NORTH AND WEST
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Barriers and Opportunities to Palliative Care service provision for People with lived experience of a disability.

Issues Report

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Contents

Key Words

Disability, Palliative, End-of-life, Barriers, Opportunities, Research

Executive Summary

This report provides an overview of emerging issues encountered at the interface of providing palliative care for people with disabilities. Over the last decade, an increasing focus on palliative care for persons with a disability can be found in the academic literature. Despite this, many questions remain about service models inequity and little guidance is provided concerning how to address the problems identified. This report outlines existing evidence regarding palliative and end-of-life care provision for people with lived experience of a disability and their carers*.

Recurring themes identified in research in terms of barriers, include late diagnosis and diagnostic overshadowing. The high prevalence of common and multiple co-morbidities for persons with a disability presents barriers to diagnoses as well as offering opportunities to develop pathways for earlier identification and management of chronic and life-limiting illnesses. Communication barriers exist for the person with lived experience of a disability, professional and non-professional carers. Some studies have identified resources to aid communication, but research is lacking on efficacy of these at present.

Assumptions regarding capacity and how information may be understood and how a person with lived experience of disability may react, often results in no attempts to communicate at all. This highlights embedded discrimination within health care systems and inequitable resource allocation. Current service provision across health care and disability services are siloed in nature; yet palliative care services and disability support services both work from psychosocial frameworks that are very compatible in their approach.

Evidence exists to support provision of information regarding life-limiting illnesses and palliative care to persons with disabilities in a structured and supported approach. Where this is provided, outcomes are improved for the person, carers and health services alike.

Education and training across all areas is a highlighted priority for the future with a focus on communication, advance care planning and bereavement. The need for additional research is also highlighted alongside exploration of champion roles for persons with a disability to act as navigators across multiple and complex services. Attention to these priorities at national, state and local levels is recommended with additional consideration to governance, policies, procedures and guidelines across service providers.

**In this report, the term 'carers' refers to professional, paid and unpaid carers unless specifically identified as one of these sub-groups.*

Background

The World Health Organisation (WHO)[52] defines palliative care as an approach that prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. WHO states that currently, across the globe, only about 14% of the general population who would benefit from palliative care receive it. Evidence exists to demonstrate that persons with a disability are less likely to receive palliative care than people without disabilities[2]. The World Health Organisation recognises disability as a global issue with palliative care as an international human right[29,52]. The United Nations Convention on the Rights of Persons with Disabilities determined that persons with disabilities "retain the legal capacity to make treatment decisions even though some may require more support than others to do so"[23]. Contemporary recommendations support palliative care service provision across all disabilities, in all settings, as a fundamental right[28,31].

Timely palliative care aligns well with the person-centred and psychosocial model of care currently provided to people with lived experience of disability. It does not need to be considered as a separate way of caring but rather as a complementary model of care. Palliative care principles were found to be embraced when similar philosophical underpinnings were demonstrated to disability care workers[18]. The ageing population within the disability sector are increasingly likely to have multi-morbidity and need to access palliative care services[6,10,19,30,31,37] This population are also increasingly likely to be exposed to death and dying of others[50]. Recognising the needs of the dying in this population will be as important as meeting the needs of the living, and a proactive empowerment model of care results in better outcomes while reducing demands on traditional healthcare organisations[22].

Methodology

A search of existing literature utilising three databases over a 12-month period was conducted. Search terms combined disability/ disabled and palliative/ end-of-life/ terminal. This result was then compounded with evidence /barriers /research /outcomes. Search criteria returned a high number of results, although after reviewing titles and abstracts, many were found to lack relevance to the review question "What evidence exists regarding palliative and end of life care for person with a disability?".

Additional material was sourced through hand searching reference lists, government reports and international consensus documents. Forty-six articles were found relevant to the subject, with an additional six supporting documents to provide background information /data.

Each article was reviewed with themes identified through individual analysis[11]. Themes identified were then broken down into sub-categories utilising thematic analysis. Two main themes were identified as barriers and opportunities. Barriers are further delineated into diagnostic barriers, communication, service fragmentation, discrimination, capacity for decision making and access to resources. Opportunities were themed into choice and control, education and training across both the disability workforce and the health sector, bereavement needs, the role of a champion for a person with a disability and lastly, further research needed.

Findings

Barriers

Diagnostic barriers

Persons with disabilities die younger and with fewer indications of decline before death than that of the general population which may contribute to reduced ability in identifying end-of-life symptoms[19,22]. Palliative care needs are frequently only realised in very advanced stages of illness[27,39]. This has resulted in an increasing need for age-related illness management, including palliative care. The need for these services has been exacerbated with the onset of the COVID-19 pandemic with disability as a risk factor second only to age in COVID-19 related deaths[31].

Adults with disability are more vulnerable and at risk and have frequently experienced adverse health service interactions and therefore require specific attention as a population regarding specialist palliative care[47].

The Australian Institute of Health and Welfare[5] data indicates that increasing layers of complexity for a person is likely to negatively impact access to health services i.e., lower socio-economic status, non-English speaking background and multiple co-morbidities will all contribute to poorer health outcomes. For person with a disability, this results in additional barriers to positive health outcomes and inequities in care which could be avoidable[30,40]. Hunt identified in a post-bereavement survey of person with a disability, that more than twice the deaths that had occurred during the study period were considered “sudden” as compared to the general population, indicating a failure to identify the end-of-life in the disabled population[19].

Causes of death for persons with disabilities differ from that of the general population[6,19]. Diagnostic overshadowing (the tendency of a health professional to assume that the presenting symptoms of a people with disabilities is part of their underlying disability and not investigate other causes) leads to delayed diagnoses of life-limiting conditions. This impacts access to palliative and end-of-life care needs for the person with a disability[2,6,10,19,22]. Persons with disabilities are living longer with an average lifespan of 66 years but this remains well below the general population and compared to the general population, persons with a disability are at greater risk of earlier and avoidable death[27, 31].

People with severe and persistent mental health illnesses die up to 20 years earlier than the general population[9].

Chronic conditions such as advanced dementia, that are appropriate for referral to palliative care are under recognised generally[26]. Dementia is common for people with intellectual disabilities with an estimated mean age of onset at 51 years of age indicating a potentially unmet need within this specific group[26]. Ninety seven percent of persons with a disability will also have at least one other long-term health condition with epilepsy and cardiovascular disease highly represented alongside dementia[22]. End-of-life care can be more difficult to identify for someone with multiple underlying conditions such as Down syndrome and Dementia despite a high prevalence of coexistence[25-28]. Pain management was also noted to be under-treated, correlating with worsening severity of cognitive impairment of the person with a disability[47].

Communication

People with disability have a fundamental right to self-determination[51]. Despite progressive changes occurring with chronic conditions, the essence of a person remains, and therefore their wishes should be accommodated wherever possible. The persons’ individual needs, not the disability, nor the diagnosis, should determine what services they require[8,10,31,44].

Evidence exists that decisions related to end-of-life care, including treatment options, often do not include the person with the disability in the process, but instead focus on the family[6,41,44]. Poor communication regarding diagnosis, treatment options and care coordination with an expectation on carers to convey this information often leading to care decisions being based on the health teams’ recommendations as opposed to the wishes of the person with the disability[10].

Assumptions may be made by others regarding the person's ability to cope with treatment options, thereby potentially leading to compromised quality of life for the disabled person[10,40,51].

Although assessment for persons with disabilities may have specific nuances, the dying process is comparable across all populations[31]. End-of-life care is typically associated with the last days to weeks of a person's life and is associated with higher care needs and increased symptom management. Typically, at this time, routine medications may be withdrawn as these can add to symptom burden. The focus is on comfort, inclusive of pain relief, and care is aimed at promoting a good death (as would be perceived by the person who is dying). Everyone will have preferences at this time and the ability to exercise our will and autonomy assists in achieving a good death, yet this only occurs in people with mild to moderate disabilities 27.8% of the time[49].

The importance of language use was highlighted in the literature with the use of euphemisms (such as passed away, passed, no longer with us) are found to be confusing and misleading[31,51]. Palliative care innovations designed for the general population could be employed for person with a disability but were considered more suited once adaptations had been made (such as converting to easy English versions)[44]. Up to 85% of the people living with disability population have "mild" categorisation of disability and can live independently with minimal support indicating high potential to contribute to these care decisions[13,20,31].

In previous literature reviews, challenges were found in identifying symptoms for people with significant communication difficulties. Symptoms were often expressed as changes in behaviour[1,39]. Disability care workers may not recognise these changes as associated with end-of-life decline, yet they are crucial in detecting changes in behaviour and assisting medical staff to interpret these changes[10,16]. Specialist disability staff have an opportunity to share knowledge and understanding with generalist care workers to address communication challenges and collaborate to identify issues[6,21,31,44]. Persons with disabilities may not self-identify symptoms nor possess the language skills to provide specific detail[21,35].

Disability providers, in principle, provided unanimous support for informing persons with disabilities about dying, but limited engagement occurred in practice[50]. Evidence indicates that carers are more willing to talk about death related to other people with disability but there is a reluctance to engage in the topic of death relating to the identified individual who is dying, despite the potential for increased understanding when discussed with a familiar carer[13,21,28,44,51].

Communication skills are an area identified repeatedly in the literature, particularly related to having challenging conversations (breaking bad news), communicating through conflict, understanding and responding to changing communication needs and managing complex communication needs[13,28,31,37]. More importantly, not communicating denies the person with the disability the basic right to information and does not allow the opportunity to understand what is happening to them or be involved in significant decision-making opportunities[50].

Service fragmentation

Where services work independently of each other, unshared assumptions lead to poor care outcomes[16]. Currently, both disability services and palliative care-specific services are largely working independently of one another[6,10,31]. Palliative Care Australia has promoted a particular focus on workforce issues and developing solutions that deliver quality palliative care to all who want it, wherever they are[33]. Evidence indicates that paucity of referrals to community palliative care, late referrals, lack of time, knowledge and skills, in addition to communication barriers are challenges to accessing timely palliative care[6,10].

Health professionals have difficulty recognising the need for palliative care in the disability community, find it challenging to discuss end-of-life, and often lack the skills to undertake advance care planning with people with lived experience of disabilities[13,20,31,43]. These concerns may be amplified for people with mental illnesses where a lack of trust in building relationships with new teams can result in people under-reporting symptoms[9].

A lack of understanding from health care services regarding the limitations of direct care workers training /abilities (such as being unable to administer opioid medication) has led to poorer outcomes[47].

Palliative care professionals may be less confident managing complex presentations and medication interactions with someone with multi-comorbidities such as longstanding mental illness[3].

Within specific disability nursing training, a lack of palliative care education has been identified[37].

Disability care workers often perceived death as a medical event and therefore, not within the scope of their expertise[16]. A literature review completed in 2020 identified challenges in three areas for disability care workers including limited experience, identification and management of symptoms, and difficulties coordinating care[10]. The National Disability Insurance Scheme (NDIS) workers are paid less than other services and can be a transient workforce with few or no qualifications, which has translated to a reduction in choice and control for participants[9]. The result is a transactional rather than a quality relationship with competition between service providers leading to less collaboration and poorer outcomes for participants[9].

Recognition of the importance of the general practitioner in early identification of the need for specialist referrals is acknowledged, yet this professional group was identified as having the lowest level of training and confidence in the management of people with intellectual disabilities who were ageing[20,29].

Discrimination

Social determinants of health can be viewed as social determinants of death as they strongly predict the degree of agency in self-determination[15]. Research demonstrates that health care professionals may be discriminatory, assuming persons with disabilities have a poorer quality of life than persons without lived disabilities[10,29,31]. In addition, sporadic involvement with persons with disabilities results in fewer opportunities to apply any knowledge previously gained[16,37]. Traditional health and disability service models are geared towards enablement and independence which is a obstruct acknowledgement of palliative care needs[37].

Although high expectations of carers were prevalent from the medical community, a lack of respect for these supports was evident[9]. A lack of understanding of communication needs led to carers perceptions of incompetence and a fear of making incorrect decisions[6,10,29,31,37]. Discrimination when trying to access health services as a carer, was also identified as a barrier[3]. This was especially evident when capacity is unclear and/ or communication barriers exist.

Persons with disabilities lacked knowledge of specific end-of-life supports such as hospices, highlighting inequity and discrimination in service provision[3,9,30]. This inequity is compounded by social factors such as homelessness, stigma, lack of supports and substance dependency[9].

Capacity for decision making.

Presumption of capacity is a fundamental human right for person with a disability[13]. Yet the ability for autonomous decision-making is frequently bypassed, undermined or an assumption of incompetence occurs for the person with a disability. The concept of capacity is uniquely human and intricately linked to a “good death”[45]. The literature identified that perceived capacity determined whether conversations about death occurred with the person with a disability or not. Factors such as additional training, experience, relationship to the person and expertise all positively influenced initiation of these conversations[3,13,49].

Evidence indicates that limited communication of dying, and death occurs with people with disability. Carers and health professionals alike describe difficulties in providing these conversations[1,6,13,42,47,51]. Concerns that conversations are more likely to take place with a family member when professional health staff do not have the confidence or skills to have the conversation with the person with a disability are prevalent in the literature, potentially leading to involuntary treatment decisions[6,9,10,13,14,51]. People with disability are living longer with improvements in medical treatments, but death may be preceded by a period of increasing vulnerability and illness[44].

Over the last 50 years, the expectation in Australia has been increasingly to openly communicate diagnosis and prognosis, yet in practice this is less likely to occur for a person with a disability[50]. Advocates promote an ongoing process of disclosure that builds an understanding of the situation over time and assists in appropriate care planning[12]. The multitude of communication barriers impacts further on issues of consent and ethical treatment for person with a disability[39].
Where capacity exists, the need to support the rights of people to make care decisions is supported within a human rights framework incorporating the concept of dignity of risk[9].

Access to resources

Barriers exist concerning appropriate and timely access to needed resources, both physical and service-related[6]. Cultural differences in expectations of how palliative care provision is enacted before and following death can be an area of identified knowledge deficit for disability care workers[14]. One study identified the informational needs of carers as these changed over the trajectory of the illness: these incorporated knowledge of the disease, financial support and practical supports such as equipment needs and manual handling recommendations[28]. These needs corresponded to an increase in financial pressures and a lack of practical support when not met[28].
When the appropriate skill mix is available for a person with a disability needing a palliative approach, time remains a barrier to perceptions of quality care provision by carers, with resulting guilt around reduced care provision in relation to this[37].
Policy barriers exist to hamper dying in place for a person with a disability such as resuscitation protocols and medication administration guidelines[16]. The NDIS has added complexity to an already confusing system, despite recommending seamless transitions and coordinated support for persons with disabilities, as supports will frequently be declined if the needs are seen as 'medical' as opposed to related to the underlying disability[9]. Legal safeguards exist in different states/countries specific to persons with disabilities that can function as barriers to enable the preferred place of death[20,31]. In some states, persons with disabilities who die at home in a group supported accommodation or supported independent living situation are considered as reportable deaths (even when expected) and require investigation by the coroner. This requirement potentially places additional strain and bereavement concerns on families, disability care workers and other people living in the facility. A trend identified persons with disabilities returning to hospital for end-of-life care which may, in part, be related to this issue[6,22].

Opportunities

Communication, choice and control

Despite concerns, evidence exists that talking about the end-of-life with a person with a disability does not cause psychological distress and can decrease anxiety when the discussion is supported well[12,13,31,49]. Conversely, excluding individuals from decisions regarding their end-of-life can be harmful and counterproductive[13]. Persons with disabilities frequently can advocate for themselves and self-identify a decline in their condition. Primary carers are more likely to identify incremental changes in abilities or health that could signal an underlying health condition such as cancer or dementia, indicating a change is needed in the persons overall management. Although disability care workers may not have the authority to make treatment decisions, early recognition allows early referral and access to speciality services[14,34]. Many persons with disabilities have difficulties with communication and some have no spoken language at all. In these circumstances, the families or carers working with a person daily have potential to identify gradual changes that may indicate a decline in cognitive, behavioural, physical or mental health[6,10,31]. Communication tools exist to assist persons who are non-verbal or have limited verbal ability.

The use of speech therapy expertise and communication devices is recommended where significant communication barriers exist[1,34]. Speaking slowly, using unambiguous language, allowing time for processing, clarifying, use of pictures and repeating information are some suggestions for facilitating communication[13]. Improved awareness of body language, facial expressions, gestures, vocalisations, eye gaze, leading carers by the hand, or use of symbols can improve understanding of persons with disabilities as comprehension can be higher with people with reduced expressive language[13,47,49].
A three-point scale in assessment tools is consistently found to be more responsive than a five-point scale for persons with a disability and concrete examples are better than abstract concepts in discussions[38]. Research demonstrates that persons with disabilities wanted to know about life-limiting conditions to make decisions about their care, including practical implications inclusive of deciding about preferred place of death[30]. They also identified that this information needed to be provided in a way that they could understand[30]. Persons with a disability could participate in conversations and assessments regarding end-of-life when tailored to their individual needs[38]. Mild discomfort is not unusual when discussing end-of-life and is not a reason to cease discussions solely due to its presence[38].

Advance Care Planning

Everyone should consider what they would like at the end of their lives and discuss these preferences and values with the people they love and who take care of them. These preferences can be included in Advance Care Plans (ACPs) to communicate to a wider group of carers or hospital staff if the care environment changes or the person can no longer communicate these. Discussions regarding goals of care should begin as early as possible and be a dynamic process reviewed regularly with any changes in the persons' condition[25,43]**.**
Tailored conversations regarding place of care, preferred carers, advanced care planning, spiritual needs, funeral arrangements, wills and organ donation should include the person with a disability; ensuring decisions are made with them, not for them[28,31,37,51].
If the person with a disability is deemed to not have capacity to make decisions, a guardian may be needed to assist with medical treatment decisions[8]. Planning is important and early instigation of a guardian can assist in advocating for a persons' wishes when they are no longer able to do this for themselves. Without a guardian, decision powers may be limited and require tribunal or court intervention which can lead to delays to access treatment[9]. Multiple conversations are required to establish the person's care wishes over time and as their condition progresses[4].
Both formal and informal documentation of a person's wishes is encouraged, as evidence exists to demonstrate an absence in documentation of wishes for people with a disability[16,44]. The use of video journaling, use of personal history books and multimedia profiles to aid in decision-making, were identified as additional tools[49]. Early advance care planning is important for everyone, but especially so when underlying health or disabilities exist such as dementia[1,25,26]. Cultural and ethnic needs should be considered in conjunction with physical and care needs[25]. Good advance care planning allowed care commensurate with the person's identified needs, preferences and values[19,43].
Regular reviews are encouraged, as the person receiving care may change their mind and care may need to be provided in a hospital, inpatient palliative care unit, respite facility or residential care facility as end-of-life approaches and care needs increase[7,8,10,12,44].

Education and training

Collaborative education is seen as essential to demystify anxieties and fears when engaging with persons with disability, working from a basis of philosophical similarities to provide complementary care[3,6,18,48]. Recognising the expert as the person with the disability, family or caregivers is considered an essential starting point in the intervention process[28,31]. Education needs to occur at several points.

Education prior to partnership alliance and cross-service experiential learning is recommended[29]. Education initiatives should commence in undergraduate studies to help encourage working partnerships across both disability and palliative care sectors[29].

Where collaborative goals and approaches were established, services worked more consistently and effectively with one another[3,29]. One study also highlighted less satisfaction with deaths of persons with disabilities that occurred in a hospital setting, and an increased likelihood of the person dying in their preferred place of death if this had been identified in planning[19].

Both the disability and health sector services recognise a need for increased training and education for both sectors[10,37]. Cross-agency interdisciplinary partnership with improved communication was proposed as one potential way to address these needs and promote understanding between professionals[27-31]. Coordinated care improves outcomes with reduced polypharmacy, decreased hospitalisations and associated reduced length of stay in hospital[31,47]. To guide this work, a Disability and Palliative Care Intersectoral Partnership Framework was developed to provide a structure for collaborative service provision between the health and disability service sectors[16].

Other benefits include increased access to community services with improvement in physical and mental well-being for persons with disabilities[31,47]. Staff training and education in isolation are not effective for sustained change rather carers need to be supported in an ongoing manner to apply learning in diverse situations[3]. Prevention, identification and treatment of known chronic co-morbidities need to be incorporated into mainstream healthcare early into the healthcare journey for a person with a disability[22].

Disability Support Staff

One study highlighted that 71.8% of early referrals facilitated the person with a disability remaining within their own home until death: with community palliative care advocating this as an area for significant improvement in outcomes for persons with disabilities[6]. This is an area where service values significantly complement each other, with studies demonstrating that over twice the number of persons with disabilities died at home than the general population, and disability care workers demonstrating 80.7% agreement that this was the correct place of death for those involved, and a willingness to assist in the palliative component of care[19,28,37]. Education with family and direct care workers to understand palliative care and assist with symptom management (such as nutrition and hydration needs) has been identified as a priority area[6,14,25,26,28].

Disability-specific services will need to become more familiar with palliative care services to access support in a timely and effective manner[6]. For disability service providers, palliative care approaches that were integrated into existing workflows are seen to be more effective and motivating for the workforce which was influential in the success of the innovation[44]. Several authors identified a need for increased training and access to disability-specific staff within generalist settings, as well as education aimed towards disability care workers about palliative care[6,14,18]. Disability care workers have training needs inclusive of communicating effectively, cultural competence, legal matters and post-death logistics and managing their own and others' grief[14]. Where this training was not available, disability care workers reported high levels of stress leading to burnout and impacts on carer health[21,31,37].

Healthcare Staff

Health workers across primary, acute and sub-acute care require education to understand specific disabilities, communication and service needs[1,6,25,28]. Opportunities for healthcare staff to be exposed to direct care for people with a disability, in general, was also highlighted[6,14,18]. Training that incorporates both intellectual and physical disability alongside dementia which facilitates inclusion in decision making, is highlighted as a priority as this is currently lacking for persons with disabilities[25,28,51]. Health care professionals need to be aware of unconscious bias, ableism and discrimination and work consciously towards inclusion, competency and advocacy to promote excellent quality palliative care provision for persons with disabilities[31].

Palliative Care Staff

Palliative care services need to embrace disability-specific education and provide a person-centred approach that recognises the person behind the disability, inclusive of personality traits, routines, experiences, values, cultural and religious beliefs[47]. Communities of learning have been found to have value for sustainability and ongoing skill development in organisations that have embraced providing palliative care in the persons' home with groups of carers, although may be limited by funding restrictions[22].

Bereavement

Knowing that you are dying can create anticipatory grief for both the person with a disability and carers. In addition to this, bereavement following a death impacts all members in group home in various ways and potentially more so when a person is enabled to die at home[25]. Good palliative care should incorporate the integration of bereavement care for all family and service users who may be impacted by the death[1,12,14,30].

Opportunities to acknowledge the place of bereavement management for paid carers by enabling rituals /grieving processes that allow carers to recognise the relationships formed with long-term clientele is important[37,50]. People of all ages and abilities frequently identify home as the preferred place of death but to accommodate this, training in end-of-life and complex care needs is identified[26,44]. Place of preferred death should be considered in conjunction with how that impacts other people in that environment including family and carers. At the end-of-life, people wish to be surrounded by familiar faces, normal routines, important relationships and treasured activities[1]. Similarly, long-term housemates may benefit more from seeing deterioration in health and understand the finality of death when not shielded from it[45].

Carers

Five shifts were identified in approaches to care needed by carers of people with disabilities to enable them to care for a person at the end-of-life[7]. These included: adapting to comfort care, intertwining emotional and professional involvement, attentiveness to interpretation of distress, increased responsibility, and intensified management of the relationship between family and professional carers[7].

Bereavement needs of care workers can be easily overlooked and the long-standing relationship that they develop with their clients under-recognised as "legitimate" grief, leading to the potential of disenfranchised grief in this population[19,27,37]. Other studies indicated that even when carers had experience of providing end-of-life care, reported understanding of death and dying was poor[50]. Post-death, carers report feeling isolated from the funeral and grieving processes by family members and report limited opportunity to acknowledge and mourn due to workload pressures[37,50]. A challenging death experience can lead to an implosion within the care team and the potential of long-term distress but conversely, a positive experience enhances understanding and unity of the care team[10,37].

The role of the co-ordinator

Several studies identified the potential of a central support person/ co-ordinator (sometimes termed champion) for the person with a disability /family /carer. This person would have specialised palliative care knowledge but were engaged within the disability services network, as this was seen to be the primary source of support for these people[20,28,29,31,44,45]. This position had the ability to coordinate services as indicated, and identify when further support and information were required[28,31]. For a carer to undertake this work on top of existing responsibilities was problematic[44]. The NDIS does not currently fund care co-ordination despite this being a recognised and highly valued role for persons with disabilities who had complex care needs with co-morbidities[9].

A co-design model was recommended for future service delivery planning[22,28]. Without appropriate funding and workforce development support, initiatives in these sectors are unlikely to succeed[16]. Organisational cultural change is needed in both service sectors to enable high-quality care to be delivered to person with a disability[22].

Research

Research is limited regarding palliative care in relation to disabilities, contributing to the needs of this group of consumers being overlooked and, in some ways, invisible[9,26,41]. When it comes to identifying and providing palliative care to persons with disabilities that is inclusive of the views of all these stakeholders, more research is required concerning the needs of people with lived experience of disability, caregivers, families and health workers [1,13,25,26,31,41,44]. Alongside this, is the need to develop policies, procedures, guidelines and tools to assist carers and health care workers in providing person-centred, evidence-based, excellent palliative care to persons with disabilities[1,9,10,13,16,20,25,26,31,40,44].

A white paper developed for palliative care provision for people with intellectual disabilities in Europe identified thirteen consensus norms as aspirational goals for care[40]. These norms encompass equity of access, communication, recognition of the need for palliative care, assessment, symptom management, end-of-life decision-making, involving those who matter, collaboration, support, preparing for death, bereavement, education and development of services[40].

Some models and tools currently exist, such as tools to assess symptom severity including the DisDAT - Distress Assessment Tool[1,12,36], the Rotterdam Elderly Pain Observation Scale or REPOS[24], the Abbey pain scale[1] (Abbey et al., 2004) and PALLI- PALliative care Learning to Identify in people with intellectual disabilities, a tool for use by proxies for diagnostic purposes[46].

Increased use and testing of these and other tools will help to determine the most useful diagnostic groups to implement their use and guide future practice. Development of communication guidelines, resources and training for palliative care staff is recommended[13]. Both carers and consumers rated pain, shortness of breath, depression and co-morbidity as being high amongst unmet needs, and were grateful to be able to access tools to provide measures to medical staff that also provided clarity in terms of what to do next[32].

In addition, consumers specifically highlighted loneliness as an issue causing high distress and poor quality of life that is not identified elsewhere in the literature[32]. Palliative Care Victoria has determined that need for palliative care services across Victoria has increased at an annual growth rate of 11% per year over the last five years and will continue to increase at a similar rate in the future[34]. The report identified that unmet need was underestimated in the figures available and did not specifically discuss the disability sector. Therefore, early recognition and appropriate planning will be essential to direct service requirements effectively for people with lived experience of disability requiring palliative or end-of-life care.

Advocates for a compassionate communities method to address inequities with a bottom-up approach that engages social networks of support, alongside a top-down approach to address inadequacies in systems, policies and procedures is recommended[15,17].

Although interdisciplinary cross-training has been heavily promoted in the literature, there is little evidence available to identify successful strategies for implementation[26]. Equitable, effective and accessible palliative care for people with a disability needs to acknowledge their specific needs[12].

Another area of potential investigation is the transition between child and adult services, as carers indicated a significant reduction in support when this changeover of care occurs[27,30].

Limitations

The database search could have been extended to include psycho-social databases. In addition, criteria for this report could have used other search terms to expand findings, as research relevant to the disability sector is not always categorised in similar methods to other health-related literature. Search terms needed to be restricted to major headings as the general search terms identified a significant amount of unrelated information. Evidence from population groups with mental illness was significantly lacking, particularly from people with lived experience[3,9]. Search criteria was limited to the last ten years to reflect recency of practice which may have limited findings, although hand searched articles of significant relevance were included. Only articles available in English were reviewed.

Many studies identified were based on limited population groups such as intellectual disability only. Research conducted on overseas populations may not generalise to the local settings although the potential for this was acknowledged in one study[27]. Typical delineation of services between 'mental' and 'physical' health is unhelpful in terms of conducting appropriate research and ignores the fact that many people have co-existing issues across these groups[3]. There was also potential bias in several of the studies included in this report[41,50]. Recruitment limitations in some studies meant that a higher potential for bias in the findings was possible. This included the use of arm's length and snowball recruiting[13].

Outcome measures lacked heterogeneity, and many studies lacked rigour within their designs limiting the applicability or validity of the findings[3,14]. Population data is absent regarding disability in palliative care which limits the generalisability of some findings[41].

Recommendations

Recommendations for future directions focus on putting persons with disabilities at the centre of any resource development or education. Choice and control start at engaging consumers at all stages of problem identification and management. True co-design and collaboration with consumers in an equal and reciprocal relationship within research or education is imperative to ensure it value adds.

Early advance care planning for everyone who wishes to participate allows for valuable and insightful discussions that can assist in better outcomes when a person can no longer speak for themselves.

Education is lacking across all intersections of palliative care, disability and health care. Support staff may have no related qualifications, and palliative care education is likely to be low on the list of mandatory training even in large organisations. Health services lack flexibility and awareness that for some people getting to appointments means allowing additional time to accommodate personal care, transportation and conflicting care needs.

Acknowledging and addressing bereavement needs are also a priority for people with disabilities, family and carers. Investigating the potential role of a coordinator could help bridge the gap between services as well as identify some of these needs. The Disability Liaison Officer role that exists in some areas of Victoria addresses gaps when a person with a disability may be accessing healthcare but is not funded to assist the transition back to community and beyond. These roles are also limited in number and geographical spread.

Conclusion

Health professionals need to recognise that persons with disabilities have more similarities to the general population than they have differences, especially at the end-of-life, and therefore improving care for this population will improve care outcomes across all populations[33]. Palliative care services need to reach out actively to engage with the disability community within their catchment areas and exchange experience and expertise at a local, national and international level between specialities[40]. Increased exposure and education across fragmented service providers and amongst general practitioners will result in breaking down communication barriers and stigma associated with disability as well as addressing the lack of understanding and confidence working outside of a usual area of expertise. Attention at local, state and national levels to funding models, governance and research is needed to promote best practice and provide the evidence needed to support this.

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