

SPECIAL ISSUE

Psychosocial Interventions for End-of-Life Care: An Invited Commentary

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End-of-life care impacts on emotional, physical, spiritual, and social wellbeing for both the individual and their family. Despite remarkable medical advances in the field, the empirical evidence regarding the development and efficacy of psychosocial interventions at end-of-life care is lagging behind. A number of psychosocial interventions are promising and represent important progress in the field. Psychologists have a range of suitable skills and knowledge, however, the profession is underutilised in end-of-life care. This special issue on end-of-life care highlights the need for more research into this area and could act as a call to action to accelerate our understanding of the role of Psychology in end-of-life care.

Key words: cancer; end-of-life; interventions; psychotherapy.

In 2017, it is estimated that more than 159,000 Australians will die, with a majority of these deaths occurring in acute hospital settings (Australian Bureau of Statistics, 2015; Swerissen & Duckett, 2014). Cancer remains a leading cause of death with a third of all deaths being a result of cancer (Australian Institute of Health and Welfare, 2017). The psychosocial consequences of a terminal illness are well established. End-stage cancer impacts on emotional, physical, spiritual, and social wellbeing for both the individual and their family (Clark, 2017). Despite remarkable medical advances in the treatment of cancer, the empirical evidence regarding the psychosocial treatment at end-of-life care is lagging behind.

In this special issue of the *Australian Psychologist*, five studies are presented that relate to this shortcoming. While these studies represent important progress, they also highlight the need for more research investment into the development and rigorous evaluation of psychosocial intervention at end-of-life care.

This commentary aims to: (a) describe the psychosocial impact of advanced cancer; (b) examine the predominant types of psychosocial interventions currently used in end-of-life clinical care; (c) reflect on the five articles in this special issue of the *Australian Psychologist*; (d) consider the role of the psychologist in end-of-life care; and (e) highlight research gaps.

The Psychosocial Impact of Advanced Cancer

The range of psychological concerns experienced nearing the end-of-life is broad. Clinical problems such as depression, anxiety,

post-traumatic stress, confusion, delirium, and pain are common in individuals with end-stage disease (Brintzenhofe-Szoc, Levin, Li, Kissane, & Zabora, 2009; Mystakidou et al., 2012; Uchida et al., 2015; Weiss, Emanuel, Fairclough, & Emanuel, 2001). An advanced cancer diagnosis raises a number of existential concerns, including issues of identity, demoralisation, purpose and meaning, autonomy, and a desire for hastened death (Breitbart et al., 2000; Chochinov et al., 2002; Clarke & Kissane, 2002). End-of-life may trigger changes in family roles, dynamics, communication, and everyday functioning. Additionally, witnessing a loved one deteriorate has a substantial impact on family members. Hodges, Humphris, and Macfarlane (2005) found that caregivers distress generally paralleled the distress experienced by the individuals with cancer. Rumpold et al. (2016), found that 52% of carers are at risk of having one or more suspected mental health problems including depression, anxiety, post-traumatic stress disorder (PTSD), or alcohol problems. Carer's distress often continues after the person's death and family members can experience intense grief, anger, and even complicated grief (Thomas, Hudson, Trauer, Remedios, & Clarke, 2014; Williams & McCorkle, 2011). Treating psychosocial suffering at end-of-life is an essential part of good healthcare delivery.

Psychosocial Interventions Currently Used in End-of-Life Clinical Care

The goals of psychotherapy at end-of-life are unique for each individual and family (LeMay & Wilson, 2008). End-of-life care psychotherapy presents as an opportunity for psychological growth, the potential reduction of distress and symptom burden, and the optimisation of quality of life (LeMay & Wilson, 2008; Rodin, 2013). Traditionally, end-of-life care has been centred on medical interventions and treatments and therefore research into psychosocial interventions has been limited, until

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more recently. A number of psychotherapies have been increasingly considered as potentially beneficial for those nearing end-of-life.

For clinical problems such as depression, pain, insomnia, and anxiety, there is a growing body of evidence that suggests these issues can be effectively treated with a combination of cognitive-behavioural therapy (CBT) (including psycho-education, behavioural activation, pleasant activity scheduling, relaxation, problem solving, and cognitive restructuring), and pharmacotherapy (Osborn, Demoncada, & Feuerstein, 2006; Uitterhoeve et al., 2004); however, CBT may have limitations as an end-of-life therapy, as symptoms such as poor energy, concentration, and memory difficulties may interfere with an individual's ability to complete associated cognitive and behavioural tasks (Anderson, Watson, & Davidson, 2008). In addition, challenging thinking patterns, a central component of CBT, may be difficult for those who are experiencing catastrophic thinking due to a realistic and rational reflection of their situation. Lastly, CBT does not directly address existential suffering such as loss of meaning, purpose, and identity.

Over the past two decades, there has been an increased focus on the development and evaluation of semi-structured psychosocial therapies that address distress and existential suffering at the end-of-life. The rationale for such therapies stems from a range of psychological theories, including existential, humanistic, narrative, and Frankl's logotherapy approach (Frankl, 1962). Detailed literature reviews and commentaries have identified a number of end-of-life psychotherapies (Hench & Danielson, 2009; LeMay & Wilson, 2008; Rodin, 2013). Although randomised controlled trials (RCTs) are slowly amassing, four of these interventions have been subject to a higher degree of evaluation and hold particular promise for use with people nearing end-of-life. These psychotherapies include: supportive-expressive group therapy (SEGT) (Classen et al.,

2001); dignity therapy (DT) (Chochinov et al., 2005); meaning-centred group psychotherapy (MCGP) and individual meaning-centred psychotherapy (IMCP) format (Breitbart, Applebaum, & Masterson, 2016; Breitbart et al., 2015); and managing cancer and living meaningfully (CALM) (Lo et al., 2016). As described in Table 1, these interventions have a range of aims such as enhancing meaning, reducing symptom burden and distress, improve quality of life, and assisting people with advanced disease and their families adjust to death and dying (LeMay & Wilson, 2008; Rodin, 2013).

The above mentioned interventions range in session number, format, structure, and context (LeMay & Wilson, 2008). The SEGT is the longest of the four, with a short version involving 12 sessions and a long version requiring weekly sessions for 12 months. DT is the shortest psychotherapy consisting of three sessions; one pre-session explaining the process, one semi-structured interview, and lastly one feedback and review session. DT also requires therapy time to transcribe and edit the legacy document. MCGP and IMCP use an educational teaching approach whereas the other three interventions (SEGT, DT, and CALM) utilise a non-directive, reflective approach. The four interventions outlined above are typically facilitated by psychosocial experts and advanced practice nursing staff and require various levels of training and supervision.

Group format interventions such as MCGP and SEGT may assist in normalising experiences, reducing isolation, fostering hope, and modelling adaptive coping through their peer support components. However, group delivery of an intervention can also exacerbate anxiety, especially if there is a death within the group (LeMay & Wilson, 2008). The individual-based interventions (CALM & DT) can be tailored to a person's psychological, physical, and practical needs and can also be adapted to meet the needs of individuals whom are too ill to leave their hospital beds (LeMay & Wilson, 2008).

Table 1 Psychosocial Interventions Used in End of Life

Intervention	Intervention duration	Mode of delivery	Description	Outcomes
Meaning-centred group psychotherapy (MCGP)	Group 8 sessions	Group and Individual	Manualised psychotherapy, sessions address: (1) concepts of meaning; (2) cancer and meaning; (3) life legacy; (4) limitations of life; (5) responsibility and creativity; (6) experience; and (7) termination.	Improves spiritual wellbeing, quality of life, depression, hopelessness, and the wish for a hastened death (Breitbart et al., 2012, 2015)
Individual meaning-centred psychotherapy (IMCP)	Individual 7 sessions			
Supportive - expressive group psychotherapy (SEGT)	Long version 52 sessions Short version 12 sessions	Group	Semi-structured sessions that address: fears of dying, re-ordering life priorities improving support, communication with family and friends, changes in body image and pain management.	Improves mood and post-traumatic stress disorder (PTSD) (Classen et al., 2001)
Dignity therapy (DT)	3–4 contacts	Individual	Semi-structured sessions that focus on reviewing a person's life history and hopes for their loved ones and presentation of a legacy document.	Increases a sense of meaning and improves symptom control (Chochinov et al., 2005)
Managing cancer and living meaningfully (CALM)	3–6 sessions	Individual	Semi-structured sessions that address four domains: (1) symptom management and communication with healthcare providers; (2) changes in self and relations with close others; (3) sense of meaning and purpose; and (4) future preparations.	Improves spiritual wellbeing, mood, and death anxiety (Lo et al., 2014)

To date, a number of efficacy studies for SEGT, CALM, DT, and MCGP have been undertaken. DT has been trialled across different population groups (Martínez *et al.*, 2017), whereas RCTs examining the efficacy of SEGT have largely been conducted with women with breast cancer (Classen *et al.*, 2001; Giese-Davis *et al.*, 2002). MCGP has been piloted in a number of RCTs and is being adapted for different population (Lichtenthal, Applebaum, & Breitbart, 2015). Similarly large-scale RCTs of CALM are undertaken around the world (Lo *et al.*, 2014; Scheffold *et al.*, 2015). A recently completed RCT of CALM involving over 300 individuals with advanced cancer, found that CALM improved mood, and wellbeing and over 77% of individuals adhered to the intervention (Rodin *et al.*, 2017). These studies are certainly encouraging and indicate that these therapies could play a role in improving mood symptoms, reducing death anxiety, enhancing meaning, and increasing spiritual well-being.

This Special Issue

In this special issue addressing end-of-life care, authors contribute to the debate and understanding of the effectiveness of the end-of-life psychotherapies and further elaborate on the impact that end-of-life issues have on individuals, carers, and children, as well as explore the potential role of psychologists in the field. The topics covered in the five papers include bereavement, family and child centred psychotherapies, identity, and the role of the narrative nearing the end-of-life. Two of these studies used qualitative methodology and three conducted extensive literature reviews.

Klasen, Bhar, Ugalde, and Hall (2017) in their qualitative study of former recipients of bereavement counselling, explored the outcomes of bereavement counselling and the mechanisms underlying these outcomes. Klasen *et al.* (2017) pointed out that many carers experienced significant stress including suicidal thinking and self-harm behaviour following the death of a family member and usually self-referred to bereavement counselling. Carer motivation, counsellor attributes (e.g., respectfulness, empathy, professionalism, insightfulness, and warmth) and a collaborative therapeutic relationship were associated with improved coping, greater self-awareness, and psychological growth (Klasen *et al.*, 2017). The importance of the therapeutic relationship is well documented in the broader psychotherapy literature. A good therapeutic relationship enables a client to feel safe, build bonds and be open to explore own behaviours and thoughts (Maccormack *et al.*, 2001). Klasen *et al.* (2017) emphasised that good end-of-life care goes beyond the person's death and that bereavement counselling services should identify carers at risk of complicated grief and suicide earlier in the process.

Leonard, Horsfall, Noonan, and Rosenberg (2017) in their qualitative study, explored the supporting role of psychologists in end-of-life care, emphasised that psychologists are not well represented in end-of-life care in Australia. The authors went on to identify a number of potential supporting roles for Australian psychologists in end-of-life care, including aiding individuals in the management of distress, adjustment and transition, relationship management, care coordination, and helping carers navigate the health system (Leonard *et al.*,

2017). This paper illustrates that psychologists are an underutilised resource in clinical service provision and further integration of psychologists into end-of-life care could be beneficial.

Broady (2017) explored carers' experiences of end-of-life care in a narrative literature review. Broady (2017) applied personal construct psychology (PCP) to explore alternative ways that carers can view their caring roles. PCP advocates the use of a range of different interventions and strategies including "Fixed Role therapy," Ravenette's "Who Are You?" Interview, narrative therapy, and art therapy (Broady, 2017). Although these interventions require further exploration, they may assist with deconstructing the death and dying process and could potentially help normalise bereavement and end-of-life issues and empower carers to maintain a self-identity throughout the caring role.

Steiner, Shlonsky, and Joubert (2017) examined the efficacy of psychosocial interventions for use with parents with incurable end-stage cancer and their children. The authors identified only one intervention that exclusively focused on parents with end-stage cancer: Family talks in cancer care: family support program (FTCCP). FTCCP is a family-focused, child-centred, time-limited, and structured intervention that aims to improve family communication, affirms parent's competence, and assists with the provision of resources and end-of-life planning. No objective outcome measures were used to assess the efficacy of FTCCP. Overall, this study confirmed the scarcity of published studies on evidence-based psychosocial intervention programs addressing the supportive care needs of parents with incurable end-stage cancer, leaving clinicians with limited treatment options (Steiner *et al.*, 2017).

Finally, Bentley, O'Connor, Shaw, and Breen (2017) reviewed the efficacy of DT to alleviate end-of-life distress. In this narrative review Bentley *et al.* (2017) confirmed that DT has been embraced throughout the world and across different population groups, including people who are terminally ill, the elderly, those living with dementia, motor neurone disease or mental illness, or those who are undergoing chemotherapy, and across a variety of formats, including web-based and face-to-face. These authors found that while study participants consistently reported high levels of satisfaction and acceptability of DT, the efficacy of DT in alleviating psychological distress at the end-of-life remained unconfirmed (Bentley *et al.*, 2017). The impact of DT on families was also found to vary. Some studies have reported that the legacy document employed as part of DT therapy helped families to learn about their deceased relative member and provided comfort in bereavement, while others studies found that families voiced concerns that the legacy document placed strain on family relationships. Bentley *et al.* (2017) also highlighted the importance of different cultural perspectives of death in the bereavement process and identified the need to adapt current psychotherapy to take cultural values into account. In order to provide best patient care, it may be worthwhile clarifying which patient populations are most likely to benefit from DT, so that these patients can be targeted in clinical practice.

In summary, these five studies emphasise that nearing the end-of-life impacts on an individual's and carer's wellbeing. The qualitative studies provide a detailed analysis of the carer perspectives and capture the subtleties and complexities of their grief experience. A short coming of these qualitative studies is that the conclusions cannot be generalised beyond their distinct

study populations. The three review papers identified the potential usefulness of DT, PCP interventions, and FTCCP, however, these interventions are difficult to compare as the researchers used different measures or did not include objective outcomes measures in their efficacy evaluations. These studies highlight the need for further rigorous evaluation of interventions across different cultures and populations using RCTs.

The Role of the Psychologist in End-of-Life Care

This special issue has a number of clinical implications. It acknowledges that psychologists have expertise, skills, and knowledge that are well suited to end-of-life psychotherapies but that there are very few psychologists working in end-of-life care (Leonard et al., 2017; Nydegger, 2008). Over the past decade, there have been a number of policy developments worldwide that support a more prominent role for psychologists in end-of-life care (National Institute for Clinical Excellence, 2004). For example, The European Association for Palliative Care (EAPC) taskforce (2010) identified a number of areas of need where the skills of psychologists' would be valuable, including: psychological assessment (e.g., of psychopathology, complex grief, symptom burden, relationship issues, and organic brain syndrome); the delivery of psychosocial interventions that can promote adaptive coping, meaning, a sense of purpose, and reduce symptomatology; staff consultation and education (e.g., supervision, communication training, and debriefing); and research (e.g., bridging medical and psychosocial research) (Jünger, Payne, Costantini, Kalus, & Werth, 2010). Similar roles could be established and promoted in end-of-life care in Australia. Furthermore, with an increase in the number of countries considering legislation on assisted dying, including Australia, psychologists may also have a role in policy development, and in the clinical decision-making process associated with assisted dying, such as competence assessments and working as part of a multidisciplinary team to ensure patients understand their palliative options (Australian Psychological Society, 2008).

The articles in this special issue identify a number of semi-structured interventions (e.g., DT, FTCCP, and bereavement counselling) and theories (PCP) that, with appropriate training and supervision, psychologists could use to guide and enhance their clinical work. The articles further highlight that end-of-life care requires the psychologist to adopt a flexible, person-centred approach that takes into account the unique needs of the individual and family (Klasen et al., 2017; LeMay & Wilson, 2008).

While working in end-of-life care can be gratifying and rewarding it can also be very stressful, with over 60% of Australian healthcare providers who work in oncology self reporting moderate to high rates of burnout (Girgis & Hansen, 2007). To avoid burnout and maintain personal resilience, it is recommended that psychologists working in the end-of-life care maintain a work-life balance, combined with self-care routines that help relax the body and mind (e.g., exercise, meditation, or listening to music). Organisations can also enhance staff coping by offering supports such as supervision, reflective practice, staff

communication, mindfulness-based training, and developing schedules that promote team engagement (Gillman et al., 2015).

Research Gaps

This special issue indicates that further research is needed on how to improve psychosocial outcomes for people nearing end-of-life, their carers, and families. A particular problem in the current literature is that there is a lack of robust and reliable outcome measures (Rodin, 2013), making it difficult to compare different end-of-life psychosocial interventions. To achieve this, researchers need to further investigate the psychometric properties of existing measures and make recommendations about a suite of measures to be used consistently in end-of-life research. Consistency in the use of outcome measurement at end-of-life would enable comparisons of interventions across various studies.

Future research endeavours also need to consider special populations, such as culturally and linguistically diverse groups, LGBTI (lesbian, gay, bisexual, transgender, and/or intersex), people with disabilities, people with mental illness, children, adolescents, and younger adults. The range of modalities to deliver psychological therapies also needs expansion—especially telehealth options to overcome distance for rural patients and barriers for patients whom too unwell to travel.

In planning further research, as Rodin (2013) recommended careful consideration should be given to the length and requirements of the intervention as some individuals may die, face cognitive impairments that prevent them from providing consent or experience levels of fatigue that prevent them from taking part in research.

Conclusion

The articles in this special issue reflect on the effectiveness of the end-of-life psychotherapies and further elaborate on the impact that end-of-life issues have on individuals, carers, and children as well as explore the potential role of psychologists in the field. While the evidence-base and range of therapies supporting end-of-life is gradually improving, further research needs to be undertaken to maximise the potential benefits of psychosocial interventions in this field. This should include consideration of the impact of psychotherapies on different populations, cultures, and cancer groups. This special issue of the *Australian Psychologist* is an important step in highlighting this critical issue in end-of-life care and should be considered a call to arms for further investigation by the psychology and research communities.

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