Maggie’s Centres

Upon a diagnosis of cancer, individuals are launched into a terrifying and devastating world accompanied by emotional, physical, mental and social distress. Consequently, many individuals require social, emotional and psychological support. With the increasing number of people affected by cancer, the best efforts of healthcare institutions are unable to meet the overwhelming healthcare burden. Individuals living with cancer and their families or friends are stranded with multiple unmet psychological and social needs that result in psychological morbidity and a reduction in quality of life. In the United Kingdom, Hong Kong, and Spain, Maggie’s Centres work in close partnership with local healthcare institutions to fulfil unmet psychological and social needs, as well as lead the shifting perspective on cancer survivorship and holistic care.

Maggie’s is a charity organization founded by Maggie Keswick Jencks, a writer, gardener, and designer, to provide psychological and social support for people with cancer. Through her own experience of her breast cancer diagnosis and subsequent return in 1988 and 1993, Maggie envisioned a holistic philosophy and approach to cancer care. She believed that with encouragement, informational, social, and emotional support in a welcoming and positive environment, people may change the way they live with cancer. Maggie believed that people should not “lose the joy of living in the fear of dying”. Maggie’s centres eventually became the embodiment of her vision. They sought to create a warm, familiar, and welcoming space for people living with cancer, their realities, and friends. Maggie’s centres provide psychological, social, and informational support in partnership with hospitals to improve the quality of life for people affected by cancer and encourage them to live their lives to the fullest.

Maggie’s Centres have numerous support programs and workshops for people affected by cancer, often utilising personalised approaches focusing on financial worries, stress management, depression, side effect management, and relationship and family support. Additionally, they have psychologists, benefits advisors and cancer support specialists to provide additional counselling and advice on any cancer-related worry.

Introduction

In the United Kingdom, there are 375,000 new cancer cases diagnosed annually, with almost half of all cases diagnosed at stage 3 or later (1). With significant advances in anti-cancer therapies such as immunotherapy and targeted therapy, patient prognosis has increased dramatically over the last 30 years. However, the benefits of longevity are also coupled with treatment-related adverse effects from numerous anti-cancer treatments. Although these treatments may increase longevity, they are not infallible. The chronic and unstable nature of cancer continues to be a significant challenge for clinicians, due to the possibility of relapse and clinical futility.

With the combination of significant quality of life (QoL) altering adverse effects, the possibility of progression and uncertainty of the future, individuals with cancer experience physical, psychological and emotional spiritual distress. Unsurprisingly, individuals living with cancer frequently experience greater psychological morbidity, burden and quality of life reduction than the general population. By utilising General Health Questionnaire (GHQ-12) in conjunction with logistic and cox regression, Gao et al detected a higher prevalence of psychological distress of 24.5% (95% CI: 18.5–30.5%) in cancer outpatients than in general community patients 16.5% (95%CI: 12.7–20.3%) (2). However, within the oncological community, individuals approaching the end of life and their surrounding loved ones experience extremely significant and severe psychological, social and financial distress, as well as a decrease in quality of life compared to cancer survivors. Gao et al further identified an increased prevalence of distress in palliative care patients (59.3% (95%CI: 51.4–67.2%)) (2). Patients who were in the last three months of life reported significant increases in psychological distress, 70% of palliative cancer patients and 35.3% of cancer outpatients reported psychological distress (2). Similarly, a systematic review of 29 manuscripts by Lambert et al revealed higher unmet emotional, psychological, spiritual, relationship and physical needs in individuals at end of life and their caregivers, in comparison to survivors (3). Higher levels of distress and prevalence of unmet needs in patients with advanced cancers are suspected to originate from rapid disease progression, increased pain, loss of function, anticipatory grief, existential crisis and inability to continue previous roles and activities (2). The trend is similar for caregivers of terminal cancer, increasing disease burden, shown by symptom distress and functional impairment is associated with decreasing quality of life (QoL) and increasing psychological for caregivers at end of life (4). As longer life spans increase the incidence of cancer due to ageing, and medical innovation prolongs 5-year survival rates, the population of bereaved families and individuals with cancer will increase, as they are at a higher risk for mortality and morbidity during their diagnosis. With 9.5 million cancer deaths worldwide and one-third of individuals touched by cancer experiencing bereavement, grief and worsening quality of life, it is crucial to investigate, understand and evaluate their unmet needs, and social and psychological distress to provide support for affected individuals (5).

People living with Cancer: Psychological Needs and QoL Reduction

In the current literature, individuals living with advanced cancer have frequently and commonly been identified with emotional, physical, spiritual and informational needs. Albeit this is not an extensive list, with some studies identifying up to eight areas of need, it is a common method of categorisation (6–8). Despite the identification and discussion of the patient's and caregiver's needs, they are often unmet by healthcare institutions and social support systems. As a result, unmet needs have been associated with a reduction in the quality of life for individuals living with cancer and their caregivers, families and friends (9).

Consequently, there have been significant ventures into identifying the incidence of specific unmet needs, their impact on psychological and physical health, as well as their correlation to prognosis, grief, quality of life and end of life quality. Individuals living with cancer at all stages have reported emotional support as their highest psychological need (10.1%-84.4%) (6). Common areas of support and psychological need revolve around the themes of uncertainty, fears and worry about the future, as well as concerns for their family. An Australian study of cancer survivors has indicated that the most common psychosocial issues include the fear of cancer recurrence, spread, uncertainty about the future, and worry about partners, friends and families (10). These findings have been echoed in other studies and demographics. A systematic review of lung cancer patients from 2007 to 2020 has similarly identified fear of cancer recurrence and spread among 42% of individuals surveyed. The authors further concluded that uncertainties regarding the future, fears and worry were the most common unmet needs identified (9). In another systematic review by Wang, Molassiotis, Chung and Tan, all domains of needs were investigated (6). In the emotional domain of unmet needs, patients reported "feelings of fear, hopelessness, and uncertainty of the future" or "feelings of sadness, anger, anxiety, frustration and desperation. Feelings of frustration, regret and anger may originate from unsolved issues regarding their diagnosis and treatment decisions, as well as their perceived achievement in life and unfinished goals. Individuals feel that they want to be proactive and play a part in their life, however, do not know how to do it.

Briefly, Brown et al have utilised Functional Assessment of Chronic Illness Therapy - General (FACT-G), locus of control, Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp), Hospital Anxiety Depression Scale (HADS) and Heart Hope Index (HHI) instruments to establish that patients with high external local of control surrounding chance, luck, fate, demonstrated increased anxiety and depression at the end of life. Additionally, previous literature has indicated that patients with a higher internal locus of control have improved mental well-being after diagnosis (11). However, this increase in anxiety and depression was not seen when choices were relinquished to healthcare professionals.

Wang, Molassiotis, Chung and Tan, have also noted that reassurance of their feelings, showing sensitivity and awareness of their emotional needs by healthcare professionals are prominent unmet healthcare needs (6). They wanted to feel like they had one member of staff whom they can talk to. Similarly to Wong, Molassiotis, Cung and Tan, Zhang, Nilsson and Prigerson have also reiterated the importance of the therapeutic alliance. Patients who felt that they were treated with respect, as a "whole person" by their physician were more trusting, comfortable asking questions related to their care and also predicted to have better end-of-life QoL. By utilising statistical modelling paired with cross-validation, Zhang, Nilsson and Prigerson identified and validated patient worry at baseline as one of the most influential predictors of worse end-of-life QoL. They have recommended prioritising reducing patient anxiety to improve end-of-life QoL (12). This finding is echoed by Bovero, Leombruni and Miniotti, who have identified anxiety as a relevant factor in negatively affecting QoL. The authors have noted that the low quality of life group obtained an average score of 13.0 (SD = 2.7) for the anxiety subscale and 15.4 (SD = 3.7) for the depression subscale, while the high quality of life group scores was 10.4 (SD = 3.0) and 11.6 (SD = 3.9), respectively. They further hypothesised that anxiety could be a major predictor for QoL instead of depression (13).

Communication and financial needs were also identified among advanced cancer patients. Patients indicated that they wished to be informed about the benefits and side-effects of treatment, about what actions they can take to improve their health, be provided with results as soon as possible and be informed about aspects of their care and condition (6). Reblin et al discovered that absence of communication between hospice nurses and caregivers was associated with higher levels of depression symptoms up to a year post-bereavement (14). By providing patients with actions they can take to improve their health, it is possible to extend their internal locus of control, reducing anxiety and depression. Informational support, communication and preparation are crucial to mental health, emotional wellbeing, quality of life and end-of-life QoL for informal caregivers and individuals living with cancer. It may aid in communication between families, further financial planning, managing expectations and obtaining support.

Spiritual needs were commonly explored in literature, with specific attention to the meaning of life as a common need. Spiritual needs are important in predicting clinical outcomes, management of distress in death and end-of-life despair (15). Patients at end of life may experience existential issues and further suffering regarding the meaning and purpose of life, their burden on others, maintaining their self-esteem, gaining forgiveness, reconciliation with others and religious existential crises. Patients nearing death demonstrated deterioration in existential domains (6.6 preadmission to 6.0 near death), with a significant reduction in personal existence domains (6.6 preadmission to 5.4 near death) (16). By utilising Schedule for Meaning in Life Evaluation (SMILE) and QOL with a single-item visual analogue scale (0–10), Bernard et al identified patients with advanced cancer or in palliation as likely to cite ‘family’ (OR=1.78), ‘social relations’ (OR=1.9), ‘spirituality and religion’ (OR=3.93), ‘social commitment’ (OR=1.94) and ‘growth’ (OR=2.07), and less likely to cite ‘finances’ (OR=0.15) and ‘health’ (OR=0.21) as areas relevant to their perceived meaning of life (17). Additionally, the authors have utilised a linear regression model to find a significant association between the meaning of life as a predictor of quality of life. There was a significant positive association between the index of importance and total SMILE score, as well as satisfaction and social areas. A similar association was identified by Bovero, Leombruni and Miniotti, who utilised similar instruments as Brown et al to identify the importance of spirituality in advanced cancer patients’ anxiety, depression, pain and QoL.

Higher quality of life was associated with higher association (26.7, SD=9.1) on the FACIT-Sp subscale, in comparison to lower quality of life (16.7, SD=8.1). Interestingly, authors have also identified retirement as being associated with increased QoL, while being single, widowed or divorced is associated with decreased quality of life. Social support and time to process and discover the meaning of life could have improved quality of life, and reduced anxiety (13). Additional support from pastoral care services and meaning searching has been shown to help improve end-of-life QoL by Zhang, Nilsson and Prigerson. Patients who reported engaging in prayer or meditation had better end-of-life QoL. Findings by Zhang, Nilsson and Prigerson are consistent with other studies that have revealed significant associations between spirituality, peacefulness and QoL in patients afflicted by life-threatening diseases(12).

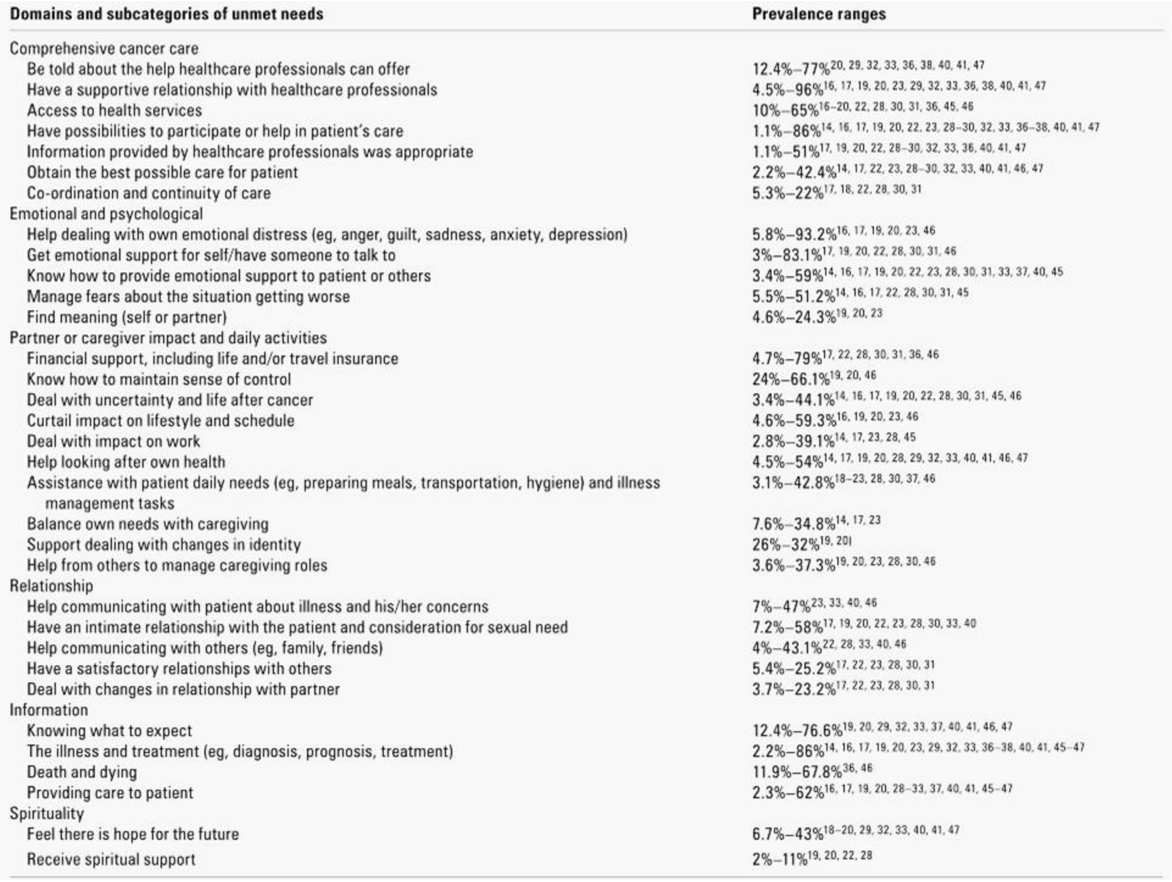
People Affected by Cancer: Psychological Needs and QoL Reduction

With heavy psychological distress and financial and social burdens levied on the patient, the impact is often felt by their friends, relatives and informal caregivers. The burden on caregivers has been explored frequently, with attention to bereavement, grief, anxiety, depression and their quality of life. The literature has commonly indicated an association between caregiver burden, patient disease burden and overall quality of life for caregivers. In a national post-bereavement survey, over 90% of respondents reported spending time caregiving in the last 3 months of the decedents' life, with a median of 69 hours and 30 minutes of care per week and a median financial expenditure of 370 GBP (18).

As a patient's disease burden increases, caregiving hours increase correspondingly. In a national census survey utilising EQ-5D Visual Analogue Scale (EQ-5D VAS) and General Health Questionnaire (GHQ)-12 instruments, Grande et al associated total time spent caregiving and on related tasks with deteriorating general health and increased psychological morbidity except for odd jobs and travelling with the patient. Conversely, increased relaxation, hours of relaxation, social care, and general practitioner (GP) input decreased psychological morbidity and increased general health of caregivers. They also noted that carers who self-sought formal help fared worse than those who had GP and social care input, as carers sought help during crisis points (8). Generally, younger female carers who had lower education, residence in deprived areas, did not volunteer or work and had lower incomes were associated with worse psychological and physical health.

Results from Song et al supported the findings from the national survey and provided more specific insights into how social factors affected psychological distress (19). By utilising EQ-5D VAS with Caregiver Reaction Assessment, Song et al surveyed family caregivers of terminal cancer patients. Health-related QoL (HrQoL) of caregivers were significantly lower than non-caregivers in usual activities (1.53±0.75 vs. 1.26±0.51, $P=0.0005$) and anxiety/depression (1.67±0.64 vs. 1.23±0.45, $P<0.0001$). Caregivers experienced more frequent depressive moods during the previous year than did controls (36.3% vs. 12.4%, $P<0.0001$). Religion was positively correlated with caregivers' HRQoL (β=6.957, P=0.0384). For caregivers and partners, absence of family support increases the risk of suicidal thoughts (aOR, 1.99; 95% CI, 1.15–3.47). Financial problems increased the risk of depression (aOR, 1.56, 95% CI, 1.00–2.42) and the impact of caregiving on health was associated with more stress. However, a "disrupted schedule" decreased the risk of suicidal thoughts (aOR, 0.40; 95% CI, 0.20–0.82). It was hypothesised that a disrupted schedule was interpreted as spending and sharing time with dying family members, fostering a close relationship and completing filial duties.

As mentioned previously in a systematic review by Lambert et al, caregivers of individuals with cancer not only has significant levels of unmet needs but caregivers of individuals in the palliative care phase or individuals with a brain tumour experience even higher unmet needs (3). The authors found that 5% - 47% of needs were unmet and up to 10% of assessed needs were unmet. At least 15.5% - 67.9% of partners and caregivers experienced at least one unmet need. Caregivers commonly indicated that “managing concerns about cancer coming back” (78.3%), “finding out about financial support and government benefits for you and/or the person with cancer” (60.9%), “help to realize patient’s wishes” (100%), and “lack of social life” (71.4%) were reported as the most common psychological, financial, spiritual, and social need. Caregivers also had feelings of sadness, loneliness, abandonment, fear, helplessness and isolation due to a lack of social activities and support from other family members and professionals. Therefore, for partners and caregivers, emotional needs and coping mechanisms are still largely unmet during the palliative care phase (3). The loss of support from healthcare can be seen in a study by Aoun et al. Only 75% of caregivers were asked about coping, with approximately 40% asked about emotional or psychological problems and 62.9% offered information about grief and bereavement services. Post-bereavement, only 50.9% were contacted about coping or questions that they might have (20).



Domains and subcategories of unmet needs	**Prevalence ranges**
Comprehensive cancer care	
Be told about the help healthcare professionals can offer	12.4%–77%[20, 29, 32, 33, 36, 38, 40, 41, 47]
Have a supportive relationship with healthcare professionals	4.5%–96%[16, 17, 19, 20, 23, 29, 32, 33, 36, 38, 40, 41, 47]
Access to health services	10%–65%[16–20, 22, 28, 30, 31, 36, 45, 46]
Have possibilities to participate or help in patient’s care	1.1%–86%[14, 16, 17, 19, 20, 22, 23, 28–30, 32, 33, 36–38, 40, 41, 47]
Information provided by healthcare professionals was appropriate	1.1%–51%[17, 19, 20, 22, 28–30, 32, 33, 36, 40, 41, 47]
Obtain the best possible care for patient	2.2%–42.4%[14, 17, 22, 23, 28–30, 32, 33, 40, 41, 46, 47]
Co-ordination and continuity of care	5.3%–22%[17, 18, 22, 28, 30, 31]
Emotional and psychological	
Help dealing with own emotional distress (eg, anger, guilt, sadness, anxiety, depression)	5.8%–93.2%[16, 17, 19, 20, 23, 46]
Get emotional support for self/have someone to talk to	3%–83.1%[17, 19, 20, 22, 28, 30, 31, 46]
Know how to provide emotional support to patient or others	3.4%–59%[14, 16, 17, 19, 20, 22, 23, 28, 30, 31, 33, 37, 40, 45]
Manage fears about the situation getting worse	5.5%–51.2%[14, 16, 17, 22, 28, 30, 31, 45]
Find meaning (self or partner)	4.6%–24.3%[19, 20, 23]
Partner or caregiver impact and daily activities	
Financial support, including life and/or travel insurance	4.7%–79%[17, 22, 28, 30, 31, 36, 46]
Know how to maintain sense of control	24%–66.1%[19, 20, 46]
Deal with uncertainty and life after cancer	3.4%–44.1%[14, 16, 17, 19, 20, 22, 28, 30, 31, 45, 46]
Curtail impact on lifestyle and schedule	4.6%–59.3%[16, 19, 20, 23, 46]
Deal with impact on work	2.8%–39.1%[14, 17, 23, 28, 45]
Help looking after own health	4.5%–54%[14, 17, 19, 20, 28, 29, 32, 33, 40, 41, 46, 47]
Assistance with patient daily needs (eg, preparing meals, transportation, hygiene) and illness management tasks	3.1%–42.8%[18–23, 28, 30, 37, 46]
Balance own needs with caregiving	7.6%–34.8%[14, 17, 23]
Support dealing with changes in identity	26%–32%[19, 20]
Help from others to manage caregiving roles	3.6%–37.3%[19, 20, 23, 28, 30, 46]
Relationship	
Help communicating with patient about illness and his/her concerns	7%–47%[23, 33, 40, 46]
Have an intimate relationship with the patient and consideration for sexual need	7.2%–58%[17, 19, 20, 22, 23, 28, 30, 33, 40]
Help communicating with others (eg, family, friends)	4%–43.1%[22, 28, 33, 40, 46]
Have a satisfactory relationships with others	5.4%–25.2%[17, 22, 23, 28, 30, 31]
Deal with changes in relationship with partner	3.7%–23.2%[17, 22, 23, 28, 30, 31]
Information	
Knowing what to expect	12.4%–76.6%[19, 20, 29, 32, 33, 37, 40, 41, 46, 47]
The illness and treatment (eg, diagnosis, prognosis, treatment)	2.2%–86%[14, 16, 17, 19, 20, 23, 29, 32, 33, 36–38, 40, 41, 45–47]
Death and dying	11.9%–67.8%[36, 46]
Providing care to patient	2.3%–62%[16, 17, 19, 20, 28–33, 37, 40, 41, 45–47]
Spirituality	
Feel there is hope for the future	6.7%–43%[18–20, 29, 32, 33, 40, 41, 47]
Receive spiritual support	2%–11%[19, 20, 22, 28]

Table 1: Summary of Domains and Prevalence Ranges for Subcategories of Unmet Needs (3)

Grief

As illustrated above, caregiver responsibilities inherently negatively affect the quality of life. However, for caregivers and people surrounding individuals living with advanced cancer, grief and bereavement pose severe psychological stressors that reduce the quality of life and return to normal function. Although complicated grief has been previously defined as an intense grief reaction that is prolonged and persistent for 6 months after death, according to the literature, the term complicated grief has been divided into anticipatory grief reactions and bereavement grief (21–23). With knowledge of their loved one's passing, pre-loss grief may occur, as families or friends begin to process the eventual loss. The terms anticipatory grief, pre-death grief and pre-loss grief have been utilised to describe this phenomenon. However, the term "anticipatory grief" has received much criticism and controversy, as it does not conform to the current Freudian psychoanalytical model of grief. Anticipatory implies anticipation of grief outcome, while pre-loss grief implies the presence of a grief experience, but not the function of grief. Recommendations by Nielsen et al and Evans et al have indicated that the nomenclature "pre-loss grief" is preferred instead of anticipatory grief (21).

The prevalence of grief is relatively high among carers of individuals living with cancer. A meta-analysis by Kustanti et al estimated the pooled prevalence of grief at 14.2% (95% CI, 11.7%–16.7%), ranging from 7% to 39% among patients with cancer. The data of this meta-analysis is supported by Treml, Schmidt, Nagl and Kertin's systematic review, estimating 14.9-33% of caregivers experience pre-loss grief with 25.9% of family caregivers reporting a high (16.1%) to severe (9.8%) level of pre-loss grief (21). Kustanti et al also concluded that grief disorders were more common in females, religious, spouses and families of patients with cancers of a neurological origin that were taking care of their family members at home (24). Similar determinants of grief were echoed by Chiu et al. Their study found that female gender (OR, 2.27; 95% CI, 1.75-2.82), spouse relationship (OR, 1.20; 1.01-1.40), parent-children relationship (OR, 1.70; 1.11-2.31), lack of religious belief (OR, 1.47; 1.19-1.75), no family support (OR, 1.42; 1.03-1.83), and history of mood co-morbidity (OR, 1.41; 1.02-1.83) were risk factors for complicated grief (25). Chiu et al also identified factors that were protective against complicated grief, including longer duration of caring (months, OR, 0.79; 0.69-0.91), medical disease history in the carer (OR, 0.77; 0.57-0.99), and patients being cared for on the hospice ward (OR, 0.60; 0.44-0.77) were factors that would mitigate against complicated grief. Specifically, they identified that a parent-child relationship (OR=1.69, 95% CI=1.11-2.29) in Asian cultures has a higher dispensation for contributing to complicated grief, compared to spousal relationships (OR=1.2, 95% CI= 1.01-1.41). Overall, trends for caregivers and individuals living with cancer were similar. The literature supports the need for social support, more sensitive and aware healthcare staff, earlier psychological interventions and searching for the meaning of life.

With a high gross incidence of grief among carers, families and friends, the causes, consequences and effects of grief have also been well defined. In a systematic review of 35 articles by Treml, Schmidt, Nagl and Kerstin, common effects of grief were explored and listed. Caregivers who experienced higher levels of pre-loss grief reported lower levels of optimism, increased pessimism and stressful events, poorer health, increased caregiver burden, denial and higher amounts of daily care. They also may have a higher incidence of unmet needs, previous or current depression, lower family functioning, greater needs for social support and perceive the physical condition of the patient as severe or not expecting the diagnosis (21). Pre-loss grief was also associated with increased intensity of anger, loss of emotional control and atypical grief responses. Carers with high degrees of pre-loss grief are likely to use emotive coping strategies while acceptance and positive reinterpretation had a negative correlation with pre-loss grief. Carers who felt closer to the patient experienced more difficulties concentrating and sleeping with less interest in day-to-day activities. Additionally, high pre-loss grief was associated with increased anxiety, post-loss avoidance, prolonged grief, higher level of post-loss grief and depressive syndromes. Therefore, pre-loss grief does not play a protective effect on post-loss grieving and depression, contrary to Lindemann's hypothesis. Additional psychosocial factors have also been associated with pre-loss grief by Tomarken et al. Levels of pre-loss grief was associated with perceived social support ($r=-0.415$, $p<0.001$), history of depression ($r=-0.169$, $p<0.05$), current depression ($r=-0.158$, $p<0.05$), current annual income (Spearman rho $=-0.210$, $p<0.01$), annual income at the time of diagnosis (Spearman rho $=-0.155$, $p=0.05$), pessimism ($r=0.320$, $p<0.001$); and amount of moderate to severe stressful life events (Spearman rho $= 0.218$, $p=0.001$). In a multi-variate analysis, pessimistic thinking (Beta = 0.208, $p<0.05$) and severity of stressful life events (Beta = 0.222, $p<0.05$) remained important factors in developing complicated grief pre-death. The authors have identified caregivers' pessimism as the strongest predictor of the development of pre-loss grief (26).

In a nationwide population-based cohort study by Nielsen et al, severe pre-loss grief symptoms (PGS) were reported by 432 caregivers. Severe PGS were associated with high caregiver burden (adjusted OR = 8.3; 95% CI, 6.3-11.1) and low level of preparedness (adjusted OR = 3.3; 95% CI, 2.5-4.4), depressive symptoms (adjusted OR = 12.4; 95% CI, 9.5-16.3), low level of communication about dying (adjusted OR = 3.2; 95% CI, 2.2-4.4) and prognostic information perceived as "too much" (adjusted OR = 2.8; 95% CI, 1.7-4.6) or "not enough" (adjusted OR = 1.7; 95% CI, 1.3-2.4). Therefore, severe PGS was associated with low preparedness for death. The authors predicted a nine-fold higher likelihood of caregivers developing severe PGS. Therefore, Nielsen et al emphasise the association between severe PGS and depressive symptoms, stressing the severe impact of PGS on caregivers (27). The association between pre-loss grief symptoms and depression was reiterated by Young et al, with 67% of caregivers sampled having high depression scores (BDI > 13), and 35% had very high depression scores (BDI > 21). By using a multiple logistic regression model and ANOVA analysis, the authors identified determinants of pre-loss grief-associated depression. Spousal female caregivers in poor health who are feeling burdened, adapting poorly, unable to function normally, or caring for a patient with poor ECOG performance status were more likely to experience depression ($P < .01$ for all values). They concluded that care burden was the best predictor (28).

Finally, pre-loss grief has been examined as a predictor of post-loss grief by Nanni, Biancosino and Grassi. In their journey to evaluate pre-loss grief as a predictive tool for post-loss grief, the authors have also identified the major components of complicated grief. By utilising bivariate and factor analysis, the authors have identified three principal factors of complicated grief. Complicated grief is characterised by trauma distress, separation distress and emotional symptoms. Contrary to Chiu et al, they found that spouses reported higher re-loss ICG scores than other family caregivers. They have also identified associations between pre-loss grief with post-loss grief. The pre-loss ICG-total score was higher among CG (54.27±4.22) in comparison with non-CG caregivers (32.61±10.33) (*t*=6.78; *p*<0.001) after death. Positive responses to pre-loss ICG items, including emotional distress, traumatic distress, and other emotional symptoms, are associated with a higher risk of post-loss grief (29).

Bereavement

In addition to previous classifications of complicated grief into pre-loss grief and post-loss grief, there are also further advancements and developments in other theoretical perspectives of grief and bereavement. Stage-based bereavement theories such as Freud's were initially proposed, emphasizing individuals emotionally detaching from the departed to return to normal functioning (30). The grief work perspective emphasised the need to confront the passing of their loved one and work through the emotions and thoughts associated with the event, with the final goal of being emotionally detached from the deceased. However, the aforementioned models did not account for alternative methods of coping with bereavement or were sensitive to non-western cultural grieving behaviours (30). The model was deemed to be passive and neglected the struggle with grief, implying that the person was undergoing instead of actively dealing with grief. The grief work notion also does not acknowledge the burden of grief, benefits of denial or other sources of stress that arise from bereavement (30). Therefore, other theories such as cognitive stress theory, attachment theory and trauma perspective have been applied to bereavement to develop a deeper understanding. However, these theories have not been unified successfully.

Consequently, the dual process model (DPM) of coping was developed to unify the applied theories and expand upon the grief work perspective (31). The DPM model expands upon cognitive stress theory to classify loss-oriented stressors and restoration-orientation stressors. Loss-orientation is the ability of the bereaved individual to concentrate, evaluate and process the experience of loss and as such, incorporate grief work. Loss-orientation involves dwelling on and searching for the lost person. Restoration-orientation is the focus of secondary stressors that are a result of bereavement, encapsulating the struggle to reorient themselves in a changing world without the decedent. The DPM classification allows the incorporation of emotion and problem-focused coping behaviours simultaneously, allowing loss and restoration stressors to be dealt in an emotion or problem-focused manner. Therefore, the DPM of coping suggests that bereaved individuals fluctuate between confronting and avoiding the loss, utilising emotional and analytical approaches to adjust to the loss of their relationships. The DPM of coping is increasingly supported by empirical evidence and novel studies. Additionally, the DPM of coping is similar to loss-attachment theory. Loss-attachment theory is commonly used to describe the experience of bereavement. Individuals bereaved lose status, power and control, with alterations and changes to their identity. As a result, the individuals must adapt and accept reality on intellectual and emotional levels to adjust to an environment where their loved one is no longer present (15). By following the DPM model, literature has encouraged bereaved individuals to continue with their daily routines and plan for their future (32). This is supported by an inverse correlation discovered between the QoL of bereaved caregiver and their likelihood of depression. Increased quality of life in the face of bereavement suggests successful coping, retaining their energy, enjoyment of life and physical or social functioning, possibly through a dual coping process (4).

Despite increased understanding of bereavement and grief, individuals who have lost a loved one still report worse quality of life, reduced mental health and increased distress than nonbereaved individuals. Up to 44% of bereaved individuals are at risk for a mental disorder, with 31% of bereaved cancer caregivers reporting suicidal thoughts (33). Individuals who were bereaved reported high bereavement and general distress 3 and 5 years after their loss, with increasing general distress and declining bereavement distress between 3 to 5 years post-loss (34). Bereaved individuals also have an overall increased risk of premature death in the years after a death of a spouse, especially in their first year of loss. Furthermore, there is also an increased risk following the hospitalisation of a spouse. Caregiving during a loved one's illness and decline may impart further strain on the caregiver which increases the risk for mortality. The physiologic stress has been associated with disrupted autonomic, immune and endocrine responses. Disturbance of sleep patterns after 6 months of bereavement correlated with worse emotional health or energy a year later (15).

Not surprisingly, bereaved individuals utilised mental health services and were administered psychotropic medication at higher rates than nonbereaved individuals (33). Bereavement services were also observed to be utilised in 36% of cases 6 months after loss and at 48% 2 months post-loss (35).

In a quality-of-life survey for caregivers in the United States, the authors found that bereaved caregivers reported higher caregiving stress while providing care to their loved ones, as well as poorer mental health than other caregivers whose loved ones were in remission. They also found that physical health 8 years after bereavement was negatively correlated to psychological distress among all caregivers. Greater caregiver esteem at two years predicted poorer physical health six years later. Spiritual adjustment was negatively correlated with psychological distress among all caregivers. However, spiritual adjustment was only significantly positively correlated to physical health among bereaved caregivers. Becoming a former caregiver due to bereavement was also associated with poorer mental health and greater psychological distress. The authors concluded that psychological distress was highly correlated with physical, mental and spiritual health. The long-term effect of caregiving stress on psychological distress continues six years later. Therefore, they suggested that programs targeting psychological distress earlier in the bereavement process may yield improvement in overall QoL after an initial cancer diagnosis (5).

Utilising the EQ-5D instrument, Song et al have quantified the impact of bereavement among caregivers of individuals living with terminal cancer (19). HRQoL of the bereaved individuals was significantly lower than the controls in the domains of self-care (1.09±0.39 vs 1.03±0.17, p =0.002), usual activities (1.19±0.50 vs 1.12±0.34, p =0.026), and anxiety/depression (1.59±0.60 vs 1.22±0.43, p <0.001). The EQ-5D index scores (0.88±0.20 vs 0.93±0.13, p =0.002) were lower in bereaved individuals than in controls. Unsurprisingly, bereaved individuals experienced more depressive moods (33.1% vs 12.5%, p<0.001) and suicidal thoughts (31.4% vs 16.4%, p<0.001). Song et al have also noted that males (EQ-5D index score: β=0.041, p=0.030) with higher incomes (EQ-5D index score: β=0.079, p<0.001; EQ-VAS: β=6.985, p<0.001) were positively correlated HRQoL in bereaved family members.

Higher-income was slightly related to lower stress (aOR=0.63; 95% CI, 0.38–1.06), depression (aOR=0.64; 95% CI, 0.40–1.04), and suicidal thoughts (aOR=0.63; 95% CI, 0.39–1.03). Additionally, perceived mental burden increased the risk of moderate or higher levels of stress (aOR=1.26; 95% CI, 1.05–1.51), depression (aOR=1.29; 95% CI, 1.08–1.53), and suicidal ideas (aOR=1.24; 95% CI, 1.04–1.48). Finally, a longer duration of survival after enrolment in palliative care was negatively related to health-related QOL (EQ-VAS: $\beta=-3.809$, $p=0.037$).

With the impact of bereavement on quality of life well characterised, studies have explored and identified challenges associated with bereavement and their relevant impact on physical and psychological health. By utilising the Bereavement Challenges Scale (BCS), SF-36 and DSM-IV results to conduct factor analysis, Trevino et al identified five BCS domains: Challenges with Connecting with Others (37.03% of total variance), Challenges with Change (8.34% of total variance), Imagining a Hopeful Future (5.92% of total variance), Challenges with Accepting the Loss (4.80% of total variance), and Guilt (4.47% of total variance) associated with bereavement adjustment and clinical interventions. BCS items of "I depress people who spend time with me.", "I'm so angry about the death that it is unpleasant for others to be around me," "Trying to force myself to move beyond grief would be a sign of weakness.", "No one will ever love, value, or understand me as much as [the deceased]", "A part of me feels like s/he is not gone"., "I'm not ready to let him/her go". "Engaging in new tasks or starting new relationships feels like a betrayal to [the decedent]" had the highest factor loading among all five factors. By utilising linear regression models to predict mental HRQoL, prolonged grief and likelihood of meeting diagnostic criteria for mental disorders, all five BCS factors were significantly and positively associated with each predicted outcome; higher BCS scores resulted in higher risk and likelihood. Therefore, the authors indicated that "challenges with accepting the loss" and "challenges with change" were associated with worse mental health and QoL, which are consistent with bereavement adjustment models. The authors further confirmed that individuals who are resistant to change are more likely to struggle with their loss. Continued attachment to the decedent proves to be a significant barrier and cause of psychological distress. Pessimism about their future was also associated with poor QoL and an increased chance of a mental disorder. As a result, the author suggested utilising the five BCS factors as a target for clinical intervention and to transform the relationship with the deceased into an adaptive continuing bond by acknowledging the persisting loving connection with the disease and suggesting the nature of the relationship needs to be altered (33).

As mentioned previously by Tomarken et al, pessimism was determined to be one of the strongest indicators of pre-loss grief. In an analysis of clinical trial data by Hoerger et al, pessimism in prognosis was also associated with worse depression ($P = 0.002$), anxiety ($P = 0.019$), prolonged grief ($P = 0.028$) and less purpose in life ($P < 0.001$) 7-months post-mortem. Not only caregivers are negatively affected by pessimism post-bereavement, but patients with pessimistic caregivers were less likely to receive chemotherapy or have inpatient visits in the 30 days before death, receiving less intense end-of-life care. Hoerger et al concluded that caregivers' pessimism could benefit patients while increasing the psychological burden on themselves, and vice versa. This phenomenon was seen commonly in their study, as Hoerger et al revealed that Caregivers ($P < 0.0001$) and oncologists ($P = 0.001$) predicted lower quality of life than what patients experienced. Among caregivers, 40.4% underestimated and 16.0% overestimated their loved one's future quality of life by at least 2 points on a 0–10 Likert scale. Only 43.6% were accurate in their estimations. 34.0%of oncologists underestimated, 15.4% overestimated, and 50.6% were accurate in their estimation. 17.3%of individuals living with cancer underestimated, 17.9% overestimated and 64.8% were accurate in the predictions of their future quality of life (36).

In addition to the five BSC factors described, bereavement's most significant impact is the possible development of depression and prolonged grief syndrome. Prolonged grief disorder (PGD) and major depressive disorder (MDD) are related but distinct diseases with a significant toll on mental health and personal and professional relationships. They are associated with increased suicidal ideation, excess morbidity, reduced quality of life and greater healthcare burden. Individuals with PGD have a distinct yearning and preoccupation with the diseased, while individuals with MDD experience persistent anhedonia and dysphoria (37). PGD is usually affected by loss-related events or the death of a person the individual is attached to, while MDD is affected by intrapersonal and interpersonal variables, such as negative perceptions of themselves, their future and the world. Unique symptom trajectories have also been identified by Wen et al, with prolonged grief disorder associated with potential recurrence and major depressive disorder associated with chronic distress. Four symptom trajectories (endurance, transient-reaction, resilience, and prolonged-symptomatic) were shared by both PGD and MDD (37). In a novel paper by Jacobsen et al, a factor analysis revealed that the top 10% distribution of grief scores was unique and associated with the wish to die (OR 10.13 [0.1.08–95.06]), but not MDD (38).

The prevalence of moderated to severe depression and prolonged grief was 15% and 40% at 6 months post-loss (35). At 13 months post-death, 11% of carers met the criteria for PGD, with a literature standard of 10-15% of bereaved individuals meeting the criteria for PGD (39). PGD has also been found to be sustained and entrenched in bereaved caregivers for at least three years post bereavement, with 5% affected and 14% slightly below the threshold for PGD (40). Unresolved grief was seen in 47.2% of bereaved siblings, of which, 52.8% had resolved grief. Therefore, approximately half of young adults experience unresolved grief 2-10 years after losing a sibling to cancer (32). In terms of general psychological distress, 36% of individuals met the criteria for one or more psychological distress measures 6 months post-death. By the 13 months post-death, the number of individuals with psychological distress only reduced to 29% (39). Of those who did recover, it took nine to ten months for the caregiver's grief, quality of life and health to return to normal (41). Overall, acute grief reactions to the death of a loved one resolve within 6 to 12 months (4). The prevalence of prolonged grief and depression might also be related to the sensitivity of professional risk assessments (35). For depression and prolonged grief, professionals correctly assessed the risk of complications in 55% of cases. The professional risk assessment utilised had a sensitivity of 27.3% and a specificity of 86.4% in depression and a sensitivity of 54.5% (95% CI, 23.4-83.3) and a specificity of 62.7% (95% CI, 49.1-75.0) in prolonged grief. Therefore, the true positive prediction of complications is 27% for depression and 21% for prolonged grief. Of those people diagnosed, 64% of the bereaved with a depression score of moderate to severe had used a type of bereavement service in the past 6 months and 47% of the bereaved with a score denominating CG had used some kind of bereavement service (35). As a result, diagnosis and anticipation still prove to be a significant challenge in early interventions.

Pre-loss grief has been explored as an indicator for PGD and MDD, with Thomas et al proposing pre-loss prolonged grief symptoms as a strong indicator of prolonged grief symptoms at 6 and 13 months post death (39). Additionally, Nielsen et al conducted a study among 2125 participants to investigate predictors of complicated grief and depression. Nielsen et al reported a higher proportion of caregivers with pre-loss grief than prolonged grief. Similarly, depression symptoms were higher after the loss of a loved one. Most interestingly, 26% of caregivers who reported severe pre-loss grief symptoms eventually developed prolonged grief and 33% developed depressive symptoms. Additionally, 28% of caregivers reported pre-loss depressive symptoms, 28% developed prolonged grief and 47% developed depressive symptoms. In comparison, among caregivers without pre-loss depressive symptoms, only 4% developed prolonged grief and 6% developed depressive symptoms. Appropriately, the authors concluded via multivariable regression modelling that severe pre-loss grief symptoms were key predictors of prolonged grief (adjusted OR = 5.4, 95% CI: 2.8–10.4; Table 5) and post-loss depressive symptoms (adjusted OR = 2.5, 95% CI: 1.3–4.7) (42). Although pre-loss grief may be a predictor of prolonged grief, Breen et al reported that the rate of change in grief, Qol and general health was unrelated to the intensity of pre-death grief. Breen et al have also reported the association of pre-death grief as a predictor for prolonged grief at 6-7 and 9-10 months post bereavement (41). Additionally, it is interesting to note that higher levels of the end-of-life caregiving burden were associated with decreased severe depressive symptoms in the first two years post-bereavement (4). It is suspected that the long-term positive effect of relief from the high caregiving burden provides support for psychological adjustment.

Current Support Available

Current support in the United Kingdom for individuals with cancer facing the end of life and their families is available, however, is limited. Overall, individuals may be provided support from the palliative care team, or by self-referral to psychological therapy. Individuals may access support from official routes such as the National Health Service (NHS) or via charity organisations.

During the end of life, National Institute for Health and Care Excellence (NICE) has indicated that offering bereavement support for caregivers and psychological support for individuals is part of their guidance. Clinicians are recommended to carry out a holistic needs assessment to provide accurate support to individuals at the end of life. Providing informational support to individuals at the end of life and involving them in shared decision-making is also recommended. This may involve providing pain relief acknowledging and respecting patient views and preferences, involving family members and carers, ensuring continuity of care, communicating the next decisions of their care and allowing them to decide (43). Healthcare professionals may include the person's budget in their care and support plan, signposting them for financial support services, and involving other organisations involved in end-of-life care to improve access to care. The goal is to ensure independence as much as possible during the end of life (44). Discussions around advance care planning will occur, as well as reviewing any needs any parties might have to provide multi-faceted care. Clinicians will aim to coordinate end-of-life care between social organisations and healthcare practitioners. The goal is to support individuals at end of life with cultural, pastoral, physical, social and psychological support (45). For parents or carers, bereavement support is explicitly indicated, such as talking to professionals, home visits, and bereavement support groups. Involving the multidisciplinary team in support plans signposting individuals to support, and involving other organisations that specialise in bereavement (46). There is also specific guidance for supporting adult carers, such as providing informational support, promoting local carer support services, promoting honesty in a discussion of prognosis and interventions, signposting to other charities, assessment of carer's needs and training programs for carers (47). For bereaved individuals, psychological is also available, either via self-referral through the Improving Access to Psychological Therapies (IAPT) services or via their GP. Wait times vary due to the increased burden on NHS after the SARS-COV-2 pandemic, although NHS aims to support individuals within a 6-week to 18-week period, dependent on urgency.

Despite the emphasis of NICE guidelines on holistic support, it is unknown how the guidelines are being adhered to. Additionally, much of the NICE guidelines are reliant on external organisations for support and referral. To obtain external specialist support and advice, there are multiple charity organisations involved in bereavement support. The largest organisations are Cruse Bereavement care for adults and Winston's Wish for children. Other organisations may also include Samaritans, Sue Ryder and Marie Curie's.

Direct bereavement support services and counselling are provided by Cruse, Sue Ryder, Winston Wishes and Grief Encounter. The former two charities, Cruse and Sue Ryder are general bereavement support charities, while Winston Wishes and Grief Encounter are targeted at younger children and teenagers. Sue Ryder provides a self-referred approach for obtaining free counselling services of up to 6 online sessions. Sue Ryder Bereavement support sessions involve an online video assessment before the commencement of counselling sessions (48). Similarly, Cruse provides bereavement services and counselling for up to 6 sessions at their local branches. Individuals may self-refer to obtain such services, or perhaps might be referred by their GP as well. Cruse also provides online helplines to talk about grief, or a hotline to call when an individual is feeling unwell (49). Cruse has also partnered with Macmillan to form the Cruse Macmillan project, which aims to improve bereavement support for individuals impacted by cancer in Northern Ireland, by conducting a systematic analysis of available literature, providing cancer-specific bereavement services, hosting a podcast for further awareness. However, this project has concluded at the end of 2021, supporting 1124 bereaved individuals either online or in person, training 60 support volunteers, and decreasing 4% of people waiting to access bereavement support (50).For individuals who are severely depressed and at risk of suicide Samaritans provide support and hotlines for individuals who have suicidal thoughts (51). For children and younger adults, Winston's Wishes and Grief Encounter provides personalised counselling sessions and talk helplines for bereavement and grief.

Overall, there are available resources and avenues for bereaved individuals to seek counselling and other methods of psychological interventions. However, these interventions are limited due to their late and specific nature. Individuals are either referred when presenting with psychological distress that impacts QoL and is aware of it. Therefore, they might be referred to support services at crisis points when their life has been severely impacted by bereavement. Furthermore, the services provided are only targeted at psychological interventions, neglecting the impact of social support and other holistic approaches. Additionally, these services are not provided pre-bereavement and do not allow for a seamless transition and follow-up at the end of life to post-bereavement and post-intervention. Ideally, continuous follow-up and support throughout the entire process should be provided, monitor and screen for individuals at high risk for Prolonged Grief Disorder (PGD) and symptoms and provide early interventions to mitigate the impact of grief and bereavement.

The services discussed in this section did not have any specific naming conventions, with all charities naming their services literally, along the lines of "Bereavement Services" or "Grief counselling". Each service has a short description, mostly revolving around the goals of the service, and what benefits it may provide. Websites utilised a warm and informal language to advertise their programs and service, as well as familiar and easy-to-navigate visual content. Feedback from users was not published publicly.

Recommendations and Actions

After a review of the literature, there has been multiple guidelines, reviews, meta-analysis and novel papers providing well-validated theories, recommendations, programs, and approaches for improving the quality of life for individuals with cancer and/or bereaved by cancer. These approaches can range from physical or behavioural changes, resolving emotional needs, mental adjustments, preparing for death and therapies.

In the current pool of reviewed studies and guidelines, the ACCP Clinical Practice Guidelines have discussed the impact of exercise and sleep on bereaved individuals. Normal sleep patterns at 6 months have correlated with better emotional health. Better sleep was also associated with better immunological health and response. Consistent exercise at least once a week and attention to caloric intake was also correlated to better physical health (15). In a systematic review of bereaved individuals in the United Kingdom by Williams et al, the physical exercise provided benefits to bereaved individuals by reducing anxiety, depression, and PTSD while providing a platform to escape from grief, express their own emotions and have a sense of freedom (52). A study into individuals bereaved with cancer and who were depressed that cancer deaths were associated with depression, but only among those who switch from high activity to low activity later in the evening, after 2300 hours (B = 7.476, SD [B] = 2.284, *t*= 3.271, *pm*=.002). The authors suspect that the bereaved individuals may be preoccupying themselves to avoid dealing with their intrusive thoughts, sadness and guilt (14). Along with previous studies mentioned, it is recommended for bereaved individuals to continue with their daily routine, exercise, sleep and settle in earlier to improve their quality of life. Better quality of life allows individuals to retain their energy, social and physical functioning and enjoyment of life, to reduce depression.

By utilising multivariate hierarchical linear modelling, pre-loss and post-loss variables associated with QoL and depression in terminal oncological patients were analysed by Wen et al. Wen et al identified that post-loss social support was significantly associated with mental HRQoL in the first two years after bereavement. Additionally, stronger perception of social support significantly reduced bereaved caregivers' likelihood of severe depressive symptoms (AOR [95% CI] = 0.949 [0.925, 0.974]) and increased their mental HRQoL (β [95% CI] = 0.192 [0.153, 0.231]). Therefore, perceived social support was concluded to be a major factor associated with psychological outcomes in bereaved individuals (4). The benefit of social support originates from resolving emotional and informational unmet needs, resulting in positive associations with carer health. Instrument support coping style was a significant predictor for QoL. It has been suggested that various clinical and social caregiver programs may aid in caregiver quality of life, depression, grief and anxiety. Programs such as caregiver allowances for financial concerns, family caregiving leave and provision of a secondary caregiver to provide relief and caregiver health management programs, workspace flexibility or provision of caregiver facilities to provide ease of care (19) Furthermore, individuals with cancer who can seek advice, assistance and information usually have a higher level of QoL, resolve informational unmet needs and can make more informed choices (13). Carers' psychological morbidity was reduced when there was a GP and social care input, and hours of relaxation were higher as determined by multivariate analysis. Caregivers with input from GP and social care fared better, but carers who self-sought formal help fared worse, possibly because carers seek such help around crisis points (8). More hours at work were associated with better physical health, and more hour's volunteering was associated with reduced psychological morbidity. It is possible these activities provided an escape from caregiving duties and bereavement roles while sustaining active social behaviours. For individuals with cancer, living with others had a significant impact on improving quality of life and quality of death, due to improvements in perceived social support (53). Therefore, it is crucial for social support and social networks to continue during end-of-life caregiving and post-bereavement, allowing earlier interventions, a continuation of daily routine and relief from caregiving duties to improve the overall quality of life.

The most important area of support is still deemed to be emotional and psychological needs. As mentioned previously, psychological and emotional needs are among the highest unmet needs in caregivers, partners and individuals living with cancer. Issues arising from an existential crisis, fear of cancer spread, anxieties, worries about their family members, and unresolved achievements in life may afflict individuals approaching the end of life. 80% of caregivers have reported helping their families or friends with cancer deal with emotions, and a third reported providing emotional support to be the most difficult of caregiving. Therefore, the psychological burden of end of life is heavy on individuals living with cancer and their partners and caregivers. As a result, psychological therapies, preparing families for end of life and mental adjustments are crucial in easing psychological distress and improving the overall quality of life.

The benefits of mental adjustment have been well studied in individuals living with terminal cancer. Path modelling has shown that patient's mental adjustment, economic status, symptom severity, perceived disease severity and quality of life outcome, suggesting that the higher mental adjustment, the better quality of life among patients with terminal cancer (53). Better mental adjustment is indicated for decreased depression and anxiety with greater life satisfaction, establishing resources for coping. Individuals with cancer with higher levels of helplessness and hopelessness, as well as an anxious preoccupation with their illness, resulted in poorer quality of life. Anxiety as a cancer-specific coping response could foster other negative emotions and thought patterns resulting in a poor death. It could deter them from enjoying life, lessen their appreciation for positive aspects of existence, fostering anxiety regarding the end of life and death, resulting in maladjustments. Social support is a protective factor in mental adjustment, due to encouragement in living in the moment, optimism in survival and making use of family support and their associated support networks (53). Consequently, perception of self, disease, and symptom severity are important factors in improving psychological well-being for individuals living with cancer. Mental adjustment is dependent on the individual's attempt to regain control over the event and in life to re-establish self-esteem and a positive attitude towards life. Therefore, Rotter's theory of locus of control is extremely important in mental adjustment. High internal locus of control has been associated with better health habits, participation in screenings and improved psychological well-being after diagnosis. In a study by Brown et al, higher locus of control scores regarding chance, luck, fate and external factors resulted in lower FACT-G total scores, emotional and functional well-being scores, as well as increased anxiety, depression, decreased hope and spiritual wellbeing. This association was not seen when perceiving others in power (e.g., medical professionals) controlling their life. It was suggested that group therapy or interventions such as group therapy and psychoeducation that targeted empowerment and decreased the locus of control surrounding chance may positively impact the overall well-being of individuals with cancer by reducing pain, anxiety and depression. In other ways, by adjusting their perception of external locus of control regarding chance and luck or fate, the sense of powerlessness and decreased QoL associated with it may be decreased as well (11). Mental adjustments may also include the process of meaning reconstruction after bereavement. Results from Currier, Holland and Neimeyer supported the notion that a bereaved individual's interpretation of the loss is a larger factor in affecting a grief response, while sense-making is an important pathway in prolonged grief instead of the objective impact of death. Keesee, Currier and Neimeyer have shown that the inability to make sense of death is a strong predictor of grief severity in bereaved parents. Therefore, Lobb et al have suggested that attachment theory, constructivist and cognitive-behavioural concepts of binding purpose and meaning are crucial in bereavement (54).

The importance of mental adjustments and shifting perceptions could not be overstated. Not only does it pre-empt quality of life but can also provide increased resilience and preparedness. Shimizu et al accentuate the impact of resilience on depression symptoms and bereavement. In a sample of 71 bereaved caregivers, 47% of pre-loss and 15% of post-loss responses were classified as high risk for MDD. However, by classifying bereaved individuals into individuals with higher and lower resilience via the Connor-Davidson resilience scale and family APGAR, Shimizu et al were able to identify the benefits of higher resilience in the face of MDD. Among participants with a high risk of MDD, individuals with higher resilience alleviated depressive symptoms better than the lower resilience group. Therefore, individuals with greater pre-loss resilience improved and relieved depressive symptoms after bereavement. Despite the high risk for pre-loss MDD, the more resilient individuals, the lesser there are of depressive symptoms However, pre-loss resilience is not associated with post-loss complicated grief. The authors concluded that resilience acts proactively against psychological distress to promote recovery, but not growth (23).

Preparedness has been a key theme in multiple novel papers and systematic reviews in reducing complicated grief, as well as depression. Hierarchical general linear modelling has revealed that perceived preparedness for the death of a loved one concurrently and prospectively predicted better adjustment to bereavement (34). Of individuals bereaved by cancer, 5.6% reported they were not all, 50.0% somewhat and 44.4% a lot prepared for the death of their spouse Stahl et al. Therefore, a significant of individuals were aware of approaching the end of life, possibly allowing pre-loss grief to occur. However, being aware of death and being prepared for death are separate paths. Nearly half of the bereaved cancer spouses were not emotionally prepared for the death of their loved one, impacting depression symptoms after bereavement (55). Individuals who lost their spouses to cancer were more depressed ($F = 6.46$, $p = .01$) and tended to experience greater grief levels ($F = 3.49$, $p = .06$) than those whose spouses were lost to other causes (56). More importantly, cancer-bereaved individuals who expected death were likely to experience bereavement outcomes and distress comparable to those individuals whose partners died unexpectedly. Loneliness among individuals bereaved by cancer did not differ between expected or unexpected deaths, while depression and grief were higher in unexpected cases. Similarly, the importance of death preparation was illustrated by Mah et al. Greater death preparation was related to less grief at patient death (past TRIG: $\beta = -.25$, $p = .04$), less current grief (present TRIG: $\beta = -.26$, $p = .03$), less complicated grief (PG-13: $\beta = -.37$, $p = .001$), and less depression (CESD-10: $\beta = -.35$, $p = .005$). Greater symptom control was related to less current grief (present TRIG: $\beta = -.27$, $p = .02$), less complicated grief (PG-13: $\beta = -.24$, $p = .03$), and less depression (CESD-10: $\beta = -.29$, $p = .01$) (22). Using multivariable analysis, Nielsen et al have also found that only low preparedness predicted prolonged grief symptoms (42). In conclusion, unpreparedness was associated with either independent or co-morbid symptoms of prolonged grief and major depressive disorder.

Therefore, preparedness is crucial in improving quality of life and reducing psychological morbidity and depressive symptoms. High preparedness may come in many forms. Nielsen et al state that high preparedness implies that caregivers are addressing practical issues such as financial affairs, as well as emotional responses to the *impending* loss (57). Preparedness may also imply better and individualised communication of prognostic information, and patient and caregiver outcomes at the end of life. Bereaved caregivers who accurate understood their loved one's prognosis were less likely to be in the transient-reaction, prolonged-symptomatic, and chronically-distressed depressive-symptom trajectories (58). In terms of medical and social support, preparedness may also indicate the provision of coping skills training, incorporation of a spirituality or meaning-based component in bereavement programs, discussion and involvement of caregivers in end-of-life trajectories, awareness of bereavement outcomes such as depressive or grief symptoms and provision of grief therapy may be helpful. Training in caregiving activities and bereavement can be utilised to promote positive outcomes, increase caregiving confidence and diminish negative feelings, as caregivers have done their best in the caring process (24). Psychometric screening of prolonged grief may also be beneficial. For families, greater connection to their loved ones nearing the end of life was associated with less grief. Meaningful communication such as saying goodbye was associated with better outcomes in depression and complicated grief for family members, instead of being present for death (59). Therefore, family involvement, presence and support towards the end of life are crucial for both individuals with cancer and all involved parties alike. Families often indicate the importance of spending time together and saying goodbye. Consequently, the facilitation of social interactions with loved ones and their presence at the moment of death may be beneficial in preparing for death and reducing negative post-bereavement outcomes.

Preparedness for death was associated with a longer awareness time, advanced financial planning, understanding and acceptance of impending death, participation in palliation, lower depressive and anxiety symptoms, higher active coping, less intense emotional management and higher levels of household management (21). Overall, better patient preparedness for death was associated with less caregiver distress and bereavement. Similarly, better caregiver preparedness also ensured better end-of-life quality and support. Despite the knowledge of the importance of preparing for death, bereaved families and caregivers have reported that they are not adequately supported or emotionally prepared for death (60). As a result, 18% to 48% of family members displayed heightened levels of bereavement-related psychological distress years after the death of a loved one from cancer.

With high rates of bereavement and prolonged psychological impact, there have been multiple therapeutic approaches discussed, applied and tested to determine the best method of supporting bereaved individuals. In an initial meta-analysis of randomised controlled trials by Currier, Niemeyer and Berman, the efficacy of therapy for bereavement was limited. After a review of 61 studies, the authors concluded that interventions post-bereavement had a small effect on individuals' self or clinically referred. However, interventions did not yield effect sizes significantly greater than zero at follow-ups, indicating that there was no benefit at follow-up. However, interventions that aided bereaved individuals who had displayed maladaptive coping had the greatest impact and outcomes compared to psychotherapies for other difficulties. The meta-analysis discusses the limitation of multiple measurements paying a lack of attention to the grief and restoration process, therefore unable to prove any new improvements in many of the studies, or perhaps ignoring the overall benefits of these interventions (61). Contrary to Currier, Niemeyer and Berman, a meta-analysis by Wittouck et al concluded that treatment grief interventions are efficacious in short- and long-term alleviation of complicated grief symptoms. Therefore, individuals displaying complicated grief symptoms should undergo treatment. However, the preventive intervention of complicated grief lacked effectiveness after the application of the intervention. Preventive intervention for complicated grief may evolve into a negative but non-significant effect in follow-ups. However, the lack of or limited effects of prevention do not imply a complete lack of benefit. Due to the age of the study and the fact that prolonged grief was not indicated in the DSM-V, Wittouck et al's study had multiple limitations (62). Recently in 2019, Johannsen et al conducted a review of the established literature regarding interventions for bereaved individuals, with a more stringent search criterion. As Currier et al included adolescents and adults, bereavement-related reactions (e.g., depression, PTSD) but not grief specifically, without official DSM-V diagnostic criteria and including dissertations or unpublished studies, a new review and meta-analysis were required. The authors discovered a positively significant effect of interventions on grief. Johannsen et al revealed larger effect sizes in their meta-analysis compared to Currier, Niemeyer and Berman's meta-analysis, suggesting robustness in the short-term efficacy of psychological treatments. However, their study echoed Wittouck's study, suggesting that longer-term efficacy may not be as robust or certain. More importantly, Johannsen et al suggested that bereaved individuals who are identified via PG-13/ICG-R 6 months post-bereavement might experience psychological effects. However, the authors did not find a correlation between a larger therapeutic effect and higher PGD symptoms. They also discovered larger effect sizes in individual interventions than in group-based interventions (63). The notion that individualised therapy is supported by the current established literature. Group-based Compassion Focus Therapy was not efficacious for individuals displaying prolonged grief symptoms, suggesting that group delivery may be less than optimal methodology (64). Work by Maas et al also concluded that group-based grief interventions are weak with a small effect size post-intervention and a non-significant effect in follow-ups. A study by Johnsen, Dyregrove and Dyregrov also confirm that participants in group interventions reported less satisfaction in those sessions and fewer improvements in QoL post-intervention (65). Therefore, recent relevant studies have indicated that psychological interventions have a statistically positive beneficial effect on complicated grief post-bereavement, with further possible benefits post-intervention and in the long term.

A recent review by Enez in 2017 has summarised and compared the efficacy of various psychological intervention methodologies. By comparing cognitive-behaviour therapy (CBT), interpersonal therapy (IPT), complicated grief therapy/traumatic grief therapy (TGT), narrative intervention, supportive counselling, writing therapy and group therapy, Enez concluded overall short-term and long-term positive outcomes for bereaved individuals, which are in line with Wittouck et al's meta-analysis. Additionally, Enez found a positive impact of these interventions on depression and anxiety, not only complicated grief. Enez interprets the lack of effectiveness in preventative interventions and small effect sizes from interventions provided immediately after death were a sign that alleviation of symptoms follows a natural healing process over time, possibly without any professional help. More specifically, Enez found that complicated grief therapy/traumatic grief therapy was superior to interpersonal therapy. However, the author did not indicate which was the most superior methodology. CGT/TGT, CBT and writing therapy was popular psychological interventions that were investigated and validated. As this review is similar to Wittouck et al's study, it also holds the same limitations of not having an official diagnostic criterion for CGD at the time of writing, with small sample sizes and older studies. Therefore, it also echoes previous systematic reviews and meta-analyses (66).

To complement Enez's review, a primer on PGD has compared and evaluated multiple interventions for PGD (67). CGT was stated to be the gold standard for treating PGD symptoms, displaying high levels of efficacy in studies with sufficient sample sizes. CGT may also be delivered individually or in a group setting. Overall, CGT incorporates seven core goals: providing informational support for bereaved individuals to understand and accept grief, manage emotional pain and symptoms, reconnect with others, look ahead to the future, learn to live with reminders, and connect with their memories and telling stories of the death. Similarly, CBT is a popular method of intervention for individuals with PGD, showing efficacy in reducing grief outcomes and promoting re-engagement in self-care. However, CBT is recommended to target symptoms displayed concurrently with PGD, such as sleep disturbance, insomnia, stimulus control and possibly depressive symptoms.

In the context of cancer or palliative bereavement, individual studies have all found positive benefits to prolonged grief symptoms and disorders. Family group therapy was found to reduce the severity and development of prolonged complicated grief, especially in low-communicating and high-conflict families. Low-communicating families who had family therapy reported the most benefit, with better outcomes in families who had ten sessions of interventions instead of six sessions. It is interesting to note that out of 91% of families who began family therapy, only half completed all sessions (68). In a novel cancer bereavement group utilising CBT, CFT and CT-PTSD, grief intensity, PTSD, depression and anxiety were reduced after the intervention, while self-compassion increased. However, in the long-term, the reduction in anxiety and increase in self-compassion were not maintained. Bereavement therapy only improved grief intensity, PTSD symptoms and depression in the long run, with larger effect sizes than Currier, Neimeyer and Berman's report. It is important to note that in this study, this intervention was developed by a charity, with high uptake by visitors, with low attrition, suggesting high acceptability of the program (69). In another study utilising Family Strengths-Oriented Therapeutic Conversation (FAM-SOTC), cancer bereaved individuals experienced decreased anxiety and stress, with decreased grief reactions than controls, suggesting a positive impact on psychological distress. The study also revealed key insights into the importance of relationships between patients and family caregivers and support systems. The quality of therapeutic relationships is important in empowering family members in coping. Furthermore, involving bereaved caregivers in therapeutic interventions before and after the loss of a close relative is important, as cancer may hide grief, suffering and reduction in quality of life after bereavement. Therefore, support before and during the death of their loved one is crucial for their post-bereavement quality of life (60). This finding and recommendation are echoed by Thomas et al, who suggested screening via PG-13 pre-loss version instrument to identify individuals who might be at high risk of prolonged grief and to provide support before bereavement, as they might already be experiencing high levels of stress (39).

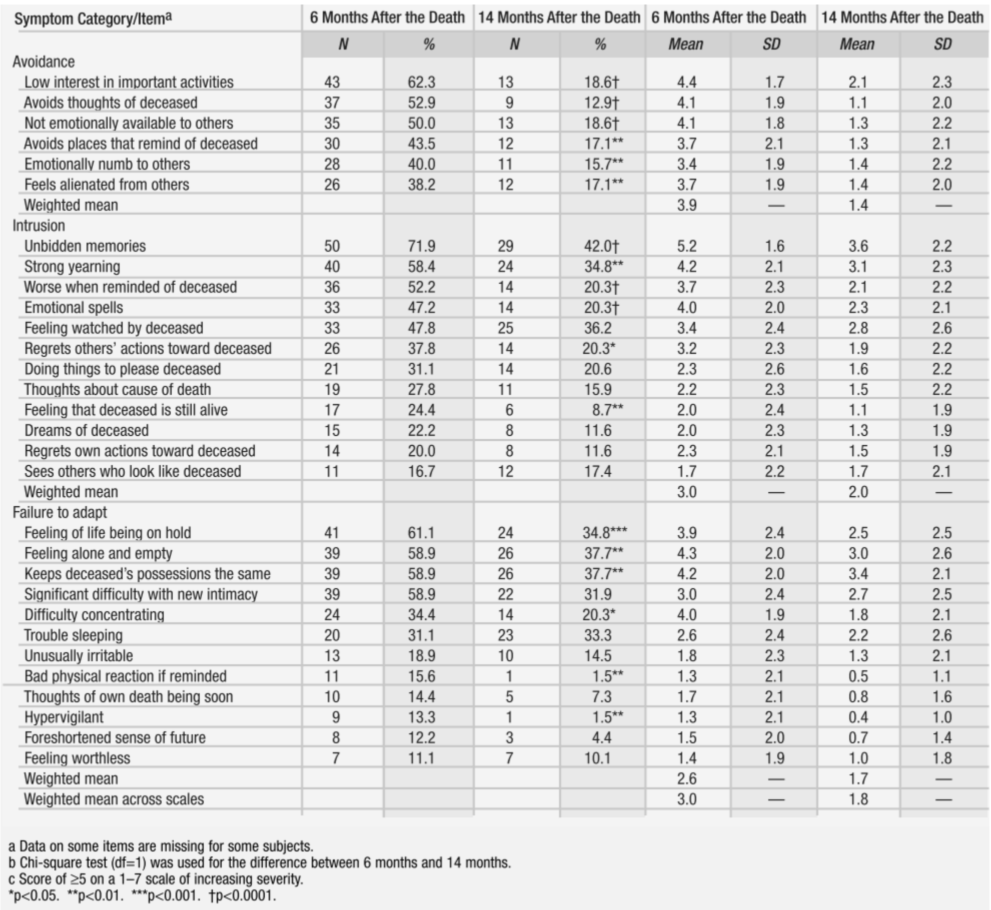
Other recommendations include the ability to contact other cancer-bereaved families to receive information and support, supportive contact from hospital staff, formal supportive services and social support from friends after bereavement from cancer (32). Recommendations by ACCP have encouraged sufficient forewarning to all parties that death is pending, as anticipatory grief is not correlated to post-bereavement grief, it is important to allow families to talk about death and begin the process of grieving. If possible, providing notice of imminent death to be present is also helpful in preventing guilt of not being present at death. Discussion of existential crisis in loved ones as well as individuals with cancer is important in preventing anxiety or depression. More importantly, following up with bereaved individuals is important to assess for maladaptive coping (15). Support may also come in teaching bereaved individuals how to utilise their social networks, developing strategies for dealing with grief and providing informational support (41).

To summarise, prevention of grief is not possible via psychological interventions, as described by the dual processing model and attachment theories. However, it is possible to mitigate maladaptive coping of grief, to prevent harm to a bereaved individual’s quality of life. The longer-term impact of the intervention might not be as clear, due to natural coping over time. However, the short-term impact of therapy is evident and robust, showing significant positive benefits to bereaved individuals who are maladaptive in coping with grief. Individual therapy was preferred over group therapy; however, it is crucial to ensure social interactions and support are introduced in other aspects of life. Although prevention is not possible, it is possible to identify individuals with high risks, provide immediate psychological support and systems of support to reduce maladaptive coping and improve the quality of life for bereaved individuals and end-of-life quality for individuals with cancer.

Diagnosis Instruments

As prevention is not possible, and mitigation is ideal, early identification of PGD and high-risk individuals are crucial in supporting bereaved individuals and individuals at the end of life. As bereaved individuals may not be aware that they are not coping healthily, it is important to screen for prolonged grief symptoms pre-loss and 6 months after bereavement by asking caregivers how they are coping (40).

An initial diagnostic criterion was proposed by Horowitz et al in 2003, with the assertions that individuals with complicated grief disorder would extremely have loneliness, avoidance of tasks associated with the decedent, disrupted sleeping, loss of interest in personal activities, severe emotions and intrusive thoughts more than a year after the loss. A minimum of three of the seven possible symptoms must be present for a diagnosis of CGD, at 6 or 14 months post bereavement (67). Despite the work by Horowitz et al, prolonged grief disorder was not recognised in common diagnostic criteria such as the DSM-4 and ICD-10. However, recently in 2021 and 2022, PGD has been incorporated into the ICD-11 and DSM-5 diagnostic instruments, based on the progress by Horowitz et al. Additionally, a prolonged grief disorder -13 (PG-13) instrument has also been utilised to assess prolonged grief disorders.



Symptom Category/Item[a]	6 Months After the Death		14 Months After the Death		6 Months After the Death		14 Months After the Death	
	N	*%*	*N*	*%*	*Mean*	*SD*	*Mean*	*SD*
Avoidance								
Low interest in important activities	43	62.3	13	18.6†	4.4	1.7	2.1	2.3
Avoids thoughts of deceased	37	52.9	9	12.9†	4.1	1.9	1.1	2.0
Not emotionally available to others	35	50.0	13	18.6†	4.1	1.8	1.3	2.2
Avoids places that remind of deceased	30	43.5	12	17.1**	3.7	2.1	1.3	2.1
Emotionally numb to others	28	40.0	11	15.7**	3.4	1.9	1.4	2.2
Feels alienated from others	26	38.2	12	17.1**	3.7	1.9	1.4	2.0
Weighted mean					3.9	—	1.4	—
Intrusion								
Unbidden memories	50	71.9	29	42.0†	5.2	1.6	3.6	2.2
Strong yearning	40	58.4	24	34.8**	4.2	2.1	3.1	2.3
Worse when reminded of deceased	36	52.2	14	20.3†	3.7	2.3	2.1	2.2
Emotional spells	33	47.2	14	20.3†	4.0	2.0	2.3	2.1
Feeling watched by deceased	33	47.8	25	36.2	3.4	2.4	2.8	2.6
Regrets others' actions toward deceased	26	37.8	14	20.3*	3.2	2.3	1.9	2.2
Doing things to please deceased	21	31.1	14	20.6	2.3	2.6	1.6	2.2
Thoughts about cause of death	19	27.8	11	15.9	2.2	2.3	1.5	2.2
Feeling that deceased is still alive	17	24.4	6	8.7**	2.0	2.4	1.1	1.9
Dreams of deceased	15	22.2	8	11.6	2.0	2.3	1.3	1.9
Regrets own actions toward deceased	14	20.0	8	11.6	2.3	2.1	1.5	1.9
Sees others who look like deceased	11	16.7	12	17.4	1.7	2.2	1.7	2.1
Weighted mean					3.0	—	2.0	—
Failure to adapt								
Feeling of life being on hold	41	61.1	24	34.8***	3.9	2.4	2.5	2.5
Feeling alone and empty	39	58.9	26	37.7**	4.3	2.0	3.0	2.6
Keeps deceased's possessions the same	39	58.9	26	37.7**	4.2	2.0	3.4	2.1
Significant difficulty with new intimacy	39	58.9	22	31.9	3.0	2.4	2.7	2.5
Difficulty concentrating	24	34.4	14	20.3*	4.0	1.9	1.8	2.1
Trouble sleeping	20	31.1	23	33.3	2.6	2.4	2.2	2.6
Unusually irritable	13	18.9	10	14.5	1.8	2.3	1.3	2.1
Bad physical reaction if reminded	11	15.6	1	1.5**	1.3	2.1	0.5	1.1
Thoughts of own death being soon	10	14.4	5	7.3	1.7	2.1	0.8	1.6
Hypervigilant	9	13.3	1	1.5**	1.3	2.1	0.4	1.0
Foreshortened sense of future	8	12.2	3	4.4	1.5	2.0	0.7	1.4
Feeling worthless	7	11.1	7	10.1	1.4	1.9	1.0	1.8
Weighted mean					2.6	—	1.7	—
Weighted mean across scales					3.0	—	1.8	—

a Data on some items are missing for some subjects.
b Chi-square test (df=1) was used for the difference between 6 months and 14 months.
c Score of ≥5 on a 1–7 scale of increasing severity.
*$p<0.05$. **$p<0.01$. ***$p<0.001$. †$p<0.0001$.

Table 2: Symptoms of Complicated Grief in 70 Subjects 6 months and 14 months After the Death of a Spouse (67)

Overall, the ICD-11 and DSM-5-TR prolonged grief disorder criteria have multiple overlaps, with DSM-5-TR having more stringent criteria for diagnosis. PGD in the DSM-5 requires the death of the loved one to occur at least a year before diagnosis, instead of 6 months earlier. DSM-5 also requires at least three other listed symptoms to reoccur almost daily for the past month, with a more specific list of symptoms displayed. The DSM-5 requires the differential diagnosis of MDD, PTSD, other mental disorders or substance abuse to be excluded as well. Therefore there have been some criticisms of the DSM-5-TR (70). Initial plans by the American Psychiatric Association categorised PGD as a depressive disorder, which was criticized by clinicians and recommended it to be re-categorised as a trauma and stressor-related disorder. Clinicians have also criticised the 12-month timing criterion and recommended that it be shortened to 6 months. Furthermore, they asserted that the 12-month criterion ignores elevated PGD symptoms in the first few months post-bereavement, which may predict chronic grief trajectories, PTSD, depression and PGD. Clinicians added that DMS-5-TR's exclusion criteria of differential diagnosis may result in PGD being mistaken for a better-known disorder, resulting in underdiagnosing of PGD and the application of incompatible therapy. The authors have also raised concerns regarding the lack of inclusion of difficulties moving on, preoccupation, loneliness and disbelief by the ICG, ICG-R and PG-13 instruments. Finally, there are concerns regarding the three out of eight cut-offs for the DSM-5. With a high stringency, clinicians are worried it may lower the prevalence of PGD, in combination with the timing criteria. Therefore, the DSM-5-TR should be utilised with caution, with a possible inclination for the PG-13 or ICD-11 instruments instead.

There also have been critiques against the ICD-11 instrument, with researchers stating that the validity of the ICD-11 PGD criteria must be confirmed. As the ICD-11 PGD criteria utilise symptoms not found in any proposed criteria set in the literature, such as guilt and blame. The generic language in the ICD-11 PGD criteria was criticised. Blame could refer to self-blame, other blame, blame for the deaths or any other reason. Interpretation of blame by the clinician influences the prevalence of PGD. Similarly, different interpretation of longing and pre-occupation by clinicians also affects the prevalence and diagnosis of PGD. The ICD-11 PGD criteria were also criticised to be extremely liberal minimal criteria, leading to higher prevalence rates compared to the DSM-5. Therefore, standardisation and clarity of interpretation are crucial to maintaining a uniform approach to diagnosing PGD. The authors have suggested utilising multiverse analysis to find a medium compromise that is valid among all interpretations (71).

However, overall the DSM-5-TR and PG-13-R criteria have been validated to be reliable and valid measures for bereaved individuals with maladaptive grief responses in multiple data sets (72). The authors found that the weakest performing item on all data sets was the "avoidance of reminders that the deceased is dead" as the removal of that factor resulted in an improvement of Cronbach's alpha in two datasets. Factor analysis confirmed the high internal consistency of PG-13-R symptom items and further analysis confirmed that a PG-13-R symptom score of 30 was the optimal threshold for all data sets studied. Therefore, PG-13-R and DMS-5-TR are reliable and valid tools for the diagnosis of PGD symptoms and the identification of maladaptive grief responses.

Self-screening questionnaires have also been suggested, with the PG-13 being the most common and popular instrument. The PG-13 is a thirteen-item self-reported questionnaire that explores feelings, thoughts and actions over the past month. Questions aim to identify the frequency of distress, emotional pain and yearning. To qualify for a diagnosis, it adheres to the principles stated by the ICD-11, with the listed emotions being displayed almost every day for half a year and bringing impairment in social, occupation or other areas of functioning (73). Overall, the PG-13 instrument mimics the ICD-11 diagnostic criteria, displaying high levels of reliability (Cronbach's α=0.84–0.92) with high validity and demonstrated construct (67). A shorter tool such as the five-item Brief Grief Questionnaire (BGQ) is available, presenting with good internal consistency (Cronbach's α=0.82), being able to discriminate grief-related symptoms from general distress. The BGQ utilises a linear score, where a score greater than or equal to 8 indicated probable PGD, and a score between 5 to 7 indicates subthreshold PGD. A longer tool such as the 19-item measure Inventory of Complicated Grief (ICG) is also available to assess the severity of PGD symptoms. ICG has extremely high internal consistency (Cronbach's α=0.94) and convergent validity. A clinical cut-off of greater or equal to 25 indicates grief with significant QoL impact.

Evaluation and summary

Throughout the report, the prevalence, determinants, causes, associations of grief, bereavement and unmet needs were identified and discussed. Furthermore, possible psychological interventions and methods of support were evaluated and suggested.

In terms of support for individuals with cancer and bereaved individuals, the role of preparation, intervention and awareness of grief, bereavement and psychological distress is crucial. Although grief cannot be prevented, it is beneficial to have interventions and support for families and the patient towards the end of life to reduce negative QoL impacts. The goal should be to mitigate maladaptive coping mechanisms in all parties, to allow better end-of-life quality for individuals with cancer and quality of life for bereaved individuals. Before bereavement, Family group therapy may alleviate the existential crisis, prevent severe emotional responses and allow a better quality of life and death for all parties involved. More importantly discussion of death, achievements in life and allowing meaningful communication are helpful in palliative patients and their families. Informational support regarding prognosis and involvement of families in end-of-life decisions may alleviate burdens of guilt, provide families with the feeling that they have done all they could, as well as improve the quality of death by informing medical decisions. Furthermore, providing informational support in avenues to obtain help is important in allowing self-referral to psychological support before crisis points for all parties. By utilising therapy, individuals can mentally adjust and cope with death, improving resilience, acceptance and future planning.

Post bereavement, grief is inevitable. However, symptomatic alleviation can improve quality of life and prevent progression into prolonged grief. Therefore, it is important to provide screenings for individuals with high risks for prolonged grief via the PG-13-R or ICD-11 and provide avenues for psychological interventions and support early as they already might be experiencing high levels of distress. Individual CGT/TGT therapy is preferred and can be coupled with CBT to reduce depression and other symptoms that might present along with PGD. Online therapy is efficacious, and writing therapy is also a possible efficacious intervention. Prolonged grief symptoms may be displayed quickly after bereavement, however, may also linger for up to a year or more after. While grief may subside, general stress will increase. Therefore, long-term monitoring and follow-up might be helpful, as long-term impacts are not well quantified and characterised. Social support and follow-up outside of therapy are crucial in bereaved individuals but are commonly overlooked. Meeting other bereaved families may help in coping, as well as maintaining their social network. Bereaved individuals need to maintain a daily schedule and continue with daily activities to improve physical, social and emotional function.

By providing holistic support through social avenues, and psychological avenues, early in the palliation process, individuals with cancer can resolve their inner conflicts, reduce psychological distress and achieve a better quality of death, while planning for events after their death. Bereaved individuals will also benefit, from being able to find support earlier, construct a new social support network, maintain daily functions and look forward to the future. Therefore, it cannot be understated the importance of support and screening pre-bereavement, ensuring seamless support throughout bereavement and following post-intervention.

The Value of Maggie’s

With less than half of bereaved individuals contacted about emotional coping and most bereaved individuals feeling unprepared for death, the burden of bereavement remains high. With an overwhelmed health care system, preparation for death and resolving psychological distress are still overlooked aspects in oncological patients.

However, Maggie’s Centres are in a unique position to be able to support individuals at the end of life and their family members in bereavement. Maggie’s centres can provide social, psychological and informational support for bereaved individuals and individuals at the end of life, fulfilling their unmet needs to improve their quality of life and at end of life.

First, Maggie’s centres can foster long-standing relationships with its visitors. Due to its architectural design and ethos, individuals are welcomed in without appointments into a warm and comforting environment. Frequent visitors are able to connect with centre staff over time and allow a therapeutic alliance to grow. This allows visitors to feel more at ease at accessing services and support before crisis points. The importance of therapeutic alliances and early intervention has been long discussed in this paper. With greater alliance and awareness, staff can signpost and provide visitors with support services such as counselling, bereavement groups, informational resources or social activities. Staff can provide early intervention and screenings frequently to identify high-risk individuals, allowing earlier individualised support. Additionally, with close support, staff can facilitate familial discussions about death, existential conflicts, worries, anxiety about family, and looking toward the future.

Second, Maggie’s are able to be present from pre-bereavement to post-bereavement process. A key challenge of support involves the seamless transition between both processes. By being present in pre-bereavement, Maggie’s able to continue following up throughout the entire process to identify the earliest point when individuals require interventions and help. With post-bereavement services, Maggie’s may redirect visitors to bereavement services after the death of their loved ones. Screening can be conducted frequently, and visitors can be followed up at routine intervals to determine their quality of life and PGD symptoms. Specific programs may be created to have a pathway/journey for individuals with cancer and their families upon an end-of-life diagnosis. Therefore, psychological interventions may flow seamlessly to address changing unmet needs and fluctuating psychological distress levels.

Third, Maggie’s is not limited to just psychological or informational support. Maggie’s is a physical space for visitors to foster communities. As social support is frequently undermined and diminished post-bereavement, visitors can make spontaneous friendships and expand their social network to encourage normal functioning, as well as improve social support. The spontaneous nature allows connections to form outside of therapeutic contexts, improving the variety of friendships and connections that might be made.

All of the support required by individuals with cancer at the end of life and bereaved individuals are provided by the living with ongoing cancer program. With “Where Now?”, “Financial, Vocational and Benefits advice” and individuals, couple and family sessions with cancer support specialists or psychology sessions, all parties are able to access support throughout different phases of bereavement, ensuring minimal maladaptive coping and negative impact to the quality of life and death.

Conclusion

In conclusion, psychological and social support for cancer patients at end of life and bereaved individuals is commonly overlooked and underprovided. Although research in these areas is limited and is a growing field, psychological interventions and social support are certainly integral in improving the quality of life for bereaved individuals and their families. With an overly burdened healthcare system, Maggie's centres are in a unique and critical position in providing support for individuals facing the end of life and their families. By providing a physical warm and welcoming location with experienced staff, Maggie's has inherent value in providing seamless support pre-bereavement to post-bereavement, improving quality of life and end-of-life quality for all parties. Therefore, Maggie's must continue their development and expansion of their living with ongoing cancer programs to ensure individuals at end of life can have the best quality of life, and support bereaved individuals in regaining normal social, emotional and physical function after bereavement.

References

1. Cancer Research UK. Cancer Research UK Cancer incidence statistics [Internet]. CancerResearchUK. 2020 [cited 2022 Jul 18]. Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero

2. Gao W, Bennett MI, Stark D, Murray S, Higginson IJ. Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. Eur J Cancer. 2010 Jul 1;46(11):2036–44.

3. Lambert SD, Harrison JD, Smith E, Bonevski B, Carey M, Lawsin C, et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. BMJ Support Palliat Care. 2012;2(3):224–30.

4. Wen FH, Chou WC, Chen JS, Chang WC, Hsieh CH, Shen WC, et al. Associations of preloss and postloss factors with severe depressive symptoms and quality of life over the first 2 years of bereavement for family caregivers of terminally ill cancer patients. Psychooncology [Internet]. 2019 Nov 1 [cited 2022 Jul 18];28(11):2157–65. Available from: https://onlinelibrary-wiley-com.libproxy.ucl.ac.uk/doi/full/10.1002/pon.5201

5. Kim Y, Shaffer KM, Carver CS, Cannady RS. Quality of life of family caregivers 8 years after a relative's cancer diagnosis: Follow-up of the National Quality of Life Survey for Caregivers. Psychooncology [Internet]. 2016 Mar 1 [cited 2022 Jul 18];25(3):266–74. Available from: https://onlinelibrary-wiley-com.libproxy.ucl.ac.uk/doi/full/10.1002/pon.3843

6. Wang T, Molassiotis A, Chung BPM, Tan JY. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. BMC Palliat Care [Internet]. 2018 Jul 23 [cited 2022 Jul 18];17(1):1–29. Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-018-0346-9

7. McCaffrey N, Bradley S, Ratcliffe J, Currow DC. What Aspects of Quality of Life Are Important From Palliative Care Patients' Perspectives? A Systematic Review of Qualitative Research. J Pain Symptom Manage [Internet]. 2016 Aug 1 [cited 2022 Jul 18];52(2):318-328.e5. Available from: http://www.jpsmjournal.com/article/S0885392416300781/fulltext

8. Grande G, Rowland C, Cotterill S, Batistatou E, Hanratty B. Factors associated with carer psychological and physical health during end-of-life caregiving: An observational analysis of a population-based post-bereavement survey of carers of people with cancer. BMJ Open [Internet]. 2021 Oct 1 [cited 2022 Jul 18];11(10):e047275. Available from: https://bmjopen.bmj.com/content/11/10/e047275

9. Cochrane A, Woods S, Dunne S, Gallagher P. Unmet supportive care needs associated with quality of life for people with lung cancer: A systematic review of the evidence 2007–2020. Eur J Cancer Care (Engl) [Internet]. 2022 Jan 1 [cited 2022 Jul 18];31(1):e13525. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/ecc.13525

10. Lisy K, Langdon L, Piper A, Jefford M. Identifying the most prevalent unmet needs of cancer survivors in Australia: A systematic review. Asia Pac J Clin Oncol [Internet]. 2019

Oct 1 [cited 2022 Jul 18];15(5):e68–78. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/ajco.13176

11. Brown AJ, Thaker PH, Sun CC, Urbauer DL, Bruera E, Bodurka DC, et al. Nothing left to chance? The impact of locus of control on physical and mental quality of life in terminal cancer patients. Support Care Cancer [Internet]. 2017 Jun 1 [cited 2022 Jul 18];25(6):1985–91. Available from: /pmc/articles/PMC5412077/

12. Zhang B, Nilsson ME, Prigerson HG. Factors Important to Patients' Quality of Life at the End of Life. Arch Intern Med [Internet]. 2012 Aug 13 [cited 2022 Jul 18];172(15):1133–42. Available from: https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/1212631

13. Bovero A, Leombruni P, Miniotti M, Rocca G, Torta R. Spirituality, quality of life, psychological adjustment in terminal cancer patients in hospice. Eur J Cancer Care (Engl) [Internet]. 2016 Nov 1 [cited 2022 Jul 18];25(6):961–9. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/ecc.12360

14. Stahl ST, Neagoe I, Smagula SF, Posluszny D, Bovbjerg DH. Cancer Bereavement and Depression Symptoms in Older Spouses: The Possible Modifying Role of the Circadian Rest-Activity Rhythm. Clin Gerontol [Internet]. 2021 [cited 2022 Jul 18];44(2):126–32. Available from: /pmc/articles/PMC7886956/

15. Griffin JP, Koch KA, Nelson JE, Cooley ME. Palliative care consultation, quality-of-life measurements, and bereavement for end-of-life care in patients with lung cancer: ACCP evidence-based clinical practice guidelines (2nd edition). Chest [Internet]. 2007 Sep 1 [cited 2022 Jul 18];132(3 SUPPL.):404S-422S. Available from: http://journal.chestnet.org/article/S0012369215355331/fulltext

16. Lo RSK, Woo J, Zhoc KCH, Li CYP, Yeo W, Johnson P, et al. Quality of life of palliative care patients in the last two weeks of life. J Pain Symptom Manage [Internet]. 2003 Oct 1 [cited 2022 Jul 18];24(4):388–97. Available from: http://www.jpsmjournal.com/article/S0885392402005043/fulltext

17. Bernard M, Berchtold A, Strasser F, Gamondi C, Borasio GD. Meaning in life and quality of life: palliative care patients versus the general population. BMJ Support Palliat Care [Internet]. 2020 Jul 6 [cited 2022 Jul 18];0:bmjspcare-2020-002211. Available from: https://spcare.bmj.com/content/early/2020/07/05/bmjspcare-2020-002211

18. Rowland C, Hanratty B, Pilling M, Van Den Berg B, Grande G. The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. Palliat Med [Internet]. 2017 Apr 1 [cited 2022 Jul 18];31(4):346–55. Available from: /pmc/articles/PMC5406012/

19. Song JI, Shin DW, Choi JY, Kang J, Baek YJ, Mo HN, et al. Quality of life and mental health in the bereaved family members of patients with terminal cancer. Psychooncology [Internet]. 2012 Nov 1 [cited 2022 Jul 18];21(11):1158–66. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pon.2027

20. Aoun SM, Rumbold B, Howting D, Bolleter A, Breen LJ. Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. PLoS One [Internet]. 2017 Oct 1 [cited 2022 Jul 18];12(10). Available from:

/pmc/articles/PMC5627900/

21. Treml J, Schmidt V, Nagl M, Kersting A. Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: A systematic review. Soc Sci Med. 2021 Sep 1;284:114240.

22. Mah K, Swami N, Pope A, Earle CC, Krzyzanowska MK, Nissim R, et al. Caregiver bereavement outcomes in advanced cancer: associations with quality of death and patient age. Support Care Cancer [Internet]. 2022 Feb 1 [cited 2022 Jul 18];30(2):1343–53. Available from: /pmc/articles/PMC8426162/

23. Shimizu Y, Hayashi A, Maeda I, Miura T, Inoue A, Takano M, et al. Changes in depressive symptoms among family caregivers of patients with cancer after bereavement and their association with resilience: A prospective cohort study. Psychooncology [Internet]. 2022 Jan 1 [cited 2022 Jul 18];31(1):86–97. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5783

24. Kustanti CY, Chu H, Kang XL, Huang TW, Jen HJ, Liu D, et al. Prevalence of grief disorders in bereaved families of cancer patients: A meta-analysis. Palliat Med [Internet]. 2022 Feb 1 [cited 2022 Jul 18];36(2):305–18. Available from: https://journals.sagepub.com/doi/10.1177/02692163211066747?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed

25. Chiu YW, Huang CT, Yin SM, Huang YC, Chien CH, Chuang HY. Determinants of complicated grief in caregivers who cared for terminal cancer patients. Support Care Cancer [Internet]. 2010 Oct 9 [cited 2022 Jul 18];18(10):1321–7. Available from: https://link.springer.com/article/10.1007/s00520-009-0756-6

26. Tomarken A, Holland J, Schachter S, Vanderwerker L, Zuckerman E, Nelson C, et al. Factors of complicated grief pre-death in caregivers of cancer patients. Psychooncology [Internet]. 2008 Feb [cited 2022 Jul 18];17(2):105–11. Available from: /pmc/articles/PMC2515552/

27. Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin MB. Preloss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study. Psychooncology [Internet]. 2017 Dec 1 [cited 2022 Jul 18];26(12):2048–56. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pon.4416

28. Young SR, Young HY, Park S, Dong OS, Kwang ML, Han JY, et al. Depression in family caregivers of cancer patients: The feeling of burden as a predictor of depression. J Clin Oncol. 2008 Dec 20;26(36):5890–5.

29. Nanni MG, Biancosino B, Grassi L. Pre-loss symptoms related to risk of complicated grief in caregivers of terminally ill cancer patients. J Affect Disord. 2014 May 1;160:87–91.

30. Gauthier LR, Gagliese L. Bereavement Interventions, End-of-Life Cancer Care, and Spousal Well-Being: A Systematic Review. Clin Psychol Sci Pract [Internet]. 2012 Mar [cited 2022 Jul 18];19(1):72–92. Available from: /record/2012-07690-007

31. Stroebe M, Schut H. The dual process model of coping with bereavement: A decade on. Omega J Death Dying [Internet]. 2010 [cited 2022 Jul 18];61(4):273–89. Available

from: http://baywood.com

32. Rasouli O, Moksnes UK, Reinfjell T, Hjemdal O, Eilertsen M-EB. Impact of resilience and social support on long-term grief in cancer-bereaved siblings: an exploratory study. BMC Palliat Care [Internet]. 2022 Jun 1 [cited 2022 Jul 18];21(1):1–8. Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-00978-5

33. Trevino KM, Litz B, Papa A, Maciejewski PK, Lichtenthal W, Healy C, et al. Bereavement Challenges and Their Relationship to Physical and Psychological Adjustment to Loss. J Palliat Med [Internet]. 2018 Apr 4 [cited 2022 Jul 18];21(4):479–88. Available from: /pmc/articles/PMC5867503/

34. Kim Y, Carver CS, Spiegel D, Mitchell HR, Cannady RS. Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement. Psychooncology [Internet]. 2017 Apr 1 [cited 2022 Jul 18];26(4):484–92. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pon.4042

35. Guldin MB, Vedsted P, Zachariae R, Olesen F, Jensen AB. Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: A longitudinal cohort study. Support Care Cancer [Internet]. 2012 Aug 4 [cited 2022 Jul 18];20(8):1679–85. Available from: https://link.springer.com/article/10.1007/s00520-011-1260-3

36. Hoerger M, Gramling R, Epstein R, Fenton JJ, Mohile SG, Kravitz RL, et al. Patient, caregiver, and oncologist predictions of quality of life in advanced cancer: Accuracy and associations with end-of-life care and caregiver bereavement. Psychooncology [Internet]. 2022 Jun 1 [cited 2022 Jul 18];31(6):978–84. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5887

37. Wen FH, Chou WC, Shen WC, Tang ST. Distinctiveness of prolonged-grief-disorder- and depressive-symptom trajectories in the first 2 years of bereavement for family caregivers of terminally ill cancer patients. Psychooncology [Internet]. 2020 Oct 1 [cited 2022 Jul 18];29(10):1524–32. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5441

38. Jacobsen JC, Zhang B, Block SD, Maciejewski PK, Prigerson HG. Distinguishing symptoms of grief and depression in a cohort of advanced cancer patients. Death Stud [Internet]. 2010 Mar [cited 2022 Jul 18];34(3):257–73. Available from: /pmc/articles/PMC2953955/

39. Thomas K, Hudson P, Trauer T, Remedios C, Clarke D. Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: A longitudinal study. J Pain Symptom Manage [Internet]. 2014 Mar 1 [cited 2022 Jul 18];47(3):531–41. Available from: http://www.jpsmjournal.com/article/S0885392413003679/fulltext

40. Zordan RD, Bell ML, Price M, Remedios C, Lobb E, Hall C, et al. Long-Term prevalence and predictors of prolonged grief disorder amongst bereaved cancer caregivers: A cohort study. Palliat Support Care [Internet]. 2019 Oct 1 [cited 2022 Jul 18];17(5):507–14. Available from: https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/abs/longterm-prevalence-and-predictors-of-prolonged-grief-

disorder-amongst-bereaved-cancer-caregivers-a-cohort-study/2AEA36FDF057DE9BC8AADA59D2A27256

41. Breen LJ, Aoun SM, O'Connor M, Johnson AR, Howting D. Effect of caregiving at end of life on grief, quality of life and general health: A prospective, longitudinal, comparative study. Palliat Med [Internet]. 2020 Jan 1 [cited 2022 Jul 18];34(1):145–54. Available from: https://journals.sagepub.com/doi/10.1177/0269216319880766?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed

42. Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin MB. Predictors of Complicated Grief and Depression in Bereaved Caregivers: A Nationwide Prospective Cohort Study. J Pain Symptom Manage [Internet]. 2017 Mar 1 [cited 2022 Jul 18];53(3):540–50. Available from: http://www.jpsmjournal.com/article/S0885392416311964/fulltext

43. National Clinical Guideline Centre. Patient experience in adult NHS services : improving the experience of care for people using adult NHS services. Development [Internet]. 2012 [cited 2022 Jul 18];(February):1–26. Available from: https://www.nice.org.uk/guidance/cg138/chapter/1-Guidance

44. National Institute for Health and Care Excellence. People's experience in adult social care services: improving the experience of care and support for people using adult social care services [Internet]. NICE Guidelines. 2021 [cited 2022 Jul 18]. Available from: https://www.nice.org.uk/guidance/ng86/chapter/Recommendations#information

45. NICE guideline. End of life care for adults: service delivery. End life care adults Serv Deliv [Internet]. 2021 [cited 2022 Jul 18];(October):1–17. Available from: https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#supporting-carers

46. NICE (National Institute for Health and Care Excellence). End of life care for infants, children and young people with life-limiting conditions: planning and management [Internet]. National Institute for Health and Care Excellence. 2019 [cited 2022 Jul 18]. Available from: https://www.nice.org.uk/guidance/ng61/chapter/Recommendations#care-and-support-for-parents-carers-and-healthcare-professionals-in-relation-to-the-death-of-a

47. National Institute for Health and Care Excellence. Supporting adult carers NICE guideline [Internet]. NICE guideline. 2020 [cited 2022 Jul 18]. Available from: www.nice.org.uk/guidance/ng150

48. Online Bereavement Counselling Service | Sue Ryder [Internet]. [cited 2022 Jul 18]. Available from: https://www.sueryder.org/online-bereavement-counselling

49. One to One Grief Support | Cruse Bereavement Support [Internet]. [cited 2022 Jul 18]. Available from: https://www.cruse.org.uk/get-support/one-to-one/

50. Phillips C, Cruse M. E-zine Understanding your cancer bereavement virtual sessions [Internet]. 2021 [cited 2022 Jul 18]. Available from: https://www.cruse.org.uk/get-help/coronavirus-dealing-bereavement-and-grief

51. Bereavement suicide services | Samaritans [Internet]. [cited 2022 Jul 18]. Available from: https://www.samaritans.org/about-samaritans/research-policy/bereavement-suicide-services/

52. Williams J, Shorter GW, Howlett N, Zakrzewski-Fruer J, Chater AM. Can Physical Activity Support Grief Outcomes in Individuals Who Have Been Bereaved? A Systematic Review. Sport Med - Open [Internet]. 2021 Dec 1 [cited 2022 Jul 18];7(1). Available from: /pmc/articles/PMC8028581/

53. Chang LF, Lin CK, Wu LF, Ho CL, Lu YL, Pan HH. Mental adjustment as a predictor of comprehensive quality of life outcome among patients with terminal cancer. Int J Environ Res Public Health [Internet]. 2021 May 1 [cited 2022 Jul 18];18(9). Available from: /pmc/articles/PMC8125235/

54. Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GKB, Davies A. Predictors of complicated grief: A systematic review of empirical studies. Death Stud [Internet]. 2010 [cited 2022 Jul 18];34(8):673–98. Available from: https://www.tandfonline.com/doi/abs/10.1080/07481187.2010.496686

55. Caserta M, Utz R, Lund D, Supiano K, Donaldson G. Cancer Caregivers' Preparedness for Loss and Bereavement Outcomes: Do Preloss Caregiver Attributes Matter? Omega (United States) [Internet]. 2019 Dec 1 [cited 2022 Jul 18];80(2):224–44. Available from: /pmc/articles/PMC5658262/

56. Caserta M, Utz R, Lund D. Spousal bereavement following cancer death. Illn Cris Loss [Internet]. 2013 Jan 1 [cited 2022 Jul 18];21(3):185–202. Available from: /pmc/articles/PMC3982618/

57. Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. Clin Psychol Rev. 2016 Mar 1;44:75–93.

58. Wen FH, Chou WC, Prigerson HG, Shen WC, Hsu MH, Tang ST. Predictors of Family Caregivers' Depressive- and Prolonged-Grief-Disorder-Symptom Trajectories. J Pain Symptom Manage [Internet]. 2022 Apr 1 [cited 2022 Jul 18];63(4):476-484.e1. Available from: http://www.jpsmjournal.com/article/S088539242100703X/fulltext

59. Otani H, Yoshida S, Morita T, Aoyama M, Kizawa Y, Shima Y, et al. Meaningful Communication Before Death, but Not Present at the Time of Death Itself, is Associated With Better Outcomes on Measures of Depression and Complicated Grief Among Bereaved Family Members of Cancer Patients. J Pain Symptom Manage [Internet]. 2017 Sep 1 [cited 2022 Jul 18];54(3):273–9. Available from: http://www.jpsmjournal.com/article/S0885392417302737/fulltext

60. Petursdottir AB, Sigurdardottir V, Rayens MK, Svavarsdottir EK. The impact of receiving a family-oriented therapeutic conversation intervention before and during bereavement among family cancer caregivers: A nonrandomized trial. J Hosp Palliat Nurs [Internet]. 2020 Oct 1 [cited 2022 Jul 18];22(5):383–91. Available from: https://journals.lww.com/jhpn/Fulltext/2020/10000/The_Impact_of_Receiving_a_Family_Oriented.7.aspx

61. Currier JM, Neimeyer RA, Berman JS. The Effectiveness of Psychotherapeutic Interventions for Bereaved Persons: A Comprehensive Quantitative Review. Psychol Bull [Internet]. 2008 Sep [cited 2022 Jul 18];134(5):648–61. Available from: /record/2008-11487-002

62. Wittouck C, Van Autreve S, De Jaegere E, Portzky G, van Heeringen K. The prevention and treatment of complicated grief: A meta-analysis. Clin Psychol Rev. 2011 Feb 1;31(1):69–78.

63. Johannsen M, Damholdt MF, Zachariae R, Lundorff M, Farver-Vestergaard I, O'Connor M. Psychological interventions for grief in adults: A systematic review and meta-analysis of randomized controlled trials. J Affect Disord. 2019 Jun 15;253:69–86.

64. Johannsen M, Schlander C, Farver-Vestergaard I, Lundorff M, Wellnitz KB, Komischke-Konnerup KB, et al. Group-based compassion-focused therapy for prolonged grief symptoms in adults – Results from a randomized controlled trial. Psychiatry Res. 2022 Aug 1;314:114683.

65. Johnsen I, Dyregrov A, Dyregrov K. Participants with prolonged grief-how do they benefit from grief group participation? Omega (United States) [Internet]. 2012 Jan 1 [cited 2022 Jul 18];65(2):87–105. Available from: https://journals.sagepub.com/doi/10.2190/OM.65.2.a

66. Enez Ö. Patolojik Yas Terapilerinin Etkinliği: Sistematik Derleme. Psikiyatr Guncel Yaklasimlar - Curr Approaches Psychiatry [Internet]. 2017 Sep 22 [cited 2022 Jul 18];9(4):441–441. Available from: https://go-gale-com.libproxy.ucl.ac.uk/ps/i.do?p=AONE&sw=w&issn=13090658&v=2.1&it=r&id=GALE%7CA516195623&sid=googleScholar&linkaccess=fulltext

67. Horowitz MJ, Siegel B, Holen A, Bonanno GA, Milbrath C, Stinson CH. Diagnostic Criteria for Complicated Grief Disorder. Focus (Madison) [Internet]. 2003 Jul 1 [cited 2022 Jul 18];1(3):290–8. Available from: https://focus.psychiatryonline.org/doi/10.1176/foc.1.3.290

68. Kissane DW, Zaider TI, Li Y, Hichenberg S, Schuler T, Lederberg M, et al. Randomized controlled trial of family therapy in advanced cancer continued into bereavement. J Clin Oncol [Internet]. 2016 Jun 6 [cited 2022 Jul 18];34(16):1921–7. Available from: /pmc/articles/PMC4966341/

69. Jerome H, Smith K V., Shaw EJ, Szydlowski S, Barker C, Pistrang N, et al. Effectiveness of a Cancer Bereavement Therapeutic Group. J Loss Trauma [Internet]. 2018 Jan 1 [cited 2022 Jul 18];23(7):574–87. Available from: /pmc/articles/PMC6461201/

70. Boelen PA, Eisma MC, Smid GE, Lenferink LIM. Prolonged grief disorder in section II of DSM-5: a commentary. Eur J Psychotraumatol [Internet]. 2020 Dec 31 [cited 2022 Jul 18];11(1). Available from: /pmc/articles/PMC7473035/

71. Eisma MC, Rosner R, Comtesse H. ICD-11 Prolonged Grief Disorder Criteria: Turning Challenges Into Opportunities With Multiverse Analyses. Front Psychiatry [Internet]. 2020 Aug 7 [cited 2022 Jul 18];11. Available from: /pmc/articles/PMC7427562/

72. Prigerson HG, Boelen PA, Xu J, Smith K V., Maciejewski PK. Validation of the new DSM-

5-TR criteria for prolonged grief disorder and the PG-13-Revised (PG-13-R) scale. World Psychiatry [Internet]. 2021 Feb 1 [cited 2022 Jul 18];20(1):96–106. Available from: /pmc/articles/PMC7801836/

73. Prigerson HG, Maciejewski PK. Prolonged Grief Disorder (PG-13) ©.