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Experience Report

Development of an evidence-informed education package for occupational therapists for palliative and end of life care: promoting occupational justice[1]

Desenvolvimento de uma proposta de educação informada por evidências para terapeutas ocupacionais para cuidados paliativos e cuidado no fim de vida: promovendo a justiça ocupacional

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Abstract

Introduction: Death is inevitable, yet hospitals and health services continue to focus on life-sustaining practices despite clients presenting with clear decline related to life-limiting illness. Social and occupational injustice is common for clients receiving palliative or end-of-life care, as they experience increased occupational disengagement and disempowerment. A gap was identified in the Occupational Therapy department of a metropolitan Australian hospital regarding clinician skills, knowledge and confidence in working with these clients. **Objective:** To describe the development of an evidence informed education package designed to support occupational therapists to provide the best possible quality of care and promote occupational justice for clients receiving palliative or end-of-life care. **Method:** Consultation with key stakeholders and a review of existing resources including a skills audit, was conducted to identify current practice. A review of professional and grey literature was completed, and benchmarking with similar organisations provided a wider perspective on current Australian practice. Review of widely available educational resources were evaluated. **Results:** Baseline data collection confirmed that promoting occupational and social justice for people requiring palliative or end-of-life care was under-recognised across the health service. Benchmarking identified significant variation in educational practices

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across similar Australian health services. The structure and content of a face-to-face clinical education session was formulated using evidence from the literature review and relevant available resources. There are plans to transfer this education package to an e-learning platform with evaluation built into the package to allow content to remain up to date. **Conclusion:** Occupational Therapy clinicians are well placed to promote occupational and social justice for people requiring palliative or end-of-life care but require additional occupationally focused education to optimise their practice in this area.

Keywords: Training, Staff Development, Professional Education, Palliative Care, End of life.

Resumo

Introdução: A morte é inevitável, mas os hospitais e serviços de saúde continuam concentrados na manutenção da vida, apesar das pessoas apresentarem declínios relacionados a doenças limitantes da vida. A injustiça social e ocupacional são comuns para as pessoas que recebem cuidados paliativos ou estão no fim de vida, pois experimentam um aumento do desengajamento e desempoderamento ocupacional. Foi identificada uma lacuna em um hospital metropolitano australiano, no departamento de terapia ocupacional, em relação às habilidades clínicas, conhecimento e confiança no trabalho. **Objetivo:** Descrever o desenvolvimento de uma proposta de educação informada por evidências, projetada para apoiar terapeutas ocupacionais para fornecer a melhor qualidade possível de atendimento e promover a justiça ocupacional em cuidados paliativos ou no fim da vida. **Método:** Consulta com pessoas chave e uma revisão dos recursos existentes, incluindo uma auditoria de habilidades, para identificar a prática atual. Uma revisão da literatura profissional e cinzenta foi concluída, e uma avaliação comparativa com organizações semelhantes forneceu uma perspectiva mais ampla sobre a prática australiana atual. Foi também avaliada uma revisão de recursos educacionais disponíveis. **Resultados:** A coleta de dados confirmou que a promoção da justiça ocupacional em cuidados paliativos ou cuidados no fim de vida era pouco reconhecida no serviço de saúde. A avaliação comparativa identificou uma variação significativa nas práticas educacionais em serviços de saúde australianos. A estrutura e o conteúdo de uma sessão de educação clínica presencial foram formulados usando evidências da revisão da literatura e recursos relevantes disponíveis. Há planos de transferir esta proposta educacional para uma plataforma de e-learning com avaliação integrada, permitindo que o conteúdo permaneça atualizado. **Conclusão:** Os terapeutas ocupacionais podem promover justiça ocupacional e social para pessoas que necessitam de cuidados paliativos ou cuidado no fim de vida, mas requerem formação adicional focada na ocupação para otimizar sua prática nesta área.

Palavras-chave: Formação Profissional em Saúde, Desenvolvimento de Pessoal, Educação Profissional, Cuidado Paliativo.

Introduction

The World Health Organisation defines palliative care as the amelioration of suffering by early identification, correct assessment, and treatment of physical, psychological, social and spiritual problems associated with life limiting illness (World Health Organisation, 2019). Disparities exist in healthcare throughout the life span, but people requiring palliative or end-of-life care have particularly limited opportunities for occupational engagement. These limitations place these clients at particular risk of occupational injustice, deprivation, alienation and marginalisation (Keesing & Rosenwax, 2013; Durocher et al., 2014). Occupational apartheid can also exist, when factors such as ethnicity, gender, place of residence, socio-economic status, age, indigenous background and diagnosis with conditions other than cancer impact on equitable access and occupational justice in palliative and end-of-life care (Keesing & Rosenwax, 2013).

Palliative care may be initiated at any point of a life-limiting illness, whereas end-of-life care is usually implemented when curative treatments are recognised as no longer effective (Pickens et al., 2016). Occupational Therapy is founded on the belief that meaningful participation in occupation generates well-being and quality of life across the lifespan (Hammell, 2015). A World Federation of Occupational Therapy position statement on end-of-life care affirms that clinicians enable function, comfort, safety, autonomy, dignity and participation regardless of a person's life expectancy, through their expertise in engaging people through occupation (World Federation of Occupational Therapists, 2016). Their deep understanding of occupation plays a meaningful and substantive role in the process of caring for clients and their families with a life-limiting illness (Pickens et al., 2016).

Hammell (2015) asserts all individuals have the occupational right to participate in activities of their choice at any point in their life trajectory. The key role of occupational therapists to a dying person is to facilitate meaning-making in daily occupations (Essential-Yeh & McColl, 2019). This role aligns closely with local state frameworks for palliative and end-of-life care, which emphasise advocating for person-centred care and respecting client choices (Victorian State Government, 2021).

Training for health professionals emphasise health and life, and do not prepare healthcare clinicians to take a palliative approach with clients or engage with the processes and aftermath of dying (Sartori & Battistel, 2017). They further highlight that death remains taboo in many Western societies, and cultural beliefs can promote ongoing inequity of service provision (Sartori & Battistel, 2017).

Preventative, restorative, supportive, compensatory and palliative approaches are all appropriate at various stages of a disease trajectory (Şahin et al., 2017). However, clinicians may not recognise nor respond to changing requirements at different stages of disease progression. As the global population ages, a strong case for greater economic investment in palliative and end-of-life care has been made across multiple sectors, particularly in healthcare clinician education (Palliative Care Australia, 2020).

Occupational Therapists provide strategies to reduce symptoms such as pain, anxiety, depression, breathlessness and fatigue (Burkhardt et al., 2011). OT provides adaptation of environmental and occupational factors to improve quality of life to enable optimised occupational engagement and to die at home if desired, providing a valuable service to both the client and the health service (Keesing & Rosenwax, 2013). Enabling participation in valued occupations throughout the disease trajectory inclusive of dying, was highlighted in a European survey conducted by Eva & Morgan (2018). However, 54% of Australian occupational therapists reported having no specific training in palliative care (Talbot-Coulombe & Guay, 2020). Without relevant, evidence-based and discipline-specific education, Martin & Herkt (2018) warned that the needs for OT in palliative care may not be recognised, leading to less access to specialist occupational assessment and intervention and increased occupational injustice for these clients.

This was confirmed in a phenomenological study by Badger et al. (2016) who found clients recognised OT as improving their social participation and quality of life but did not perceive these outcomes as part of their goal setting or inclusive of work undertaken with their OT. Eva & Morgan (2018) identified a need for both undergraduate and postgraduate OT education in palliative care to influence capacity building in service development, research, and leadership specific to occupation-based practice.

It is estimated that 95% of clinicians will work with a dying patient, either within or outside of a palliative care setting. (Talbot-Coulombe & Guay, 2020). OT for people requiring palliative or end-of-life care is a common clinical experience, yet rarely the subject of targeted professional education. However, resource constraints often contribute to a narrowing of the OT role, particularly in hospital environments where occupation-based therapy can be more challenging to provide (Badger et al., 2016).

Given that the majority of Australians die in a hospital setting (Australian Bureau of Statistics, 2021), OT clinicians may not have an opportunity to enable occupational justice outcomes for these clients and their caregivers that aim to support occupational participation and wellbeing at this time. This narrative review describes the identification for and development of an education package intended to enable OT clinicians in providing the best possible quality of care and to promote occupational justice for clientele receiving palliative or end-of-life care.

Methods

Practice setting

This description of a quality improvement project transpired in a large tertiary health service that caters to 900,000 people in a major Australian city. It has the three largest growth corridors in the city within its boundaries, and the highest number of people coming from culturally and linguistically diverse backgrounds in the Australian state of Victoria catering to more than 110 language groups. The OT department employs approximately 80 clinicians, providing services to a local community that has a rapidly growing number of older and complex health care needs clientele. Prior to this project, no specific palliative or end-of-life education was provided to clinicians within the service. Identification for the project occurred as a result of the first author's work across multiple areas of the health service and noting a lack of palliative approach in settings where palliative patients were frequently presenting.

Process

This project was guided by the Plan-Do-Study-Act (PDSA) cycle, a quality improvement method widely used across healthcare internationally (Victorian Department of Health, 2010). The method proceeds through four iterative stages which encourage clear identification of methods and shared goals (Plan), mindful implementation of practice change (Do), evaluation of implementation outcomes (Study) and planning for further rounds of improvement and innovation (Act). The overall goal of PDSA projects is to improve quality of care through experiential learning within the clinical environment. Unlike research, there is no intention to develop or contribute to broadly generalizable knowledge.

While projects using this method often report positive outcomes, significant variability in fidelity to the PDSA model has been identified and should be reported in the literature where possible (Knudsen et al., 2019). The authors have highlighted the stages of the PDSA cycle within the description below, which describes the first two phases undertaken to date. Aspects of this project that align with key features of quality improvement methodology have also been explicitly reported using the Quality Improvement Minimum Quality Criteria Set (QI-MQCS) Version 1 (Rubenstein et al., 2015) in Appendix A.

Findings

Considering the creation of the educational package (Plan)

Stakeholders including acute and sub-acute OT service managers, staff working across OT palliative specific services and the chair of the end-of-life care committee were consulted. The goal of the consultation was to identify gaps in the current skills, knowledge and confidence of OT clinicians when working with this patient group. A skills audit questionnaire completed by approximately 70% of the OT staff previously undertaken within the OT department did not include any specific evaluation of capabilities related to palliative or end-of-life care. While generic skills may be employed when working with these clients, the absence of palliative and end of life questions from the audit indicated a lack of recognition of the requirements specific to this area of practice. An obsolete educational package previously developed for oncology clients referred to palliative care as an option when no further curative measures were possible, and adopted a sole focus on rehabilitation.

Designing the educational package (Do)

Evidence from a range of sources was gathered to inform the education package including statistics from government agencies, conducting a literature review of peer-reviewed and grey literature, benchmarking with similar agencies, and review of readily available online educational resources. Having established a baseline of existing resources, recent evidence was reviewed to determine support for the development of targeted professional education.

Utilising statistics available from the Australian Institute of Health and Welfare, Australian Bureau of Statistics and the health service annual report, the most common causes of death and expected presentations to hospital in the last year of life were evaluated.

Data obtained from the health service was similar to the wider Australian population for diagnostic groups, although represented a higher number of clients from culturally and linguistically diverse backgrounds. In addition to this, a greater overall demand was experienced within the health service across all clinical service areas (Australian Bureau of Statistics, 2019; Australian Institute of Health & Welfare, 2021).

A comprehensive literature search was conducted, using the primary search terms ‘Occupational Therapy’ and ‘palliative’ or ‘end-of-life’ or ‘terminal’ and ‘education’ or ‘training’. Databases utilised were CINAHL, PubMed, Careserch and OT Seeker. The search initially returned 152 articles. This was reduced to 15 after title and abstracts were reviewed for relevance and duplicates removed. Hand searching of reference lists was then completed which resulted in identifying a further 14 relevant articles, culminating in 39 articles altogether. Articles were critiqued for quality and relevance to the primary objective of the study. Articles were excluded if they did not contain a combination of the three primary groups of search terms above, were specific only to one area of palliative care, were not relevant to the health service or were published before 2011 (publication range 2011- 2021).

Information gained was utilised to develop a list of benchmarking questions sent to five local health services known to provide targeted palliative care services. Responses were received from three public Victorian health services, one that specialised only in palliative care and two that offered palliative care as a specialised component of the health service. These services described a range of educational approaches. No universal formalised education programme in palliative /end-of-life care or communication skills was undertaken at any service or between services.

In the final stage of the information gathering process, a review of available palliative resources from both the health services e-learning platform and widely available online options were examined. These were evaluated for their relevance to OT in this practice setting, and potential for incorporation into the education package content or as adjuvant materials. Decisions for inclusion in the education package were based on accessibility, specific reference to OT within the resource and applicability to patients presenting across all areas of the health service rather than specifically within palliative care. Pre-implementation data, review of baseline practice, literature review, benchmarking, and resource evaluation occurred over a period of 5 months from February to June 2021.

End-of-life concepts and client journeys

OT clinicians have been active within palliative and end-of-life care for many decades, previous studies found professional education specific to this area of practice has been limited and confusions around definitions of palliative and end-of-life care remain prevalent (Eva & Morgan, 2018; Pickens et al., 2016; Şahin et al., 2017; Talbot-Coulombe & Guay, 2020). This highlights the need for an education package to commence with clear definitions of end-of-life and disease trajectories, alongside information on how and where these clients may present in the health service. Occupational Therapists have been found to lack awareness concerning their contribution and role at different stages of the patient journey (Essential-Yeh & McColl, 2019). For example, curative and rehabilitation interventions are relevant in palliative care, but not at end-of-life when interventions become more targeted at occupational participation and quality of life (Pickens et al., 2016).

A theme that was identified throughout the literature was the inequity of service provision to palliative care clientele generally, suggesting that people receiving palliative care may be at high risk of occupational injustice, in part, due to a lack of clinician confidence and skills working in this area (Eva & Morgan, 2018; Hammill, 2014; Sartori & Battistel, 2017; Talbot-Coulombe & Guay, 2020). OT treatment approaches that may be adopted at each phase are emphasised in the education package.

The place of occupation in palliative and end-of-life care

The next section of the education package introduces the principles of palliative approaches, communication strategies and techniques that promote occupational justice. Improved occupational justice results from occupational therapists enabling choice, meaning, balance and participation for clients (Townsend, 2012), and the package focuses on practice strategies aligned with both these outcomes and palliative principles.

End-of-life is associated with multiple layers of loss. Clients often face progressive losses of their occupational roles and identity, along with decreased functional capacity and participation across community, domestic and personal occupations. Social death often precipitates biological death, however occupational participation remains as important at the end-of-life as it is at earlier stages (Pickens et al., 2016). The incorporation of palliative care with doing, being, belonging and becoming concepts is supported (Hitch et al., 2017).

Meaningful occupations at end-of-life are an essential mediator for exploring connections regarding living and dying (Benthall & Holmes, 2011), and can also prevent occupational alienation through the loss of occupational identity and roles. Cultural, spiritual, social and physical contexts must be taken into account in relation to anticipated disease progression, particularly with regard to its potential to reduce occupational participation and to cause occupational injustice (Cooper et al., 2015).

Assessment of the palliative client must also include an understanding of their view of life and expectations of dying (Occupational Therapy Australia, 2015). Implementing a client's occupational choices allow expression of self, affirms meaning in life and reduces anxiety and pain (Essential-Yeh & McColl, 2019). Rehabilitation within palliative care enables improved occupational performance, increased satisfaction and quality of life in clients living with neurological or physiological and degenerative conditions (Arbesman & Sheard, 2014; Talbot-Coulombe & Guay, 2020).If OT clinicians move away from an occupation-based approach, they may inadvertently contribute to reduced occupational participation and enhance experiences of occupational injustice (Badger et al., 2016).

Adaptive and compensatory strategies become increasingly important to completing occupations as diseases progress (Occupational Therapy Australia, 2015). Eventually, desired occupations may need prioritising as endurance and fatigue levels change, and increased assistance is required (Cooper et al., 2015; Essential-Yeh & McColl, 2019). Occupational engagement takes on additional significance for the dying person, as a means of self-expression and a mechanism for closure and preparing for death (Lala & Kinsella, 2011).

A lack of attention to leisure and social occupations during rehabilitation may inadvertently result in occupational alienation and deny the clients' occupational rights as a full citizen in their community (Nilsson & Townsend, 2010). Enabling new occupations for these clientele may also promote feelings of self-worth, control, choice, competence and identity (Hasselkus, 2011; Mills & Payne, 2015). This enablement potentially counteracts feelings of isolation, helplessness, uselessness and hopelessness that are frequently associated with increased reliance on others at end-of-life (Lala & Kinsella, 2011). Occupational disengagement and deprivation have previously been identified as key issues in occupational justice for palliative care clientele (Keesing & Rosenwax, 2011).

Finding the balance between supportiveness and coerciveness as a therapist can be challenging when a client is disengaged, for this reason, a client centred approach is reinforced in the literature (Hammell, 2015; Keesing & Rosenwax, 2011). Creative pursuits allow participants to create connections to life and cope with loss, while the act of gifting restored patterns of reciprocity often lost by clients towards the end-of-life (Pickens et al., 2016). Putting personal affairs in order, reconciling relationships, saying goodbye and passing on mementos are all potential acts of legacy in addition to completing a life review/ recording life history (Hasselkus, 2011).

Legacy of actions and artefacts are closely associated with both the client's occupational identity and its transmission, enabling end-of-life comfort and reducing existential anguish (Hasselkus, 2011). Occupational justice for palliative clientele is an aspect of care in which occupational therapists could lead and develop. These occupations have been described as "spiritually refreshing" (Martin & Herkt, 2018, p. 27) at a time where spiritual needs may take precedence over physical needs. Acceptance, improved quality of life, increased occupational participation, wellness and occupational justice are all potential gains for clients and/ or caregivers if an occupational perspective is maintained (Pickens et al., 2016). The education package promotes occupational engagement across these domains and encourages the need for innovative clinical reasoning to identify when occupational performance is no longer an appropriate goal and may well increase emotional distress (Pickens et al., 2016).

Apostol et al. (2021) highlighted that moving from a purely rehabilitative focus to maintenance and compensation is challenging to most traditionally trained occupational therapists employed within a biomedical healthcare services model. Current practice in Australia has a relatively limited scope, with an emphasis on equipment prescription, carer training and discharge planning rather than occupational engagement (Keesing & Rosenwax, 2011). Organisational expectations may constrain the OT role in palliative care, depriving clients of opportunities to exercise their occupational rights at end-of-life (Eva & Morgan, 2018).

A model for occupation based practice in palliative care

Incorporated into the education package is a model of occupation-based palliative care (Essential-Yeh & McColl, 2019) providing occupational therapists with a framework specific to palliative and end-of-life but applicable to any area of service provision.

This model is structured around five key concepts: 1) The importance of valued occupations at end-of-life, 2) Integration of doing, being, becoming or belonging occupations, 3) The balance between affirming life while preparing for death, 4) Occupational change over an illness trajectory, and 5) An emphasis on safe and supportive environments for effective palliative care (Essential-Yeh & McColl, 2019). The model closely aligns with occupational justice concepts, promoting the rights of people at any life stage to engage in occupational participation (Nilsson & Townsend, 2010).

The model describes a dynamic interaction between all the themes, and valued occupations are defined as "[...] a subjective activity with a shape, a pace, a beginning and an ending, a shared or solitary aspect and a cultural meaning to the person" (Essential-Yeh & McColl, 2019, p. 110). Occupations and their meaning to the client can only be identified and implemented utilising a client centred approach, and with occupational justice in mind as an end goal.

Occupational deprivation impacts wellbeing and health negatively when individuals cannot participate in the diversity of occupations of their choice (Polatajko et al., 2013). Essential-Yeh & McColl (2019) describe doing occupations as those which may be witnessed objectively. Being occupations as those which reinforce existence, humanity and identity and belonging occupations are such that tie a person to others (Essential-Yeh & McColl, 2019). Lastly, becoming occupations as those that allow individuals to engage with the future (Essential-Yeh & McColl, 2019). However, the Occupational Perspective of Health and the Pan Occupational Paradigm describe these four dimensions as all co-existing within every occupation, acknowledging that the emphasis may be more present in one dimension than others (Hitch et al., 2017).

The model also recognises the role of temporality in palliative care to reflect that occupations change over time with illness progression and alterations to individual priorities (Essential-Yeh & McColl, 2019). Integration of this model into the education package assisted in highlighting the place of occupation in palliative care and bringing together essential elements of OT service provision identified in the literature search.

Supporting bereavement and resilience

The education package includes content regarding bereavement and self-care, to assist therapists in identifying their own and others support needs. The needs of caregivers is a strong focus in palliative care, where the caregiver is an additional recipient of care and an integral contributor of collaborative care (beyond the more usual role as a provider of collateral information) (Pickens et al., 2016). Underutilisation of OT services by caregivers has been identified as an emerging issue within palliative care, highlighting another stakeholder group at potential risk for occupational injustice (Pickens et al., 2016).

Rituals of healing and memory holding are important for the expression of bereavement, and occupational therapists understand the importance of occupations which may foster recovery from bereavement, allowing carers to explore new occupations and create new occupational roles and habits following a death (Pickens et al., 2016). The ability to recognise and understand the difference between complicated and uncomplicated bereavement is an important skill for palliative care clinicians to identify the need for additional specialised supports (Breen et al., 2013).

As a member of the inter-professional team, occupational therapists are ideally placed to work collaboratively to address the needs of caregivers in a timely manner and prevent occupational injustice peri and post the death of a loved one viewed from an occupational perspective. Justification for the inclusion of self-care and resilience strategies in the educational package is indicated by the high proportion of palliative patients seen elsewhere in the health service (Talbot-Coulombe & Guay, 2020). Breen et al. (2013) identified a lack of grief education for palliative care clinicians as a barrier to developing effective grief management skills, which is endorsed by evidence of burnout rates as high as 50% (Koh et al., 2019). Koh et al. (2019) identified a model of Transformational Growth for clinicians to assist in recognition of their own emotional responses to clients at end-of-life and to promote psychological safety and career longevity. This framework aims to reduce burnout and compassion fatigue and highlights the importance of personal and collective responsibility for building a culture of team resilience (Koh et al., 2019).

Key considerations for OT education in palliative and end-of-life care

Information on advanced care planning and voluntary assisted dying were incorporated into the education package to ensure occupational therapists are well informed about local legislation and statutory requirements. The inclusion of all of these elements into an education package ensures it addresses the recommendations for occupational therapists in palliative care identified across the literature (Breen et al., 2013; Essential-Yeh & McColl, 2019; Hammill et al., 2014; Keesing & Rosenwax, 2011; Mills & Payne, 2015; Talbot-Coulombe & Guay, 2020).

A scoping review by Talbot-Coulombe & Guay (2020) identified three themes in end-of-life education for occupational therapists; 1) Exposure to relevant knowledge, 2) Content required for competent practice and 3) Effective educational strategies. The inclusion of the model of occupation based palliative care and specific content around advanced communication skills and psychosocial aspects of end-of-life were incorporated into the education package after being emphasised during consultation and benchmarking as essential for competence (Talbot-Coulombe & Guay, 2020; Essential-Yeh & McColl, 2019).

To enable a safe learning environment with opportunities for reflection, the overall package is multimodal, utilising face to face instruction post completion of background generic recognition of end of life education. The OT specific education incorporates existing resources, links to expert speakers, practical scenarios and interactive evaluation measures (Breen et al., 2013; Koh et al., 2019; Talbot-Coulombe & Guay, 2020).

As advocated by Keesing & Rosenwax (2013), the education package also includes case scenarios and practice examples to assist clinicians make the link between theory, evidence and their own practice. For example, specific and explicit links are made between communication skills and the ability to facilitate family meetings within palliative and end-of-life settings (Campbell et al., 2021).

Discussion

Review of current practice highlighted gaps in both knowledge and skill base of occupational therapists when working with clients and their caregivers receiving palliative or end-of-life care at our health service.

The work completed thus far informs the first two stages of the PDSA cycle, implementation and evaluation will provide further opportunity to share findings that may be applicable to a wider group of OT clinicians than initially identified for this quality improvement process.

Limitations experienced during the project included having to exclude educational approaches that would not be considered appropriate to the resources and governance of the health service. For example: supervised exposure to death can be an effective education strategy, but is ethically challenging to deliver (Breen et al., 2013; Talbot-Coulombe & Guay, 2020). Simulation approaches were also proposed as an appropriate medium by Vemuri et al. (2020), but require significant resources in the set-up phase and may potentially raise difficult issues around vulnerability, privacy and/or consent. Given the evolving theme of occupational justice in relation to palliative care service provision, inclusion of occupational justice into the search terms may have uncovered a wider range of reference and resource materials that could have added value and greater depth to the development of the educational package.

Despite these limitations, the educational package achieved its aim of integrating and utilising as many of the recommended resources as possible Face to face contact with clients at end-of-life can complement the flexible use of clinical scenarios, workshops and content targeted to specific topics as proposed in the package developed (Apostol et al., 2021; Breen et al., 2013).

Organisational barriers identified include that while only 1.6% of the Australian OT workforce is employed in explicitly palliative or end-of-life services, in reality many clients are never admitted to these services due to access barriers and availability shortages (Keesing & Rosenwax, 2013). Clients that are admitted to these services also experience unnecessary delays in referrals to OT, leading to crisis management that will likely diminish an occupationally focused approach (Keesing & Rosenwax, 2013). Eva & Morgan (2018) noted the importance of promoting the palliative and end-of-life role of OT more broadly to generalist services and interprofessional team members but identified concerns that demand would outstrip supply as an important barrier. Without access to OT, clients may not receive the specialist assessment and treatment needed to promote occupational justice at the end of life.

The literature review identified substantial evidence for OT within palliative and end-of-life care provision and provides a solid and ever-expanding evidence-base. However, OT specific educational initiatives are limited to undergraduate and postgraduate studies currently. Following graduation, the majority of professional education occurs in the workforce which utilises different pedagogical approaches to higher education.

The fundamental importance of maintaining an occupational perspective in any evidence-informed education package developed for occupational therapists was emphasised in the literature (Breen et al., 2013). Disempowerment for clients and their caregivers throughout their palliative and end-of-life care journey is commonly experienced. OT has a powerful philosophical and skill base from which to advocate for occupational justice, through the provision of client and carer centred education, advocacy, problem solving and case management (Keesing & Rosenwax, 2011).

Benchmarking against other healthcare services contributed a range of information and highlighted the variability in education between sites and services but was limited in response range and may not reflect all currently utilised educational strategies.

Available online resources provide excellent coverage of skills for clinicians working solely in specialist palliative care services, however, they are too lengthy for clinicians providing end-of-life care sporadically and are not occupationally focused in content. Although a wide range of resources were reviewed, there is potential limitation that some relevant resources were not identified. There is a recognised need to better understand the educational requirements of generalist occupational therapists in regard to palliative and end-of-life care, alongside the most appropriate educational approaches for work-integrated learning for this cohort.

A developing theme around the OT role at end-of-life is the disciplines ability to contribute to the experience of a ‘good death’ in the place of their choice, which closely aligns with the key occupational justice concept of meaning. Place (2019) argue that OT has an essential role in facilitating return to the preferred location of death while ensuring caregivers are appropriately supported in this non-clinical environment. Badger et al. (2016) found that clients valued the comfort and safety afforded by OT interventions and trusted the expertise of their occupational therapists to know what was needed for them to achieve their goals.

The facilitation of death at home or in other non-clinical locations, is an opportunity to highly value OT intervention at end-of-life and provide leverage for a shift toward a more occupationally focused perspective within the service culture.

Future Directions

There is a danger of inadvertently contributing to occupational alienation and occupational marginalisation when OT practice becomes limited by narrowed expectations and perceptions of other disciplines or service limitations. The time limited nature of working with this client group may also hamper efforts to promote occupational justice, as these goals may be perceived as longer term aspirations. While focusing on increasing the knowledge, skills and confidence of the OT workforce, meaningful change in this area will also require a cultural shift within our inter-professional teams in the health service towards occupational engagement and an explicit commitment to occupational justice (Nilsson & Townsend, 2010). Implementing this educational package is a first step in a longer process of change, led by occupational therapists in partnership with clients and caregivers towards occupational participation and justice.

Following implementation of the face-to-face session, feedback gained will assist in evaluating content which will then be transferred into the e-learning package and implemented as mandatory for all new OT clinical staff. This stage of the PDSA cycle is expected to take place over the next 12 months. Although the initial design was undertaken within a specific health service, given the variability of working areas within this service, there is potential for the learning package to be utilised elsewhere for occupational therapists working within the Australian health care context.

A course plan template and PowerPoint presentation for this education package is available from the first author upon request.

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Author's Contributions

Karen Kessner and Danielle Hitch were responsible for the design of the text, organization and analysis, writing, and revision of the text. All authors approved the final version of the text.

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Appendix A. Quality Improvement Minimum Quality Criteria Set (QI-MQCS) Version 1 (Rubenstein et al., 2015).

Domain	Minimum standard	Score
1. Organisational motivation. The health service recognise the need to advance priorities of this group with the formation of the End of Life care committee. Majority of deaths still occur in hospital settings and current data supports this. Minimal attention to palliative or end of life care is provided in available education.	A strong case for greater economic investment in palliative and end-of-life care has been made across multiple sectors (Palliative Care Australia, 2020), particularly in regard to healthcare clinician education.	Met
2. Intervention Rationale Current OT service provision within the health service identified that OT assessment and intervention was primarily focussed on rehabilitation and equipment provision and was not inclusive of occupational participation for palliative and end of life care clientele.	54% of Australian occupational therapists' report having no specific training in palliative care (Talbot-Coulombe & Guay, 2020).	Met
3. Intervention Description Development of an evidence informed education package aimed to enable OT clinicians to provide the best possible quality of care and promote occupational justice for clients receiving palliative or end-of-life care.	OT for palliative or end-of-life care is a common clinical experience, yet rarely the subject of targeted professional education. Talbot-Coulombe & Guay (2020) estimate that 95% of OT clinicians will work with a dying patient.	Met
4. Organisational characteristics This quality improvement project transpired in a large tertiary health service that caters to 900,000 people in a major Australian city. It has the three largest growth corridors in the city within its boundaries, and the highest number of people coming from culturally and linguistically diverse backgrounds in the Australian state of Victoria catering to more than 110 language groups.	Local state frameworks for palliative and end-of-life care, which emphasise advocating for person centred care and respecting client choices (Victorian State Government, 2021). Hammell (2015) asserts all individuals have the occupational right to participate in activities of their choice at any point in their life trajectory.	Met
5. Implementation The need for development of a targeted education package was identified from consultation with key stakeholders to discuss gaps in the current skills, knowledge and confidence of OT clinicians when working with this patient group. Further evidence to support this approach was gained from a literature review and benchmarking similar health services.	Without relevant, evidence-based and discipline specific education, Martin & Herkt (2018) warned that the needs for OT in palliative care may not be recognised, leading to less access to specialist occupational assessment and intervention and increased occupational injustice for these clients.	Met
6. Study design An obsolete educational package previously developed for oncology clients included minimal information related to palliative care and adopted an inequitable focus on rehabilitation.	54% of Australian occupational therapists' report having no specific training in palliative care (Talbot-Coulombe & Guay, 2020).	Met

Appendix A. Continued...

Domain	Minimum standard	Score
7. Comparator A skills audit questionnaire previously undertaken within the OT department did not include a specific evaluation of capabilities related to palliative or end-of-life care. The absence of palliative and end of life questions from the audit indicated a lack of recognition of the requirements specific to this area of practice.	Without relevant, evidence-based and discipline specific education, Martin & Herkt (2018) warned that the needs for OT in palliative care may not be recognised, leading to less access to specialist occupational assessment and intervention and increased occupational injustice for these clients.	Met
8. Data Source A review of professional and grey literature was completed to establish evidence available, and benchmarking with a limited number of similar organisations provided a wider perspective on current Australian practice.	Data reviewed represented a higher number of clients from culturally and linguistically diverse backgrounds and greater overall demand experienced across all service areas compared to general Victorian population (Australian Bureau of Statistics, 2019; Australian Institute of Health and Welfare, 2021).	Met
9. Timing Pre-implementation data, review of baseline practice, literature review, bench marking and resource evaluation occurred over a period of 5 months from February to June 2021. The face to face session is anticipated to be provided within the following six month period.	Following implementation of the face to face session, feedback gained will assist in evaluating content. Plans to transfer into an e-learning package and implement as mandatory for all new OT clinical staff. This stage of the PDSA cycle is expected to take place over the next 12 months.	Met
10. Adherence /Fidelity Future plans to transfer this education to an e-learning platform where evaluation will be built into the package to allow continuous improvement.	To enable a safe learning environment with opportunities for reflection, the overall package is multimodal (Breen et al., 2013; Koh et al., 2019; Talbot-Coulombe & Guay, 2020). The education package includes case scenarios and practice examples to assist clinicians make the link between theory, evidence and their own practice (Keesing & Rosenwax, 2013).	Met
11. Health outcomes Disempowerment for clients and their caregivers throughout their palliative and end-of-life care journey is commonly experienced.	Acceptance, improved quality of life, increased occupational participation, wellness and occupational justice are all potential gains if an occupational perspective is maintained (Pickens et al., 2016).	Met
12. Organisational readiness Development of an evidence informed education package aims to enable all OT clinicians across all areas of the health service to provide the best possible quality of care and promote occupational justice for clients receiving palliative or end-of-life care.	1.6% of the Australian OT workforce is employed in explicitly palliative or end-of-life services, in reality though, many clients are never admitted to these services due to access barriers and availability shortages (Keesing & Rosenwax, 2013).	Met

Appendix A. Continued...

Domain	Minimum standard	Score
13. Penetration /Reach Initial design was undertaken within a specific health service, however recognises the variability of working areas, identifying a potential for the package to be utilised elsewhere for occupational therapists within the Australian health care context.	Eva & Morgan (2018) noted the importance of promoting the palliative and end-of-life role of OT more broadly to generalist services and multidisciplinary team members.	Met
14. Sustainability Formulation of structure and content of a face-to-face clinical education session is completed Plans to transfer this to an e-learning platform with ongoing evaluation to allow continuous improvement.	Eva & Morgan (2018) noted the importance of promoting the palliative and end-of-life role of OT more broadly to generalist services and multidisciplinary team members but identified concerns that demand would outstrip supply as an important barrier.	Met
15. Spread Once the face to face session is held, feedback gained will assist in fine tuning the e-learning content which can be implemented as a mandatory training package for all new OT clinical staff.	To enable a safe learning environment with opportunities for reflection, the overall package is multimodal (Breen et al., 2013; Koh et al., 2019; Talbot-Coulombe & Guay, 2020).	Met
16. Limitations OT specific educational initiatives are limited to undergraduate and postgraduate studies. Following graduation, the majority of professional education occurs in the workforce which utilises different pedagogical approaches to higher education. Benchmarking highlighted the variability in education between sites and services.	Supervised exposure to death can be an effective strategy, but is ethically challenging to deliver (Breen et al., 2013; Talbot-Coulombe & Guay, 2020). Simulation approaches were also proposed as an appropriate medium by Vemuri et al. (2020), but potentially raise difficult issues around vulnerability, privacy and/or consent.	Met