ONCOLOGY SOCIAL WORK AUSTRALIA

SUBMISSION TO THE SENATE INQUIRY INTO PALLIATIVE CARE

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Executive Summary

Oncology Social Work Australia (OSWA) recognises the significant contribution by the Australian Government to the National Palliative Care Strategy (2010) and the investment in palliative care development through national and state palliative care programs.

OSWA seeks to be an active participant in health care reform. We would be pleased to assist the Senate in their understanding of the role of social work in this important area of health care to ensure that all domains of care - the emotional, social, psychological, spiritual and physical, are appropriately addressed.

National and international standards for palliative care recognise the importance of a holistic approach - one that recognises the social, emotional and spiritual needs as being of equal importance to physical needs (Fitch 2000). It is well documented in the literature that depression, anxiety and demoralisation (Kissane 2009, O'Connor 2010, Clarke 2008, Kelly 2009) are closely associated with physical illness and this association becomes stronger with a progressive life-threatening illness. However the responses from Federal, State and Territory governments in Australia regarding the mental health of people with advanced chronic and terminal illnesses, their families and care givers, is not consistent across the country. It is OSWA's contention that psychosocial care that meets best practice standards is under-supported and under-funded.

The Australian Association of Social Workers (AASW) states that there are 19,300 social work members in Australia (AASW 2011) and based on these numbers, social work make up the largest group of allied health professions in Australia. In 2011, OSWA's membership was 160 and it is this membership that has contributed to this submission. In health, social workers have largely lacked an effective political voice. This is one reason appropriate resourcing to effectively respond to patient and family psychosocial concerns has not changed. It is timely that OSWA takes this opportunity to redress this imbalance and articulate our concerns. While OSWA is totally committed to collaborative interdisciplinary psychosocial care, it is social workers who numerically provide the largest component of this specialist care across all health care settings and this is supported by Fitch (2000). (See Supportive Care Policy for Victoria at http://www.supportivecancercarevictoria.org).

Good psychosocial care increases quality of life of patients and their families and in the long run is cost effective (Fletcher 2008, Pfaff 2009, Loewy 2000). It reduces or eliminates the high cost of responding to mental health crises when much of this distress and suffering can be reduced or prevented. Social workers are uniquely placed to contribute significantly to the relief of such suffering because they respond not only to the individual person who has the illness but also to the other factors in their environment that can make the difference between a respectful and dignified death and a traumatic one (Berzoff,J & Silverman P 2004). Alongside interdisciplinary colleagues who can relieve physical symptoms and alleviate physical suffering, social workers support individual and family adjustment to diagnosis and prognosis and addresses family relationships, housing, financial and socio-legal concerns.

Working with interdisciplinary colleagues in a shared care approach provides the optimum possibilities for providing a good palliative care service to people whose needs are complex and varied – whether by age, disability, culture, geographic or social isolation. Patients and their families confirm that a shared care approach works best for them (Cohen 2009, Woodhouse, G 2009). No one profession can provide expertise across this spectrum. Models of shared care that respect and value the unique contribution of all team members – patient, family, allied health, volunteers, nursing and medical – will deliver the best outcomes (AHPA 2008, PCA 2011).

To support this approach, the education and training of all members of the workforce need attention, support and resourcing. It should be recognised that currently segments of the workforce, such as allied health, often have to fund their own specialist training and ongoing professional development.

The development of standards in palliative care for allied health workers including social workers will provide a framework for and identify gaps in training and service provision. Support for translational research that assists in turning knowledge into practice in psychosocial palliative care will provide the impetus and mechanism for the provision of evidence based care in Australia.

OSWA Key Recommendations

1. All palliative care patients and their families have access to a social worker as a right

2. Social work be recognised and funded as a pivotal and essential profession within palliative care teams, across all health care settings;

3. Models of shared care that recognise and respect the particular expertise of each professional group be funded and evaluated,

4. Psychosocial translational research is supported and funded so that service delivery matches the evidence

5. Development of minimum and gold standard levels of performance for psychosocial screening, assessment and therapeutic interventions are funded and include a strong social work perspective from recognised national, state and territory based social work organisations.

Introduction

Oncology Social Work Australia (OSWA), an organization representing the professional body of social workers in cancer care in this country, welcomes the opportunity to participate in the Senate Inquiry into Palliative Care. As the largest group of mental health professionals providing psychosocial services in both hospice and palliative care (Connor, 2008) social workers are in a strong position to offer reflections and recommendations to this Inquiry.

Clearly many of the identified needs of patients and families in the palliative setting – including transitioning from acute care, practical resources, adjustment to end of life, alleviation of psychosocial and spiritual suffering, goal setting and managing relationships with family, health care teams and others require specific social work skills. As Dr Rodger Woodruff recently stated; “I have often felt that a good social worker is probably the most important member of the palliative care team, sitting as they do across the line between the medical/nursing and the psycho/social aspects of care.”

Oncology Social Work Australia

Oncology Social Work Australia Inc. (OSWA) is a non-profit, incorporated national organisation, with 160 members (OSWA 2011), dedicated to the enhancement of psychosocial services to people with cancer and their families. Oncology Social Workers work in a variety of settings from large metropolitan centres of excellence to providing a service from small centres across large geographical regional, rural and remote areas. OSWA acknowledges that, in addition to cancer, palliative care includes a broad range of life threatening and terminal illnesses. However, many of the challenges faced by people with a diagnosis of cancer needing palliative support are common across all illnesses.

OSWA conducted a survey of its membership addressing the questions raised in this Senate Inquiry. Responses from the OSWA membership are supported and included here and expanded upon using current evidence

Unique Role of Social Work

Social workers take into account not only the psychosocial and spiritual needs of the individual diagnosed with a life-threatening illness but also how this impacts their relationships, work, housing, family and other responsibilities. Thus social work is concerned with the individual as well as the wider context of illness and care (Powazki, 2010) and recognises that death and dying are not just private affairs, but concern the broader family and community context of the person’s life. Given that the World Health Organisation (WHO 2005) definition of palliative care identifies a broad notion of the of patient and family as the Unit of Care, and the prevention, assessment and relief of suffering, social work is uniquely placed to ensure that this occurs across all settings.

Thus, social, work in the palliative care setting involves a wide range of roles including:

- Comprehensive social, emotional, existential, psychological screening and or assessment
- Individual, couple and family counselling
- Working with children and young people
- Practical assistance and referral to other services

- Advocacy to address socio-economic issues
- Education and assistance with end of life preparation – enduring power of attorney, wills, guardianship, early access to superannuation, funeral planning
- Bereavement follow-up for families, caregivers, groups and communities Community education and community development.

Typically, social workers provide assessment and counselling support for complex psychosocial-spiritual issues including, but not limited to:

- Depression, anxiety and existential distress
- Developing care plans for school age children following the death of their parent
- Supporting patients to manage the social and emotional needs of family members while preparing for their own death
- Socio-legal issues
- Financial issues
- Housing issues
- Managing family conflict
- Pre-existing mental health, physical, sensory or intellectual disability of patient or family member
- Imprisonment or recent release from prison
- Social isolation and those people with few supportive networks
- Ensuring cultural sensitivities are respected regardless of ethnicity or culture

Provision of Palliative Care in Australia

Background

In many ways Australia leads the world in palliative care. As a country we have been at the forefront of community based care and transitioning patients from the acute to the palliative setting as well as developing world standard symptom control strategies. However, as is the case with other western countries, barriers continue to exist in the provision of psychosocial care as standard to all patients and families in the palliative setting.

Australian studies demonstrate that many barriers exist to the provision of effective individual and familial psychosocial care during the course of the oncology illness. A major problem is the under recognition and under treatment of significant distress, incorporating emotional vulnerability and distress, anxiety and depression. Oncologists consistently under diagnose depression and anxiety in their patients and 75% of patients with clinically significant anxiety or depression receive no counselling or psychological help (Pascoe...2000, Boyes 2009, Breen 2009,Kelly 2009, Zisook 2009). Yet, having a life threatening illness and facing an uncertain future can lead to a sense of helplessness and significant suffering (Clarke, 2009).

Many medical staff still believe that patients only expect them to provide medical care, and many wait for patients to raise psychosocial concerns with them whereas patients expect clinicians to initiate such discussions (Detmar, 2000, Maguire, 1985). Clinicians often cite lack of time as a barrier to initiating discussion of psychosocial concerns but Clayton et al (2007) found that responding appropriately to emotional cues from patients may shorten consultation time. Doctors may also avoid raising emotional concerns with patients who have a poor prognosis as a way of protecting themselves from their patients' distress (Maguire, 1999).

A lack of resources directed towards palliative care as a whole, means that psychosocial care can easily be considered less important than limited medical resources leading to a chronic underfunding of psychosocial support.

Yet the evidence is now clear that not only is there an association between physical illness, depression and anxiety but that depression and anxiety can be improved through quality psychosocial care (Clarke & Currie, 2009). Attending to patient and family psychosocial needs also increases their satisfaction which in turn is a 'predictor of medical outcome and potential predictor of longer term quality of life' (Walker, Ristvedt and Haughey, 2003, p.298). In addition, Walker et al. (2003) found that those patients who were asked how they were coping with their diagnosis, informed about support services and common emotional reactions to the experience of having cancer, experienced enhanced patient satisfaction. This is likely to be true regardless of diagnosis particularly if treatment is of palliative rather than curative intent.

Unless psychosocial concerns are given equal weight to physical concerns, it is unlikely that improving psychosocial care will be made a high priority in daily practice, argue Schofield, Carey, Bonevski and Sanson-Fisher (2005, p.865). It is not enough for clinicians to know of psychosocial concerns they must also know how to effectively respond and when to make referrals to allied health specialists (Sholfield et al, 2005).

A model of shared care or integrated care will go some way to answering this need (Clarke, 2009, Neergaard, Olesen, Jensen & Sondergaard, 2010,). Indeed, the Palliative Care Role Delineation Framework (2007) identifies the specialist team as a minimum standard for all palliative care patients - including a social worker with palliative care expertise. Shared care means improved cooperation between health professionals, proactive planning, clear referral pathways and above all a willingness to be equal team partners with mutual respect and better knowledge of each other's professional competencies and personal merits' (Neergaard, Olesen, Jensen & Sondergaard, 2010, p.1076).

Meeting the needs of Australians

Rural and Regional

In Australia, approximately one third of the population live in rural areas, and another half a million reside in remote communities of the country (White 2007). There is general recognition that access to health care for people in rural and remote areas is problematic, with increased costs of travel, health care, commodities including medications, decreasing numbers of rural health care providers, and a growing trend towards centralisation (White 2007). The paradox here is that whilst there is a reduction in health care delivery the needs remain high, particularly in regard to palliative care.

As access to specialist palliative care in rural communities is based on a consultancy outreach model of care, referral to such services is generally limited to those people with clinically unstable or complex health care needs. Clinical needs always take priority, and this often leaves psychosocial, psychological, emotional and spiritual concerns unattended to. In rural communities, community nurses receive many of the referrals for people requiring palliation from specialist centres and the person’s general practitioner. Many social workers, even when members of multidisciplinary palliative care teams, report that nurses act as gate keepers to referral for psychosocial or psychological support or intervention, therefore limiting a person’s access to specialist allied health care. The 2012 Oncology Social Work report cites many reasons for this including: lack of knowledge and understanding of the social work role in providing therapeutic support and counselling, lack of appreciation of the benefits of referral for such support and care to the person’s experience of illness and bereavement care, a belief that nurses provide comprehensive holistic care and that further referrals cause confusion for patients and families who are already stressed and a lack of appreciation by generic social workers of the valuable input social work can provide into psychosocial aspects palliative care. Other reasons include the underrecogntion of the benefit of providing appropriate therapeutic interventions that can and do make a difference for individuals and their families and for some families, the stigma associated with having a mental health problem prevents them from voicing their psychosocial concerns. For many people, there is a belief that suffering is a natural part of the disease and dying process.

There is still a stigma associated with a referral to palliative care, with many clinicians, patients and families believing that such a referral means that hope is lost, and that dying is imminent.

Many rural communities have not had access to community education programs regarding palliative care, such as Alan Kelleher’s Health Promoting Palliative Care (Kelleher 1999) or the Respecting Patient Choices® Program (Austin Health 2002), or Sydney’s Life Circle Program (2011), so information regarding the benefits of Palliative Care is limited.

The location of specialist centres and therefore specialist palliative care services in regional centres, with limited outreach to rural communities further alienates people living in rural and remote communities from accessing such care. This situation is further exacerbated by a lack of rural primary health care providers, including social workers, having skills in the palliative approach and palliative care. Providing best practice interventions for people living with dying and their families can be met to some degree by generic health care providers, however funding and programs need to ensure that primary health care clinicians can offer quality psychological, existential and spiritual support, counselling and interventions to people who are living with dying.

People living in remote communities have stated that they don’t want to travel large kilometres to regional centres for hospice care. Instead local health and aged care facilities in rural and remote communities could have increased capacity to offer hospice and palliative services to their local communities with enhanced support from the local community based services, such as Home Care, Carer Respite, community nursing, and from palliative care specialists on a consultancy basis.

Indigenous People

Current research into Indigenous relationships with palliative care (Maddocks and Raynor 2003, McGrath 2002) suggest that Indigenous communities in all parts of Australia have a close association with death and dying. This could be in part due to the fact that death rates for Indigenous Australians are among the highest in the world. An intimate awareness of death and dying is also facilitated by the close involvement of extended family in supporting a patient during terminal illness, and in the ceremonies that follow a death — gatherings that may extend over several weeks.

Major conditions such as cancer often come to medical attention only late in the course of the illness, and many Indigenous people only access services when their disease becomes terminal. Statistics from palliative care services and research (DoHA 2003) indicate that within Aboriginal and Torres Strait health services few Indigenous people access palliative care services.

Except where there are well-established Indigenous medical services, healthcare facilities of all types are used reluctantly by Indigenous people. According to Maddocks (2003) major conditions such as cancer often come to medical attention only late in the course of the illness. The services offered by Indigenous healthcare providers often have no link with mainstream services and may be unaware of what local palliative care services can offer. Similarly, mainstream providers may have little awareness either of the special needs of Indigenous patients or the services, networks and cultural supports available to them. In many communities, Indigenous people have not accessed palliative care services to any great extent. Many have not heard of palliative care, or associate it only with inpatient care and cancer.

People from Culturally and Linguistically Diverse Backgrounds

“Dying, perhaps more than any other moment in the course of a persons’ health care, can accentuate cultural differences” (PCA 2011) between patients, families, health care providers and communities. Indeed, the complexity of need for patients and families at the palliative stage of life is exacerbated when they are from a culturally and linguistically diverse background. Care for these patients must use the patient centred care model as a minimum in order to begin care with an understanding of what is appropriate in relation to the notion of death and dying from a different cultural perspective. Highly developed communication skills are required in this setting, where often the use of an interpreter is required and cultural barriers can impede care planning. In addition to communicating with the patient and family directly, the social worker often works with them to be able to communicate with the rest of the care team and may advocate for their specific beliefs and needs to be given an appropriate response.

It is important for health care professionals to respect individual differences and values within each cultural group and community, as no group is homogenous, and cultural practices are not the sole determinants of patient preferences. Quality care at the end of life is realised when it is individualised to meet the person’s needs and upholds their preferences which are based on many factors, including individual cultural beliefs.

Yet there remains a lack of bi-lingual workers and interpreters available for staff in both the community and acute setting. . In non-metropolitan areas, interpreters may only be available via a telephone service and, while better than no service, can complicate already compromised communication. This lack of interpretation can lead to poor health literacy and can increase suffering. There needs to be a commitment for community education and community capacity building programs in areas of high need in relation to palliative and end of life care.

People with Disabilities

The need for quality palliative care services is well accepted in the general population. It is becoming increasingly evident that the same need exists in people with intellectual disability especially in those who also have high support requirements. The decision about when to initiate palliative care in people with intellectual disability and high nursing support needs is complex (DADHC 2004). The need for palliative care may not be easily recognised in an individual who has had significant life long medical problems. Thus the provision of such care may be unnecessarily delayed or never initiated.

A person with intellectual disability and high medical support needs may be incapable of making such decisions and an ethically sound means of substitute decision making must be established. Nelson (2003) makes a clear statement that any palliative care decisions should be made in the best interest of the patient, rather than in the interests of the hospital, the physicians, the legal system or someone else. This is where the provision of a social worker, skilled in such conversations and assessments is invaluable.

Review of the literature (Tuffrey-Wijne, 2003) highlights some concerns about the quality of palliative care offered to individuals with intellectual disability. Diagnostic overshadowing (the phenomenon of attributing symptoms to the disability, rather than looking for an underlying physical or mental health problem), may affect decisions made regarding palliative care. People who have intellectual disabilities may not be able to communicate suffering or pain and its potential cause may be overlooked. Similarly some people with intellectual disability may have pain insensitivity or indifference that complicates diagnosing an acute episode or deterioration in an existing condition. These people need strong advocates that are capable of understanding the complex nature of not just capacity, but issues relating to end of life decisions and preferences for care at end of life. It is expected that all health care professionals should have the best interests of the individual at heart in such decisions, information and support. It is, however, the social worker's distinct and specialised role to work at all levels of intervention – the micro - with the individual, advocating that their needs are being understood and met, the mezzo – with the family, group support or accommodation and community, and the macro – the broader community and socio-political context.

Context:

In NSW in 2003, between 250-300 people with intellectual disability (congenital or acquired, mainly secondary to Traumatic Brain Injury) and high nursing support needs were cared for in Department of Ageing, Disability and Home Care (DADHC) funded residential settings. Another 15 children in this situation were cared for at home and approximately 30 people under the age of 30 years were in nursing homes (DADHC). If this situation is replicated in other states, this is a situation that requires urgent attention. (DADHC 2004)

When people that are living with a mental health or co-existing mental health and drug dependence disability, there are enormous complicating issues. These relate to drug interactions, understanding how mental health symptoms impact on the experience and perceptions of palliative care, careful planning to manage potential episodes of mental health crises that may accompany the physical and emotional burden of coping with end of life issues, and advocating for the rights of these people to empathetic and compassionate care, and their family or caregivers. A Palliative Care Social Worker skilled in mental health screening and assessments, has the capacity to work effectively with people with co-morbidities, as their disease changes and becomes more complex. Focussing entirely on the clinical presentation or symptomology ignores the important psychological, social, emotional and spiritual needs of these people. Once a person has an additional diagnosis of a terminal illness, then referral to such a social worker should occur early in the disease process so that interventions and care and support can be provided in a trusting and transparent relationship.

Current research has indicated (Ng & Li 2003 as cited in DOHA 2004), that palliative care is not a skill set normally held by people who work with people with intellectual disabilities. A recent project undertaken by Whyte 2011, indicated that comprehensive mental health and psychosocial assessments were not carried out with people with pre existing mental health issues, and there was a delay in referring them to palliative care services, with many people being admitted to aged care facilities or hospitals for their end of life care. Support workers in group homes have also reported a lack of knowledge and a fear of death and dying, fears of finding their patient unexpectedly dead, fear of not knowing what to say, and also fear of breaking bad news (Reid 1998). Involvement of social workers, in a shared care approach with the existing support workers would assist in demystifying the situation, and provide the necessary support and interventions for appropriate end of life information, education and care.

Children and Adolescents

There are two key components related to palliative care with and involving children. Firstly, for children and adolescents diagnosed with cancers and other chronic illness at a young age, daily living, let alone advanced illness and palliative care in children are overwhelming but critical areas of care for families living in our Australian community. The second area, of no less importance is the care of children and families left with the care of an adult family member- namely a parent or other significant family adult, confronted by end of life experience.

Context

In Australia 2011 AIHW figures indicate that more than 114,011 cancers were diagnosed in adults at or over 20 years. National Cancer Institute (NCI 2009) figures further estimates that 24% of the total proportion of diagnosed adults has children. Therefore approximately 27,360 children across Australia under 18 years and proportionately more than 6840 Victorian children were, in 2010, living with or in regular contact with a parent with cancer (Thursfield (2011); AIHW. Cancer in Australia: Cancer Series no 46.CAN 42).

For this group of 27,360 children, such an event permanently changes family dynamics, evoking many fears, doubts and questions. Diagnosis in itself can be overwhelming, yet the changes in family roles and lifestyle patterns, and unpredictability of treatment outcomes are where the effect of the disease most impacts. There has not a great deal of hands on help available for patients and parents to talk about issues raised by parental cancer diagnosis and the changes involved with their children. We know though that when families communicate and remove silence as the family code, they can learn to cope and better manage the experience of parental cancer in the family (Visser(2004)). .

Holland (2011) demonstrates that the model and interventions built in recent years for children actively involved in parental palliative care are a critical feature of the family palliative treatment paradigm. Appropriate parallel interventions for fathers can then be developed and later extended to family members enduring other life-threatening chronic illnesses- namely to grandparents, and to families where young children witness the struggles of a sibling diagnosed with any range of life challenging chronic illnesses.

Funding Arrangements

Funding strategies need to consider the unique and often complex multidisciplinary needs of patients and their families. Strategies should include adequate consideration of their social, emotional, existential and psychological needs as equal determinants of health as their clinical and physical needs. Executing this requires a whole of Government approach, recognising that access to palliative care crosses all health care and community service boundaries, and requires flexible, innovative approaches that looks outside traditional thinking.

Palliative care funding that is attached to aged care services or inpatient pathways to care, such as the Marie Curie Liverpool Care Pathways (LCP) (2004), fail to take into account the fact that only a small percentage of older people actually live in residential aged care, and that similar pathways needs to be developed to ensure that community aged and respite care providers offer quality palliative care pathways. The need for quality palliative care transcends organisational funding streams that silo service delivery into residential aged care, community care, disability services, primary health care and acute, rehabilitative or ambulatory care. Funding palliative care in only one sector fails to take into account the multifactorial and complex nature of the needs of people who are dying and their families.

The clinical and psychosocial needs of people who have a terminal illness can vary, and for many there is not a clear or predictable trajectory. Many people have varying periods of clinical or psychological complexity and needs as well as periods when their needs are relatively stable. Funding streams need to recognise this fact and people need to be able to remain in a palliative care service even when they are determined to be clinically stable, and not have to be re admitted or referred when their condition or situation changes.

To be truly person centred, the funding ideally should follow the person through each health care setting, and across the course of their illness.

According to the literature (Garrard.J 2010) , patients and families commonly express the wish to be cared for at home for as long as possible and practicable, and wherever possible, to die at home. The lack of appropriately and timely services that can respond to such needs often means that patients are admitted to acute care facilities or respite care and therefore they cannot achieve their goal of dying at home, or at a place of their preference or have their values and preferences in relation to their care respected. Tailor made packages that transcend aged entry criteria need to be made available, and administered by services that are cognisant of the holistic clinical, psychological and spiritual needs of dying people and their families.

Efficient Use of Palliative Health and Aged Care Facilities

Sixty six percent of all Government funding on aged care is spent on residential aged care facilities, however only 11% of people aged over 70 years reside in such facilities (AIHW 2010). Of all deaths in Australia in 2008–09, just over half (52%) occurred in an admitted patient setting within a hospital, therefore the majority of older Australians died in public hospitals or home, not aged care facilities (AIHW 2011).

As the complexity of chronic illness increases and the number of people being cared for at home and in the primary health care sector rises, funding arrangements will have to be flexible and innovative to provide the level and degree of care that people deserve and expect. Separation of funding streams for palliative care from aged care is required to best meet the needs of people living in the community and enable them to have real choice as to with whom and where they die.

Only a small percentage of older Australians die in residential aged care facilities. Dying in acute hospitals however, is not the ideal for many people, and palliative care funding needs to be flexible, innovative and cross health care boundaries and settings so that people have real choice as to where and with whom they die.

There is evidence that many older people are inappropriately transferred into aged care facilities from acute care or inpatient hospice care, even when their prognosis is short. The uncertainty of prognosis and the stress of changing care facilities places undue hardship and strain on families already coming to terms with the death of a loved one. Ideally acute care and rehabilitation facilities need to have a “step down” (Garrard 2010) facility or level of care where people can be cared for when unable to return home, but are not imminently dying.

Effectiveness of Palliative Care Arrangements and the Composition of Palliative Care Workforce

It is now well established that palliative care is best delivered by multidisciplinary teams, with specialist palliative care services being available for consultancy and support. Palliative Care Australia (PCA) has developed documents relating to role delineation and models of care, however, in reality, particularly in rural and regional regions, these teams consist of a part time nurse with access to other health care professionals on an ad hoc basis (Loscalzo 2009, White 2005, PCA 2010,). According to Loscalzo, in his chapter in Psychiatry in Palliative Medicine (2009), he states that ‘a major problem in palliative care is the under recognition, under diagnosis, and thus under treatment of significant distress...ranging from existential anguish, to anxiety and depression.’ Based on this and other research into psychosocial issues in palliative care, (Kissane 2009, White 2005, Loscalzo 2009, PCA 2010) that no single profession on their own, such as a nurse led or nurse alone or doctor-nurse only team has the necessary skills and expertise to assess and relieve distress and thus improve quality of life.

The benefits of shared care models are clearly documented (Woodhouse, G. 2009) with services evolving their systems to meet local needs. Such care systems require flexible funding arrangements across health and community care systems, with barriers to effective interdisciplinary care being identified and resolved.

The benefits of having a competent social worker, trained in end of life and palliative care as part of the consultancy palliative care team, and also an essential part of the primary health care team, has been well established. Having appropriate and evidence based models of care that can support these teams and assist in developing appropriate responses to people’s total needs and their families will ensure that care is provided in a way that ensures that people have their values, goals and preferences respected at the end of their lives. It is the goal of any palliative care service to ensure that people who are dying are afforded a respectful and dignified death (Berzoff, Silverman 2004), one where their values, goals and preferences for care are understood, respected and planned for.

In the field of Oncology, Social Workers provide palliation and end of life care as many of their patients and their families face the reality of their disease not being amenable to further cancer treatments, or clinical trials. The Oncology social worker is skilled in providing this psychosocial support and engaging with the patient and their family in understanding their hopes and preferences for the next stage of their disease trajectory. Ideally this conversation and support commences early as they become aware of the course of their disease, rather than later when death is imminent, and if lucky, are referred to a palliative care team. Generally social workers in Oncology do not receive specific funding to provide a palliative care service with the exception of specialist cancer centres that have both Oncology and Palliative Care teams working collaboratively. In regional and rural settings the role of the oncology social worker is largely limited to the acute care system.

Meeting needs of Ageing Population

From a social work perspective, meeting the needs of an ageing population is increasingly difficult due to lack of positions to meet current need. This will only worsen unless workforce issues in psychosocial care are addressed and specifically through the employment of social workers who are specialists in this field.

Currently, the inclusion of a social worker in palliative care teams is very variable. It is more likely to happen in hospices and bigger centres. Rural, remote and regional areas often rely on social workers employed in other health fields to fill this gap. All oncology social workers work with people whose treatment is palliative. Where there is no palliative care social worker, oncology social workers will work with their clients and families through end of life care and this adds to a workload that is exploding due to more people being diagnosed with cancer and requiring support over longer periods because many people now live longer (OSWA 2012).

Social workers in aged care teams should have as a minimum an understanding of the palliative approach to care and use of quality assessment and screening tools and in addition be aware of appropriate interventions for a range of psychological and mental health problems that are common for people who are ageing and facing multiple losses in their lives. These social workers should have a thorough understanding of how to elicit patients and their families needs in regard to Advanced Care Planning, and advocate for and support their decisions to ensure that their future care is governed by their cultural and familial values and preferences. A palliative approach needs to be incorporated across all aged care teams, especially social work, so that such support and discussions are not left until people are coping with their dying.

Workforce Education and Training

While there are some good training opportunities for social workers they are limited. OSWA is aware and actively promotes the use of many excellent websites for information and education for their members. These include, but are not limited to - Palliative Care Australia, CareSearch, the Victorian Centre for Palliative Research and Education (CPRE), which provides quality periodic palliative care training for allied health workers and the PEPA program which is available for social workers to experience immersion in the palliative approach.

However, meeting and continuing to meet Australian standards in palliative care requires a more consistent and well supported approach to education and training that addresses the requirements of specialist palliative social workers. The Australian Association of Social Workers requires social workers to receive regular professional supervision and nationally we have a lack of experienced palliative care social workers who can provide this supervision and grow the profession. Social workers often have difficulty getting released from work to attend training and receive little help to meet the often significant costs (OSWA 2012).

Standards

The Palliative Care Standards are considered to be holistic and challenge people working in palliative care to provide effective person centered care that considers the person, family and caregiver as the Unit of Care. Barriers, however, to the delivery of the standards at a level of excellence, and that expected by adherence to the Standards, have been identified.

In addition to the Palliative Care Standards (2005) three seminal documents have been produced:

- Therapeutic Guidelines in palliative care (2^{nd} Ed. 2010)
- Psychosocial care of Adults with Cancer (NBCC & NCI 2003)
- Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advanced stages of a life limiting illness, and their caregivers (Clayton et al. MJA 2007)

While these documents are excellent in providing a holistic and generic approach to psychosocial care, they need further development so that they provide clinician guidelines that address specific psychosocial concerns and recognise the training and skill level required in order to meet these. Such standards need to include a ‘detailed description of the knowledge, skills and values that are requisite for the unique, essential and appropriate role of social work’ (Gwyther et al., 2005, p.88).

The Palliative Care Standards (2005) provide a mechanism to which agencies and services can aspire to, in order to ensure that people can have a respectful and dignified death and ensure that their families are supported in bereavement. However, the reality is that the thirteen standards are voluntary and presently data is only being captured for dedicated palliative care services. All other services that support people at the end of their lives, such as community and primary health care services are not bound to follow, and many do not know of, these Standards (OSWA 2012, Whyte 2011). All services providing palliative care for people, regardless of diagnosis and place or setting of care, who are living with an advanced chronic and eventually terminal condition, their families and care givers, need to be able to understand, implement and evaluate these standards. Ideally funding should be provided for the development of quality activities that assist services in the implementation, trialling and evaluation of the thirteen standards. Additionally, education and resources need to be provided across health care sectors, including oncology, to ensure that these standards become the reality for all people living with dying regardless of diagnosis, geography and culture.

Advance Care Planning

For many people in the community, advanced care planning (ACP) is confusing and there is poor understanding about how such planning can improve how well people live until death (NSW Health 2011).

Ideally ACP should be a dynamic, phased approach, as patients' wishes and choices are informed by their 'experience of illness, and we know that their treatment options change as illness progresses and death approaches' (NSW Health 2011).

Social workers understand that they are not experts in medico-legal aspects of end of life, nevertheless it has been identified that discussions around care preferences, options available, individual and family values regarding living with dying and death and notions of suffering, are areas that social workers consider important and integral to the social work role (OSWA 2012). Social workers are knowledgeable about and can guide individuals and families through discussions about the need for various legal arrangements that reflect what is important to them in relation to their likely disease trajectory. This includes guardianship, ongoing care and protection of children or other dependent family members, wills, enduring power of attorney and make referrals as appropriate to legal experts (OSWA 2012). Including social workers early in the referral and intervention process will ensure that these conversations are not left for the time that people are planning their dying.

Communication and Multidisciplinary teams

Communication is a key element of integrated, holistic palliative care. For a multidisciplinary team to be effective, pathways for communication have to be understood and respected. Barriers to this have been well documented, and efforts must be put into working through these barriers so that the person and their needs are the central focus of care.

According to Kuziemsky (2009) the complex nature and demands of the health care work environment requires the expertise and knowledge of differing individuals or specialists who can work together to solve multifaceted and complex patient care problems. Research (Hearn, 1998, Cummins 1998, O'Connor 2008) suggests that good interdisciplinary communication leads to improved patient and family outcomes (i.e. high levels of patient and family satisfaction, symptom control, reductions in length of stay and hospital costs). As well, this research has demonstrated that interdisciplinary teamwork can improve the diagnostic and prognostic abilities of health professionals, more than individual health professionals working alone.

Good team work requires good leadership, with values respectful of each professions contribution to the discussions. No single profession should have ownership of the multidisciplinary care in palliative care, and all voices in the discussion, including those of the patient and their family and care givers, needs to be respected and valued. There is evidence of lack of clear role delineation and boundaries in interdisciplinary palliative care teams in respect of psychosocial care (O'Connor & Fisher, 2011). They argue that this flies in the face of literature that teams are more likely to be effective when members are clear about their own roles, respectful of others and know when and how to refer to colleagues.

Goals of care must to be patient centred and patient directed, therefore these needs to be established early in the person’s involvement with the team, and re-evaluated as their care needs as well as their preferences change.

Sharing of health information is problematic across health care settings, as patient and their families have to be excellent health historians to ensure that care is appropriate to their needs. Collaboration and ways to facilitate information sharing need to be implemented for this group of people, as for many patients and their families time is not a resource they have a lot of. Home Diaries and patient held notes, and other resources that are part of Chronic Disease management programs can be excellent resources for palliative care patients and their families. To be effective, however, health care services, including general practitioners and medical specialists, have to be committed to working with the patients and families in using and recording important health information in them to ensure that they are shared across health care settings (OSWA 2012).

Funding of Research Information and Data

There is growing evidence that the demand for quality end-of-life care is outstripping the resources provided to meet that need (PCA 2010). Increased and flexible investment is required in trialling and implementation of initiatives in health system reform that crosses all health care sectors. Funding needs to place equal importance on the development of minimum and gold level standards of performance in psychosocial care and the measurement of holistic health care outcomes, and not just in clinical and physical symptoms.

It is vital that translational research projects are funded. These could include those that examine the psychosocial aspects of palliative care, the transition from curative treatment to palliation in diseases other than cancer, and the value of upskilling social workers and other allied health practitioners in the quality delivery of psychosocial care for people facing the end of their lives is vitally important. Improvements in the provision of quality psychosocial care will struggle to occur unless a firm commitment is made to funding of translational research projects that address core competency and practice standards for social work and other allied health interventions for this cohort.

The new competitive Flexible Funds (DOHA 2012), which are broad and encompassing, will make it difficult for organisations to submit quality tenders for palliative care initiatives as they have to compete against all other health care priorities and global funding streams. As a result it will be challenging to develop a palliative approach to projects.

The current focus on and funding for generic roles in health care needs to be examined.

An emphasis on evidence based practice requires that we honour the complex psychosocial needs of people facing the end of their lives, those that care for and love them in the same way that people expect that their physical health needs are addressed by people who have advanced skills and knowledge in the relevant speciality

GLOSSARY OF TERMS

AASW	Australian Association of Social Workers
ACP	Advanced Care Planning
AHPA	Allied Health Professions Australia
CDDS	Centre for Developmental Disability Studies
OSWA	Oncology Social Work Australia
PEPA	Program for the Experience in the Palliative Approach
PCA	Palliative Care Australia
WHO	World Health Organisation

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