack of financial resources, and limited occupational therapy staff. Respondents noted that paperwork required by the regulatory board took up a lot of their time, leaving less time for clients. Administrative expectations included constraints on occupational therapists' practice imposed by their managers. In some cases, managers allocated little or no time for occupational therapists to explore clients' meaningful occupations. Also, established procedures for the loan and delivery of equipment were sometimes too restrictive or even non-existent. The lack of financial resources impacted

Table 2.
Description of Practice Processes Used to Achieve Overall Goals.

Overall goal	Description	Evaluation	Intervention	Examples of participants' answers*
Optimize comfort and safety	Increase comfort and safety in transfers, mobility, feeding, sleep, hygiene, or other significant occupations	Assessing the risk of falls and wounds Evaluating the need for restraint measures	Optimize positioning in bed, chair, or wheelchair Provide technical aids/therapeutic surfaces Recommend restraint or alternative measures, such as a bed or chair mobility monitor Teach safe mobility techniques, pain and wound management, and fall prevention to a client, caregivers, and members of the care team	"Ensure that the person and staff have taken all possible measures to limit the risk of wounds/minimize the wound" <i>Participant 57.</i> "Evaluation of needs in terms of positioning in the room, but also for hospital departure if necessary. It is common for our clients to experience discomfort in the sitting or lying position due to location of the tumour or cancer" <i>Participant 44,</i>
Adapt activities and modify the environment	Preserve client's autonomy and increase comfort and safety through adaptation of some aspects of personal care, including transfers, mobility, hygiene, dressing and feeding, or through environmental modifications to the client's home, specifically including bed, toilet and shower/bathtub	Selecting the right equipment for the client's environment	Adapt vehicle or request a parking sticker Provide and install technical aids and equipment such as an electric bed, grab bars or floor-to-ceiling poles Teach how to do the adapted activities or use equipment/technical aids	"Adaptation of the bathroom, bedroom, living spaces in the house used by the person" <i>Participant 10.</i> "Adapt the activity or environment to allow the person to perform the activity he or she considers significant (personal care, transfer, leisure or productive activity (household chore), how to assume a role (e.g. grandparent))" <i>Participant 50.</i>
Makes changes to maintain functional abilities	Preserve clients' autonomy for as long as possible are: transfers, hygiene, mobility, dressing, meal preparation, feeding, medication management, and leisure activities	-	Provide technical aids and equipment Teach energy management principles	"According to the client's wishes, certain important activities are targeted, often hygiene and using the toilet" <i>Participant 17</i>
Support caregivers	Inform, educate, and answer questions from caregivers Encourage caregivers and provide them with psychological support and help with decision-making Support caregivers to prevent burnout	-	Advocate for access to various services such as adapted transportation, respite, hygiene assistance and home adaptation grants Provide instruction on principles of falls and wound prevention, stress management and energy conservation Use active listening techniques Teach safe mobility techniques and correct use of assistive devices. Teach optimal pain control, the different stages of the terminally ill patient's disease, the stages of loss of autonomy, available services, and philosophy underlying end-of-life care	"Teaching techniques to help family members understand how to move the person, how to position them in bed, how to work to avoid injuring themselves or the client" <i>Participant 37</i> "I try to do a lot of teaching so they understand end-of-life care and feel as well equipped as possible" <i>Participant 4</i> "Maximizing the role of the caregiver in identifying the right resource or decision (making an informed choice based on everyone's limitations, e.g., relocating to a palliative care facility)" <i>Participant 39</i>

* Translated from French for this paper.

Table 3.
Frequency of Reasons for Occupational Therapy Referral, Evaluation Methods, Goals and Intervention Methods.

Characteristics of the practice	n (%)
Reasons for referral*	
Evaluation	
Need for restraints or alternative measures	2 (3.0)
Risk of falls	3 (4.5)
Functional autonomy	5 (7.5)
Presence or risk of wounds	26 (38.8)
Intervention	
Therapeutic surface	3 (4.5)
Education	4 (6.0)
Adapting the environment	8 (11.9)
Technical aid	12 (17.9)
Positioning	14 (20.9)
Systematic client follow-up	1 (1.5)
Evaluation methods**	
Questionnaire or standardized test	7 (10.4)
Non-standardized tools	25 (37.3)
Non-standardized questionnaire	28 (41.8)
Interview caregivers	55 (82.1)
Situation analysis	60 (89.6)
Interview client	64 (95.5)
Clinical observations	66 (98.0)
Consult client's file	66 (98.0)
Overall goals	
Optimize comfort and safety	67 (100.0)
Adapt activities and modify the environment	59 (88.1)
Make changes to maintain functional abilities	41 (61.2)
Support caregivers	41 (61.2)
Specific goals*	
Person	
Balance (risk of falls)	10 (14.9)
Wound prevention and care	30 (44.8)
Occupation	
Mobility in bed	4 (6.0)
Communication	1 (1.5)
Sleep	3 (4.5)
Leisure	4 (6.0)
Meal preparation	4 (6.0)
Feeding	8 (11.9)
Dressing	14 (20.9)
Hygiene	27 (40.3)
Mobility	33 (49.3)
Transfers	42 (62.7)
Environment	
Bedroom	6 (9.0)
Bathroom	18 (26.9)
Intervention methods**	
Improve capacity	5 (8.1)
Recommend or test technological aids	8 (11.9)
Recommend or test strategies	44 (65.7)
Psychosocial intervention	52 (77.6)
Recommend or test technical aids	58 (86.6)
Positioning	60 (89.6)
Education	61 (91.0)
Recommend or test therapeutic surfaces	61 (91.0)

*Frequency of emergence of the code in open-ended questions.

**Frequency of use: "always" or "often."

the availability of material and human resources. Respondents reported that technical aids and equipment needed to meet clients' needs were often obsolete or not available. When clients could not afford these aids and equipment and loans were not an option, homecare could be compromised. As one respondent noted: "Since it's not always easy to get the equipment quickly, clients sometimes stay in hospital much longer than expected" *Participant 37*. Respondents pointed to a significant shortage of occupational therapy staff in palliative and end-of-life care, resulting in insufficient time to meet clients' needs. This shortage was seen as having various negative impacts on occupational therapy practice, including creating waiting lists and a growing sense of being unable to do the job properly. For example, one participant wrote:

The fact that I'm now the only occupational therapist in palliative care...I have to have a waiting list...it's ridiculous...it puts a lot of pressure on me. I see the most urgent cases but my intervention comes too late. Sometimes people on my waiting list die or are hospitalized. And for those who are lucky enough to exceed their prognosis... I have trouble doing meaningful follow-ups because I don't have time. *Participant 49*

Respondents reported that other healthcare professionals (e.g., nurses and physicians) and the general public knew little about the occupational therapist's role with terminally ill patients. This role appeared to be mainly associated with doing home adaptations and providing technical aids, with no conception of the full range of what occupational therapists could bring to palliative and end-of-life care. As one respondent said: "Other professionals do not really understand the role of occupational therapists. For instance, nurses often think of the occupational therapist as the 'equipment delivery person'." *Participant 48*. This lack of knowledge had various impacts on the practice of occupational therapists, and especially on referrals. The referrals participants received were often extremely specific and always limited to the same tasks, namely adapting the home, wound care, and providing equipment. Occupational therapists felt that they could offer more than what they were being asked to do. According to one respondent: "Referrals by other team members are too specific (e.g., referral to an occupational therapist for a raised toilet seat) rather than letting us do our own analyses" *Participant 18*.

Discussion

To our knowledge, this is the first survey to explore the practice of occupational therapists in palliative and end-of-life care in Québec, including barriers encountered. The results provide a preliminary picture of occupational therapy services and occupational therapists' role in palliative and end-of-life care in Québec. Findings are discussed below with respect to three key elements: (1) consistency of the description of the practice with the literature, (2) reduced scope of practice and possible reasons, and (3) impact of limited practice on clients.

The description of the practice emerging from our findings is consistent with the results of studies done in Europe and Oceania. For example, we found that occupational therapists mainly manage pain and discomfort using therapeutic surfaces, technical aids, positioning or teaching. Participants also assessed autonomy in personal care, such as in transfers and hygiene. These practice components were recently documented in similar studies (e.g., Eva and Morgan, 2018; Martin and Herkt, 2018). We also found that occupational therapists in palliative and end-of-life care in Québec play an important role in preventing, assessing, and treating wounds. According to a literature review (Stinson et al., 2013), occupational therapists perform seating evaluations, recommend technical aids and therapeutic surfaces to prevent and treat wounds, and educate clients and staff regarding pressure-relieving maneuvers and safe transfers, which is consistent with our results. Their contribution to wound care was also reported in Europe, where more than 60% of occupational therapists provide this type of care frequently or very frequently (Eva & Morgan, 2018).

In theory, the role of occupational therapists covers the full range of meaningful occupations, i.e., what clients prioritize for themselves (e.g., American Occupational Therapy Association, 2016; Canadian Association of Occupational Therapists [CAOT], 2017), but our findings suggest that the actual scope of practice is much more limited. Occupational therapists mainly focus on assistance with transfers, mobility, and hygiene. To a lesser extent, they are involved in dressing, eating, and other personal care occupations. Occupations such as leisure, activities related to death (e.g., saying goodbye, making plans for when the time comes), and doing chores if living at home (house cleaning, gardening, etc.) were not addressed by our participants. These findings are troubling considering that in a recent study all patients with advanced chronic diseases followed by a specialized palliative care team reported having problems with leisure, and 52% reported having difficulty playing with their children/grandchildren (Høgdal et al., 2020). In addition, according to Park Lala and Kinsella (2011), the focus of occupations at the end of life is partly on living with death, which includes making end-of-life arrangements and spending time with family and friends. Although these occupations might not have been addressed because clients did not need them, the occupational therapists in our study may have focused mainly on “necessary” occupations, such as transfers and hygiene. As the range of occupational needs at the end of life varies from one person to the next (Tavemark et al., 2019), occupational therapy practice should include not only necessary occupations but also meaningful ones that help clients fulfill social roles and cope with losses, and that improve quality of life and well-being (American Occupational Therapy Association, 2016; Canadian Association of Occupational Therapists [CAOT], 2017).

This practice limitation is not specific to palliative and end-of-life care clients. Systemic problems might explain why the full scope of occupational therapy practice is not deployed. According to Carrier and colleagues (2016), homecare occupational therapists’ interventions were limited to the reason for

referral, which was usually related to personal care. As most of our participants worked in home care, they may not have been asked to consider occupations related to leisure, death, or living at home. Also, the inability to address the full range of occupational needs might be due to the barriers our participants reported in their practice. These included insufficient time, possibly linked to a shortage of therapists. Although a staff shortage was observed in Western Australia (Keesing & Rosenwax, 2011), other factors might account for the lack of time. First, occupational therapists spend a lot of time on record-keeping and paperwork (such as for equipment loans and technical aids) (Cooper & Littlechild, 2004), which leaves less time for direct client care. Second, over the last few decades, the healthcare system in Québec has undergone a major reorganization of services, known as the shift to ambulatory care. This shift has resulted in a significant reduction in hospital stays and a transfer of care to people’s homes. The increase in services delivered in community settings led occupational therapists to limit the number of interventions with each client in homecare (Hébert et al., 2002), including those in palliative and end-of-life care.

Barriers to practice included limited knowledge of the occupational therapist’s role and a lack of material and human resources. Previous studies had identified these barriers in Québec (Falardeau et al., 2012) and elsewhere (Halkett et al., 2010; Keesing & Rosenwax, 2011; Knecht-Sabres et al., 2019). According to our findings, referrals are often late, as well as extremely specific and restrictive. This may simply mirror general practice in palliative and end-of-life care. It can be difficult to make timely referrals with this population whose condition can change rapidly, with the result that referrals often arrive too late and opportunities to intervene for various healthcare professionals in palliative care are missed (Den Herder-van der Eerden et al., 2018). However, this may also be the result of other healthcare professionals’ lack of knowledge about the occupational therapist’s role with palliative and end-of-life clients (Knecht-Sabres et al., 2019). For this vulnerable population to receive quality services, interprofessional collaboration in palliative and end-of-life care is essential (Higginson & Evans, 2010; O’Connor et al., 2006). This collaboration requires knowledge, understanding, and recognition of what other professionals can bring to the team.

Whatever the reasons for the reduced scope of practice, it can have negative impacts on clients. Although some clients developed their own strategies to manage specific occupations, some of these strategies were shown to be counterproductive. For instance, the habit of ordering online and having their groceries delivered increases the social isolation of individuals living alone in a rural area (Peoples et al., 2017). Ultimately, some clients view their social participation as being limited to what occupational therapists have time to work on. Satisfaction with participation in social roles, more than personal care occupations, is one of the best predictors of quality of life (Levasseur et al., 2008). However, according to our findings, occupational therapists in palliative and end-of-life care do not address this aspect. Furthermore, the limited scope of

practice is not consistent with occupational therapy (Townsend & Polatajko, 2013) and government (Gouvernement du Québec, 2015) guidelines calling for a client-centred approach. Pizzi (2015) notes that it is especially important to use a client-centred approach to foster quality of life, health and well-being at the end of life. Moreover, according to the CAOT Profile of Practice, occupational therapists should adopt a systematic client-centred approach in the delivery of their services, which includes identifying clients' occupational needs (Canadian Association of Occupational Therapists [CAOT], 2012). Occupational therapy interventions in palliative and end-of-life care should be based on clients' wishes and prioritized according to their motivation and abilities (Tavemark et al., 2019).

Implications for Practice and Policy

This paper provides an opportunity to question the potential scope of practice of occupational therapy in palliative and end-of-life care. Based on our findings and the available evidence, we can visualize the potential contributions of occupational therapists to this field of practice. This paper is of interest, first, to occupational therapy practitioners who wish to learn more about palliative and end-of-life care. Second, our preliminary description of this practice can also inform clinicians interested in maximizing their role in palliative and end-of-life care. According to the Profile of Practice (Canadian Association of Occupational Therapists [CAOT], 2012), occupational therapists also need to act as change agents and promote their role and its benefits (Canadian Association of Occupational Therapists [CAOT], 2012). When acting as change agents, they could promote their expertise in palliative and end-of-life care supported by our findings (e.g., optimizing comfort through positioning, optimizing safety by teaching safe mobility techniques).

A fuller range of occupational therapy practices could make care easier and safer for volunteers working in hospices. It could also help children play with their siblings. There is no doubt that occupational therapists could play a role in these areas of practice. However, to facilitate their involvement, additional steps, such as securing the active support of professional associations and improving education, need to be taken. Indeed, CAOT's strategic priorities include increasing awareness of and access to occupational therapy (Canadian Association of Occupational Therapists [CAOT], 2019). Professional associations should work with occupational therapists to promote their role, especially in emerging areas of practice (Holmes & Scaffa, 2009), such as palliative and end-of-life care with children and with adults in hospices. CAOT is already involved in doing this through its community of practice called Palliative and End-of-Life Care Practice Network.

Educating future occupational therapists and clinicians involved in this care about the scope of this practice could be beneficial. It could better prepare occupational therapists to work in palliative and end-of-life care and thus give clients

better access to their entire scope of practice. Education could also help occupational therapists to promote their own role in interdisciplinary teams. In addition, enhancing education based on our findings may contribute to meeting a need identified in the literature, namely to provide a clearer picture of day-to-day practice in palliative and end-of-life care (Hammill et al., 2014). Ideally, every professional on palliative and end-of-life care teams would be educated about the other professionals' roles. Being better informed about the scope of occupational therapists' practice, for example, could lead to more relevant and timely referrals. Issues surrounding education and referral pathways are generalized throughout most palliative care practices and need to be standardized (Den Herder-van der Eerden et al., 2018).

Lastly, our findings could help healthcare system managers and decision-makers to better understand the reality of occupational therapy practice and barriers encountered. This understanding will help them meet the needs of occupational therapists and, in doing so, the needs of palliative and end-of-life care clients also.

Future Research

More research is needed, particularly concerning optimizing the scope of occupational therapists' role in palliative and end-of-life care. Furthermore, to justify the relevance of improving practice and education about the role of occupational therapy, it would be useful to have a comprehensive picture of the quality of services currently provided by occupational therapists in palliative and end-of-life care. This picture could potentially serve as a baseline to assess the impact of enhanced education on the services provided and on occupational therapy practice.

Strengths and Limitations

This is the first survey to collect data specifically on the practice of occupational therapists in palliative and end-of-life care in the province of Québec. Combining quantitative and qualitative data produced a description of this practice and highlighted some important issues that warrant more attention in research and practice.

However, it was not possible to determine if the survey respondents were representative of the population of occupational therapists in palliative and end-of-life care in Québec and therefore a non-response bias cannot be ruled out. The views of occupational therapists who chose not to respond to our survey may have differed from those of our participants. Also, our view rate (13%) was low compared to that of other electronic surveys involving Québec occupational therapists (Gobeil et al., 2019; Jasmin et al., 2019). This could be due to technical difficulties during the launch of the survey. For reasons out of our control, it was not accessible for the first two days. We may have lost some potential participants as the best view rate occurs during the first few days (Dillman et al., 2014).

Conclusion

Our study aimed to provide a preliminary description of the current practice of occupational therapists working in palliative and end-of-life care in Québec. Our findings show that, despite having a role to play that could go well beyond the provision of equipment, the scope of practice of occupational therapists in palliative and end-of-life care is still limited. Various obstacles currently hinder the deployment of their full scope of practice, including a lack of material and human resources as well as limited knowledge about their role. Identifying barriers to their practice could help to pinpoint specific solutions to optimize their services. One of these solutions could be to educate other healthcare professionals about the full range of occupational therapy services. Our findings could be useful to clinicians who want to learn more about palliative and end-of-life care practice or wish to advocate for a broader scope of practice in their workplace. Lastly, our findings could contribute to giving healthcare system managers and decision-makers a better understanding of the reality of occupational therapy practice and the barriers that occupational therapists encounter. This understanding could enable them to promote change at the strategic level, provide better support for occupational therapists and, in doing so, improve the quality of life of clients with a life-limiting illness. To achieve this goal, professional associations should also get involved in promoting the profession to various levels of government.



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Key Messages

- Occupational therapists providing palliative care in Québec work mostly in home care and mainly on transfers, mobility, and hygiene.
- Occupational therapists must act as change agents to develop their practice in palliative and end-of-life care.
- A more detailed description of their day-to-day practice may help occupational therapists to improve their understanding of the scope of their role.

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References

American Occupational Therapy Association (2016). The role of occupational therapy in end-of-life care. *American Journal of*

Occupational Therapy, 70(Suppl. 2), 7012410075. <https://doi.org/10.5014/ajot.2016.706S17>

Ashworth, E. (2014). Utilizing participation in meaningful occupation as an intervention approach to support the acute model of inpatient palliative care. *Palliative & Supportive Care*, 12(5), 409–412. <https://doi.org/10.1017/S1478951513000734>

Canadian Association of Occupational Therapists [CAOT] (2012). Profile of Practice of Occupational Therapists in Canada. Retrieved from <https://www.caot.ca/document/3653/2012otprofile.pdf>

Canadian Association of Occupational Therapists [CAOT] (2017). CAOT Position Statement: Occupational Therapy and End-of-Life Care. Retrieved from https://www.caot.ca/document/6130/PS_EndofLife.pdf

Canadian Association of Occupational Therapists [CAOT] (2019). 2019–2022 Strategic Priorities. Retrieved from <https://www.caot.ca/document/6890/CAOT%20Strategic%20Plan%202019-2022.pdf>

Carrier, A., Levasseur, M., Freeman, A., & Desrosiers, J. (2016). Reddition de compte et optimisation de la performance : impacts sur le choix des interventions ergothérapeutiques. *Santé Publique*, 6(28), 769–780. <https://doi.org/10.3917/spub.166.0769>

Cooper, J., & Littlechild, B. (2004). A study of occupational therapy interventions in oncology and palliative care. *International Journal of Therapy and Rehabilitation*, 11(7), 329–333. <https://doi.org/10.12968/ijtr.2004.11.7.13362>

Den Herder-van der Eerden, M., van Wijngaarden, J., Payne, S., Preston, N., Linge-Dahl, L., Radbruch, L., & Hasselaar, J. (2018). Integrated palliative care is about professional networking rather than standardisation of care: a qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. *Palliative Medicine*, 32(6), 1091–1102. <https://doi.org/10.1177/0269216318758194>

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, phone, mail, and mixed-mode surveys: The tailored design method*. John Wiley & Sons.

Éditeur officiel du Québec (2019). Charte de la langue française. Retrieved from <http://legisquebec.gouv.qc.ca/fr/pdf/cs/C-11.pdf>

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>

Eva, G., & Morgan, D. (2018). Mapping the scope of occupational therapy practice in palliative care: A European association for palliative care cross-sectional survey. *Palliative Medicine*, 32(5), 960–968. <https://doi.org/10.1177/0269216318758928>

Eysenbach, G. (2004). Improving the quality of web surveys: The checklist for reporting results of internet E-surveys (CHERRIES). *Journal of Medical Internet Research*, 6(3), e34. <https://doi.org/10.2196/jmir.6.3.e34>

Falardeau, M., Arpin, J., & Lambert, E. (2012). Une pratique morcelée qui invite à l'intégration des services. *Revue internationale de soins palliatifs*, 27(2), 45–50. <https://doi.org/10.3917/inka.122.0045>

Gobeil, J., Larivière, N., Carrier, A., Bier, N., Bottari, C., Veillette, N., & Levasseur, M., (2019). Portrait des pratiques évaluatives des ergothérapeutes œuvrant au Québec. *Canadian Journal of Occupational Therapy*, 86(5), 388–399. <https://doi.org/10.1177/0008417419839867>

- Gouvernement du Québec. (2015). Soins palliatifs et de fin de vie. Plan de développement 2015–2020. La Direction des communications du ministère de la Santé et des Services sociaux. pp.17-35. Retrieved from <http://publications.msss.gouv.qc.ca/msss/fichiers/2015/15-828-01W.pdf>
- Halkett, G. K. B., Ciccarelli, M., Keesing, S., & Aoun, S. (2010). Occupational therapy in palliative care: Is it under-utilised in western Australia? *Australian Occupational Therapy Journal*, 57(5), 301–309. <https://doi.org/10.1111/j.1440-1630.2009.00843.x>
- Hammill, K., Bye, R., & Cook, C. (2014). Occupational therapy for people living with a life-limiting illness: a thematic review. *British Journal of Occupational Therapy*, 77(11), 582–589. <https://doi.org/10.4276/030802214X14151078348594>
- Hammill, K., Bye, R., & Cook, C. (2017). Workforce profile of Australian occupational therapists working with people who are terminally ill. *Australian Occupational Therapy Journal*, 64(1), 58–67. <https://doi.org/10.1111/1440-1630.12325>
- Hammill, K., Bye, R., & Cook, C. (2019). Occupational engagement of people living with a life-limiting illness: Occupational therapists' perceptions. *Australian Occupational Therapy Journal*, 66(2), 145–153. <https://doi.org/10.1111/1440-1630.12557>
- Health Canada (2018). Framework on Palliative Care in Canada. Retrieved from <https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf>
- Hébert, M., Maheu, B., & Potvin, L. (2002). Théories qui émergent du quotidien de la pratique communautaire de l'ergothérapie. *Revue Canadienne D'ergothérapie*, 69(1), 31–39. <https://doi.org/10.1177/000841740206900103>
- Higginson, I. J., & Evans, C. J. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *The Cancer Journal*, 16(5), 423–435. <https://doi.org/10.1097/PPO.0b013e3181f684e5>
- Høgda, N., Eidemak, I., Sjøgren, P., Larsen, H., Sørensen, J., & Christensen, J. (2020). Occupational therapy and physiotherapy interventions in palliative care: a cross-sectional study of patient-reported needs. *BMJ Supportive & Palliative Care*. Published Online First: 11 August 2020. <https://doi.org/10.1136/bmjspcare-2020-002337>
- Holmes, W. M., & Scaffa, M. E. (2009). An exploratory study of competencies for emerging practice in occupational therapy. *Journal of Allied Health*, 38(2), 81–90. PMID: 19623789
- Jasmin, E., Ariel, S., Gauthier, A., Caron, M. S., Pelletier, L., Curren-Briggs, G., & Ray-Kaesler, S. (2019). La pratique de l'ergothérapie en milieu scolaire au Québec. *Canadian Journal of Education/Revue Canadienne d'éducation*, 42(1), 222–250.
- Keesing, S., & Rosenwax, L. (2011). Is occupation missing from occupational therapy in palliative care? *Australian Occupational Therapy Journal*, 58(5), 329–336. <https://doi.org/10.1111/j.1440-1630.2011.00958.x>
- Knecht-Sabres, L. J., Weppner, A., Powers, C., & Siesel, B. (2019). Do health-care professionals really understand the role of occupational therapy in hospice care? *American Journal of Hospice and Palliative Medicine*, 36(5), 379–386. <https://doi.org/10.1177/1049909118812858>
- Levasseur, M., Desrosiers, J., & St-Cyr Tribble, D. (2008). Subjective quality-of-life predictors for older adults with physical disabilities. *American Journal of Physical Medicine & Rehabilitation*, 87(10), 830–841. <https://doi.org/10.1097/PHM.0b013e318186b5bd>
- Martin, E., & Herkt, J. (2018). The reality and potential of occupational therapy within hospice care. *New Zealand Journal of Occupational Therapy*, 65(2), 23–29.
- Montagnini, M., Javier, N. M., & Mitchinson, A. (2020). The role of rehabilitation in patients receiving hospice and palliative care. *Rehabilitation Oncology*, 38(1), 9–21. <https://doi.org/10.1097/01.REO.0000000000000196>
- O'Connor, M., Fisher, C., & Guilfoyle, A. (2006). Interdisciplinary teams in palliative care: a critical reflection. *International Journal of Palliative Nursing*, 12(3), 132–137. <https://doi.org/10.12968/ijpn.2006.12.3.20698>
- Park Lala, A., & Kinsella, E. A. (2011). A phenomenological inquiry into the embodied nature of occupation at end of life. *Canadian Journal of Occupational Therapy*, 78(4), 246–254. <https://doi.org/10.2182/cjot.2011.78.4.6>
- Peoples, H., Brandt, Å, Wæhrens, E. E., & la Cour, K. (2017). Managing occupations in everyday life for people with advanced cancer living at home. *Scandinavian Journal of Occupational Therapy*, 24(1), 57–64. <https://doi.org/10.1080/11038128.2016.1225815>
- Pickens, N. D., & Long, T. (2016). Occupational therapy practitioners working with caregivers in adult palliative care and end-of life care. *OT Practice*, 21(3), CE1–CE8. <https://doi.org/10.5014/ajot.2016.706S17>
- Pizzi, M. A. (2015). Promoting health and well-being at the end of life through client-centered care. *Scandinavian Journal of Occupational Therapy*, 22(6), 442–449. <https://doi.org/10.3109/11038128.2015.1025834>
- Stinson, M., Gillan, C., & Porter-Armstrong, A. (2013). A literature review of pressure ulcer prevention: Weight shift activity, cost of pressure care and role of the occupational therapist. *British Journal of Occupational Therapy*, 76(4), 169–178. <https://doi.org/10.4276/030802213X13651610908371>
- Tavemark, S., Hermansson, L. N., & Blomberg, K. (2019). Enabling activity in palliative care: focus groups among occupational therapists. *BMC Palliative Care*, 18(1), 1–9. <https://doi.org/10.1186/s12904-019-039>
- Townsend, E. A., & Polatajko, H. J. (2013). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being & justice through occupation*. CAOT Publications. <https://www.caot.ca/client/product2/69/itemFromIndex.html>
- World Health Assembly (2014). Strengthening of palliative care as a component of comprehensive care throughout the life course. Retrieved from https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

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