How do researchers conceive of spousal grief after cancer? A systematic review of models used by researchers to study spousal grief in the cancer context

Léonor Fasse1,2*, Serge Sultan2, Cécile Flahault1,2, Christopher J. MacKinnon3,6,7, Sylvie Dolbeault1,4,5 and Anne Brédart1,2

1Institut Curie, Paris F-75006, France
2Université Paris Descartes, LPPS EA 4057, IUPDP, Paris, France
3Department of Educational and Counseling Psychology, McGill University, Montréal, Québec, Canada
4Inserm, U 669, Paris, France
5Université Paris-Sud and Université Paris Descartes, UMR-S0669, Paris, France
6Palliative Care Research, SMBD Jewish General Hospital, Montréal, Québec, Canada
7Psychosocial Oncology Program, Montreal General Hospital, Montréal, Québec, Canada

*Correspondence to: Institut Curie, 26 rue d’Ulm, 75005 Paris F-75006, France. E-mail: leonor.fasse@curie.net

Received: 29 October 2012
Revised: 28 August 2013
Accepted: 28 August 2013

Abstract

Background: Although spouses bereaved after cancer are considered vulnerable people, there have been few empirical studies to explore grief specifically in this context.

Methods: Using PsycINFO, Medline, and the PRISMA statement, we systematically searched the literature by intersecting ‘cancer’ and ‘grie*’, ‘cancer’ and ‘bereave*’, and ‘cancer’ and ‘mourn*’.

Results: Gathering 76 studies (2000–2013) that met the inclusion criteria for bereavement in adulthood, bereavement of an adult loved one and evidence-based research, we found the following:

(1) Spousal relationships are not systematically examined in the current dominant models of grief.
(2) Theoretically derived determinants of spousal grief after cancer and empirically derived ones converge toward the necessity to include the caregiving experience as determining grief reactions.
(3) A growing body of literature concerning prolonged grief disorders now provides integrative reflections regarding the characteristics of spousal loss, predictors, and associated therapeutic interventions in the cancer context.

Conclusions: Few empirical studies (20 of 76) target spousal bereavement specifically after cancer. The process of adaptation to loss is usually decontextualized, removing any consideration of the relationship to the deceased or the experience of caregiving and dying. Our findings suggest that this topic warrants more studies that use both prospective and mixed methodologies, as well as explore typical grief needs and experiences of bereaved spouses.

Copyright © 2013 John Wiley & Sons, Ltd.

Introduction

Recent statistics published by the World Health Organization suggest that cancer accounted for 7.6 million deaths in 2007 (around 13% of all deaths worldwide). Deaths from cancer are projected to continue to rise, with an estimated 13.1 million deaths in the year 2030 (World Health Organization, 2009).1

Over recent years, several studies have emphasized the psychological vulnerability of spouse caregivers2 [1–4], especially in terms of anxiety and depression patterns. Indeed, among the adult patient’s relatives and friends, spouses appear to encounter the most serious difficulties in their daily lives in relation to the following: (i) their experience during the cancer trajectory and into bereavement [5,6]; (ii) their feelings of helplessness and incapacity [7]; and (iii) the risk of complicated grief [8,9]. In summary, during the course of illness, partners may perceive psychological distress and low quality of life because of the fear of losing their loved one, because of the provision of care and support and the restriction of their social activities [10]. Conversely, the support provided by the spouse–caregiver can sometimes be a source of satisfaction and is associated with feelings of personal growth [11,12].

Although specificities of the cancer experience should be underlined, a general response to death can be identified in our society. Overall, authors emphasize a decreasing recognition of the importance of death in most cultures [13–15]. This is due in part to the growing disappearance of bereavement rituals (societal prerequisites and no more symbolic rituals), as well as an observed denial of certain issues related to death (decline, aging, disease, etc.) [13–15,19].
This societal tendency of death denial further raises the issue of the isolation of the dying and their families [16], a situation that palliative care began to address in the 1980s.

The field of psychology has developed a number of ways to approach grief including identifying common features or typical issues of the grieving process. These features are of critical importance because they are currently leading the way clinicians build their interventions. Variations in the forms of grief reactions raise a number of questions concerning the dichotomy between the normal and the pathological. This is reflected in current discussions concerning the ‘Persistent Complex Bereavement-Related Disorder’ (PCB-RD) (formerly called prolonged/complicated) grief in the DSM-5. Although the relevance of this category is controversial [17–19], the array of signs for prolonged grief may help identify more reliably those bereaved individuals presenting with severe psychological distress necessitating psychological support [9,20]. Although they often constitute a basis for diagnosis and orientation, models of spousal grief after a cancer remain vague for the majority of professionals working with end-of-life patients and their close relatives [21]. Indeed, any existent models are poorly integrated in nurses’, physicians’, or even psychologists’ curricula [22], and findings related to new and integrative models remain hardly known [23,24]. These facts, and the added one that the cancer context is a particularly harmful one for the mental and physical health of bereaved spouses, beg the question of whether a specific grief model after cancer does exist. Professionals are yet in great demand to access elaborate theoretical models so as to offer relevant listening and care to the growing population of spouses bereaved after cancer [25]. Research in the field bereavement and grief should fill this gap, as training and theoretical and practical skills are viewed as important buffers against professional burnout and as factors improving quality of care [26,27].

Research objectives

We undertook a systematic search of the literature on models of grief after cancer. This was aimed at exploring two research questions: (i) What theoretical models or reflections are predominantly guiding current published research about spousal grief? (ii) Are there any factors identified in the literature moderating adjustment to spousal bereavement, and do these factors relate specifically to cancer?

Through this process, we aim to gain important insights into the strengths and limitations of the models that are commonly used by grief researchers.

Methods

A systematic review of the literature was performed on PsycINFO and Medline databases, which provide systematic coverage both of the psychological international literature and of the biomedical one. Two authors of the present paper (LF and CF), familiar with death and bereavement topics, looked for all research published over the last 10 years (from 2000 to 2013) by intersecting the term ‘cancer’ with: ‘grief*’ (for grief, grieving…), ‘bereav*’ (for bereaved, bereavement…), and ‘mourn*’ (for mourning…) in the full text of articles. To reduce methodological bias and to offer a relevant data trail, we used the PRISMA statement (Preferred Reporting Items for Systematic Reviews and Meta-Analyses, [28]). This search yielded between 646 and 526, 553 and 882, and 87 and 78 references for each of these combinations, respectively. There was a large degree of overlap with these search terms.

The abstracts of these articles were reviewed by the first investigator (LF) to investigate the main themes on this subject, and the articles were read in full when they specifically concerned spousal bereavement in cancer. On the basis of the abstracts, 186 references including data on the impact of the death of a loved one were selected. Eighty-four of these 186 references were excluded, as they were not based on empirical data (critical reviews and expert opinions). Qualitative, quantitative, and mixed methods studies were included. A total of 102 studies, both peer-reviewed journals and book chapters, were finally included in the analysis. These 102 articles were read in full, and 76 were selected for the present review if they strictly matched the following criteria: (i) adult bereavement; and (ii) bereavement of a loved one; (iii) empirical research conducted according to an evidence-based approach (i.e., data from randomized controlled trials, observational cross-sectional studies, and secondary data analyses) [19]. The second investigator (CF) assessed 70% of the abstracts to confirm the appropriateness of the article selection. Fifty percent of excluded material was also checked by the second reviewer (CF) to confirm exclusion. Only 20 of these 76 studies (26%) concerned spousal bereavement. The other 56 articles largely studied familial bereavement including various relatives (e.g., grandmothers/fathers or adult children). As our major purpose is to study how spousal grief after cancer is specifically conceived of, we adopted a ‘funnel-shaped’ methodology. That is, we included on purpose papers dealing with other losses than spousal ones so as to have the broadest insight on theoretical models of grief in adulthood. This broad perspective allowed us to identify specific features of spousal grief precisely in the cancer context. The reviewed studies are marked by an asterisk * in the bibliography (Figure 1).

Results

Theoretical models of grief: how spousal grief is conceptualized

In this subsection, we first describe grief work, then models of social cognitive coping. Stage models of grief
are discussed thirdly. We conclude this presentation with models of attachment (include Table 1).

Only 15 studies out of 76 (19.7%) explicitly referred to one or several theoretical models of coping with grief. The principal models refer to three traditions: the grief work hypothesis [29–31], cognitive coping strategies [32,33], and attachment theory [34–36]. Although the grief work hypothesis has become a very popular theoretical framework, to date, no scientific consensus supported by empirical validation has been reached [19,36]. To our knowledge, no empirical studies have been specifically designed to test the central components of this hypothesis (emotional and cognitive confrontation with all reminders of the deceased and their loss) specifically in the domain of spousal bereavement related to cancer [19].

We found nine studies on the basis of models of social and cognitive coping, whose relevance has been confirmed by a number of empirical studies. These studies, sometimes in conditions other than cancer care, evaluated the predictive nature of coping patterns in adjustment to death. Benight, Flores, and Tashiro [37] reported that feelings of self-efficacy for bereaved women in relation to their husband’s death were negatively correlated with emotional distress, as well as positively correlated with psychological, spiritual, and physical well-being. Some coping styles, including active coping, may have a buffering effect by reducing the psychological and physiological consequences of loss [38]. Guided by a stress process conceptual model, a recent study examines social and psychological determinants of complicated grief symptoms. Higher conflict at the end-of-life, difficulty accepting the illness in the family members, and greater fear of death among the patients predicted higher complicated grief symptoms [39].

We also found the importance of coping models to inform clinical practice significantly. In a survey conducted among health care professionals implicated in the care and treatment of bereavement, coping capacities were described as being one of the main adaptive resources to the loss of a spouse [40]. Descriptive empirical studies have tried to define the coping strategies preferentially used by loved ones after the death of a cancer patient [e.g., 41,42]. The role of religious beliefs as a form of coping strategy was also studied as a protective factor in adaptation to bereavement [43].

Models of social and cognitive coping are not the only theoretical ground for research on bereavement. Two studies referred to the stage model of the grief process [44,45]. This stage model was described in detail by various scholars [46 a,b,c–49 a,b] In parallel with Bowlby’s...
Table 1. Articles related to theoretical models of adaptation to loss of a loved one (2000–2013)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Population (N)</th>
<th>Methods</th>
<th>Results</th>
<th>Theoretical model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benight, Flores, and Tashtiro</td>
<td>2001</td>
<td>101 bereaved spouses of patients who have died from cancer</td>
<td>Quantitative cross-sectional study</td>
<td>Protective nature of feelings related to bereavement coping self-efficacy.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Goodkin et al.</td>
<td>2001</td>
<td>119 bereaved partners</td>
<td>Quantitative cross-sectional study</td>
<td>Protective/buffering role of certain coping styles (especially the search for social support). Highlighting the value of therapeutic interventions targeting these coping styles or bereaved subjects.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Grbich, Parker, and Maddocks</td>
<td>2001</td>
<td>20 family caregivers of terminal cancer patients</td>
<td>Qualitative/quantitative longitudinal study</td>
<td>Intense use of coping strategies (e.g., emotional support seeking) during the terminal phase (more than during bereavement).</td>
<td>Coping model</td>
</tr>
<tr>
<td>Ellifritt, Nelson, and Walsh</td>
<td>2003</td>
<td>262 hospice bereavement professionals</td>
<td>Quantitative cross-sectional study</td>
<td>Poor coping skills as rated by professionals were found to be a major risk factor for complicated grief.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Fenix et al.</td>
<td>2006</td>
<td>175 family caregivers bereaved after cancer</td>
<td>Prospective, quantitative longitudinal study</td>
<td>Protective role of ‘religiosity’ coping strategy in emotional adaptation to loss.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Johnson et al.</td>
<td>2006</td>
<td>170 bereaved individuals of general population</td>
<td>Quantitative longitudinal study</td>
<td>Dependence to the deceased as a predictor for completed grief reactions and suicidal risk.</td>
<td>Attachment theory/PGD</td>
</tr>
<tr>
<td>Schneider</td>
<td>2006</td>
<td>Bereaved spouses and significant others</td>
<td>Qualitative longitudinal study</td>
<td>Grief support group beneficial to spouses within the first year of loss.</td>
<td>Stage model</td>
</tr>
<tr>
<td>Vanderwerker, Jacobs, Parkes, and Prigerson</td>
<td>2006</td>
<td>283 recently (an average of 10.6 months post-loss) bereaved community dwelling residents</td>
<td>Quantitative retrospective study</td>
<td>Association between separation anxiety in childhood and complicated grief.</td>
<td>Attachment theory/PGD</td>
</tr>
<tr>
<td>Johnson, Zhang, Greer, and Prigerson</td>
<td>2007</td>
<td>218 bereaved adults spouses</td>
<td>Quantitative retrospective study</td>
<td>Dependency on the deceased spouse mediates a significant association between parental control during childhood and post-loss depression symptoms.</td>
<td>Attachment theory/PGD</td>
</tr>
<tr>
<td>Maciejewski, Zhang, Black, and Prigerson</td>
<td>2007</td>
<td>233 bereaved individuals</td>
<td>Qualitative longitudinal study</td>
<td>Counter to the original stage theory proposed by Kübler-Ross (1969), disbelief was not the initial, dominant grief indicator, but acceptance and yearning.</td>
<td>Stage model/PGD</td>
</tr>
<tr>
<td>Ando et al.</td>
<td>2010</td>
<td>378 bereaved family members of cancer patients</td>
<td>Quantitative retrospective study</td>
<td>Religious care is reported to be useful for relief of psycho-existential suffering in patients and in caregivers.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Asai et al.</td>
<td>2010</td>
<td>24 bereaved spouses of cancer patients</td>
<td>Qualitative cross-sectional study</td>
<td>Both negative and positive psychological states are reported by bereaved spouses. Bereavement-specific coping strategies (such as ‘continuing bonds’ and ‘reconstruction of life’) were identified.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Shinjo et al.</td>
<td>2010</td>
<td>670 families of cancer patients in palliative phase</td>
<td>Quantitative cross-sectional study</td>
<td>Determinants of high-level distress: a younger patient age, being a spouse, and bad communication with nursing staff. Families reporting high-level necessity of care improvement were less likely to have encountered attempts to ensure the patient's comfort, received less family coaching on how to care for the patient, and felt that insufficient time was allowed for the family to grieve after the patient's death.</td>
<td>Coping model</td>
</tr>
<tr>
<td>Hales, Gagliese, Nissim, Zimmermann, and Rodin</td>
<td>2012</td>
<td>22 bereaved caregivers</td>
<td>Quantitative cross-sectional study</td>
<td>The quality of dying and death, perceived by the caregivers, is a complex construct based on multiple perspectives and standards of comparison.</td>
<td>Coping model</td>
</tr>
<tr>
<td>O’Callaghan, McDermott, Hudson, and Zalberg</td>
<td>2013</td>
<td>8 bereaved caregivers</td>
<td>Quantitative cross-sectional study</td>
<td>Musical memories were used to minimized sadness using music therapy in support groups.</td>
<td>Attachment theory</td>
</tr>
</tbody>
</table>

PGD, prolonged grief disorder.
Cancer, which has now become a chronic disease, brings with it unique aspects (e.g., cancer management, treatment characteristics, and experience of caregiving: [55,56]).

The authors have classified these moderators of spousal bereavement reactions into four thematic groups, which are described in the succeeding texts: (i) involvement in a palliative care setting; (ii) experience of being a caregiver; (iii) characteristics related to cancer or its treatments; and (iv) individual or social representations of cancer. These factors are not strictly theoretically derived; they rather appear as major determinants in empirical studies.

Impact of contact with palliative care on the adjustment of spouses after the death of a cancer patient

To begin with, 11 empirical studies suggest that involvement in a palliative care setting (e.g., service in an outpatient setting; admission to inpatient units) tends to have a significant impact on the close friends’ and relatives’ grief. Experiences in a palliative care unit frequently induce specific psychological reactions (i.e., pre-anticipatory or anticipatory grief processes) in family caregivers of advanced cancer patients [e.g., 56–59]. Hauksdóttir, Steinbeck, Fürst, and Valdimarsdóttir [58] indicated that men reporting low levels of preparedness before the death of their spouse because of cancer were at high risk for psychological disorder and sleep disturbance 4 at 5 years post-death, compared with bereaved men reporting better preparedness.

In a seminal article regarding loss and bereavement, Rando [60] points that the events preceding an individuals’ anticipated death have a profound influence upon both the individual’s dying experience, as well as on pre-death and post-death bereavement among survivors. Specifically, Marwit, Chibnall, Dougherty, and Jenkins [61] identified the presence of cognitive and emotional features prior to the patient’s death. For example, prior to the cancer patient’s death, spouses can experience affliction because of feelings of multiple losses, estrangement, or emotional distance [61–63]. A diversity of literature is also available on anticipatory grief reactions experienced by patients themselves [64 a, b, c,65].

Finally, recent results have emphasized the protective role of a palliative care setting in bolstering the emotional well-being of bereaved people [68]. Nonetheless, the influence of palliative care settings on grief reactions remains controversial and vague [60]. For instance, Song et al. [69] found that longer duration of survival after palliative care referral was negatively correlated with health-related QOL in bereaved relatives of cancer patients.

Aspects linked with greater satisfaction of bereaved relatives appear to be the following: better nursing and medical care, effective pain management, respect for the patient’s and loved ones’ dignity, and more open communication with the medical team [59,68].
The impact of being a caregiver to a cancer patient at the end of life

Twenty-three studies report that the caregiving experience both facilitated and, conversely, impaired the spouse’s adaptation to loss. With regards to impairment, feelings of helplessness, injustice, as well as the stress proliferation phenomenon have been reported to be frequent [69–73]. Even in cases where the patient was hospitalized, spouses tend to experience feelings of being burdened that may persist after the patient’s death [70]. Specifically, such feelings include emotions of helplessness, anxiety, depression, and being overwhelmed, as well as posttraumatic stress disorder [73–77]. Furthermore, feelings of being burdened have been related to perceived expectations of patient’s needs or demands, including medical, financial, and social requirements [74].

Various authors have highlighted the psychological vulnerability of caregivers, before and after their loved one’s death from cancer [1–3,70–73,78–83]; this distress coexisting sometimes with the satisfaction of caregiving [e.g., 81,83]. However, few studies have investigated grief reactions associated with the characteristics of caregiving (e.g., duration, type of care, and caregiver’s experience) [54,82]. Besides, only three studies have investigated the variability related to the spouse’s gender in the adaptation to loss after cancer. In both cases, women whose husband has died from cancer appeared to constitute a population at higher risk of emotional distress compared with widowers (male) [2,37,58]. It appears critical to note the lack of specificity of studies exploring the caregiving context at the end-of-life. One important feature is the lack of discrimination between a gender effect and a role effect (caregivers versus noncaregivers) on spousal adjustment. Related to this gender perspective, Yopp and Rosenstein [85] called for development of research agendas and clinical interventions for single fathers because of cancer.

Cancer-related bereavement

Third, although 43 of all the reviewed studies mentioned cancer as the cause of the death, only nine studies among these investigate characteristics of bereavement related to the context of cancer or related to cancer treatments (e.g., physical suffering or patient’s cognitive disorders). Studies suggest that atypical grief reactions are associated with patients who experienced delirium, as well as associated symptoms experienced by cancer patients during the terminal phase of the disease (e.g., psychomotor agitation). Bereaved spouses who encountered these symptoms experienced a greater burden and higher levels of distress than those who did not encounter delirium or its derivatives [86 a, b]. Curative and palliative care of cancer and their sometimes traumatic nature (for instance, surgical interventions to reduce pain symptoms in a palliative context) also have an impact on the bereaved spouse’s adjustment with corresponding a decreased reported quality of life and increased anxiety [82–90]. In addition to these nine studies, a chapter in a reference book devoted to psycho-oncology was especially dedicated to bereavement issues. The authors underline the critical necessity of taking into account the characteristics induced by the cancer experience to enhance the quality of care for bereaved relatives [91].

Individual perceptions of cancer

Lastly, individual perceptions of cancer constitute a distinct factor influencing spousal grief reactions. Two studies [i.e., 89,92] mentioned both individual and social representations of cancer as moderators of spouses’ reactions to death-related loss. Indeed, the fewer spouses perceive social support, the less they show an adaptive response [89].

Moreover, the literature indicates that perceptions of death because of cancer differ from those of death because of other diseases (e.g., HIV). Although there tends to be less stigmatization with regards to cancer compared with HIV, the risk is that the spouse bereaved after cancer may be less likely to receive sufficient empathy and sympathy from their social network.

As evidenced, the four factors influencing the grief reactions of spouses in the context of cancer reflect only a few aspects of the main theoretical models mentioned previously. Specifically, they are mostly related to the coping model of stress and/or empirically derived. The coping model [93] postulates that adjustment is determined by the caregiving experience, by death parameters, and by cognitive (e.g., appraisal), behavioral, and interpersonal processes. Strikingly, a significant part of the papers in the present review deal with another theoretical perspective on grief among spouses of cancer patients: grief as a psychiatric disorder in the cancer context.

Grief as a psychiatric disorder in the cancer context

The focus on grief as a psychiatric disorder is infrequent in the cancer literature, whereas very wide-spread in the more general grief literature [94,95]. This focus corresponds to 25 out of the 76 studies surveyed (33%) [43,50–52,96–99,103–119]. An important body of literature underlines an increased mortality risk for bereaved spouses, particularly through heart disease, cancer, accidents [100], and autoimmune disorders [30,101,102]. However, these results remain debated. For instance, King et al. [119] did not confirm increased mortality in cohabiters of people dying from cancer in a vast cohort study. Emotional vulnerability is also reported in terms of higher posttraumatic stress disorder prevalence [76,103] and diminished quality of life [104] or suicidality and poor mental health service use [118]. These studies are not always specific to spouses bereaved by cancer, and the characteristics of this cancer-related bereavement
experience are still poorly understood [100,105,112]. The study by Holtslander and Duggleby [56], which is not dedicated to prolonged grief disorder (PGD), constitutes a notable exception, with its qualitative investigation of the psycho-social context of older bereaved women after their spouse’s cancer.

The studies that focused on complicated grief are mostly devoted to the development of clinically and statistically valid criteria for PGD as a verifiable mental disorder [e.g., 96,99]. Recent empirical studies have indicated that certain prolonged (or complicated) forms of grief comprise a series of symptoms persisting for more than 6 months after death. For instance, symptoms may include a searching behavior, disbelief in relation to death, and stunned feelings. These symptoms of prolonged grief are postulated to be distinct from other psychiatric disorders such as anxiety disorders or clinical depression [8,95,99]. However, the diverse ways in which prolonged grief has been conceptualized remain somewhat disparate. For instance, some authors consider that PGD represents a qualitatively distinct clinical entity with some pathognomonic symptoms such as trouble accepting death, whereas others consider it to be a disorder that can be measured in terms of severity, frequency, and intensity of symptoms common with other disorders [e.g., 106]. A study conducted by Holland, Neimeyer, Boelen, and Prigerson [107] examined the underlying structure of grief with 1069 participants who had lost a close relative. The authors concluded that a dimensional model might be a more appropriate conceptualization of pathological grief.

Using an epidemiological approach, certain studies focused on identifying predictors of pathological grief reactions. Some studies focused on gender [112], cognitive processes such as negative meaning of the loss [115], alexithymia [116], attachment styles [51,52], and others on the characteristics of caregiving [52,108,109], or place of death (hospital versus hospice) [110]. According to Chiu et al. [112], female gender is associated with severe anxiety; however, it is not associated with prolonged grief. On the other hand, an insecure attachment developed during childhood has been identified as both a predictor of complicated grief and a high level of emotional and practical dependence on the deceased person [52]. Lobb et al. provide a recent systematic review of predictors of complicated grief [111].

Some papers regarding psychological interventions are part of this PGD-centered approach. For instance, Greer [120] highlighted that cognitive-behavior therapy can be effective in the management of PGD, whereas Lichtenthal and Cruess [121] suggested that directing written disclosure on topics associated with adjustment to may be useful for bereaved individuals with PGD or depression.

Only three studies were specifically devoted to examining the intersections of spousal bereavement and complicated grief [96,97,113]. First, the central aspects of complicated grief appeared to be related to the spouse’s adjustment to loss but were less relevant to describe the grieving process of young adult women following the death of their mother. Indeed, caregiver role strain formulations predicted more difficult bereavement adjustment for husbands, as the complicated grief model had theoretically suggested [96]. Gauthier and Gagliese [113] provided a systematic review examining outcomes of bereavement interventions for spouses of cancer patients; their data underline the difficulty to conclude about the effectiveness of interventions for bereaved spouses after cancer.

Third, Johnson et al. [97] underlined in a prospective longitudinal investigation that to be diagnosed with PGD can be a source of relief for some relatives. In a community-based sample of 135 widowed participants, more than 90% of persons diagnosed with PGD in this sample reported that they felt relieved to know that the diagnosis indicated an identifiable disorder. Additionally, two other studies address the relationship to the deceased as a risk factor for PGD [95,109].

Results summary

Next to the theoretical approaches (grief work hypothesis, coping model, and attachment theory), which offer insights concerning predictors of grief reactions in our target population, a more phenomenological, and seemingly ’a-theoretical’, perspective emerges and is related to the identification of a mental disorder: PGD. Nevertheless, more and more considerations argue for an integrative model of spousal grief, which might include critical aspects of past models (for instance, oscillation and avoidance in the grief work hypothesis and influence of appraisal in the cognitive coping model of stress). The dual process model of coping with bereavement [122] offers such an integrative perspective, taking into accounts theoretical ground, predictors, and outcomes concerning adjustment to the loss of a loved one. Precisely, the DPM integrates the abovementioned predictors, such as attachment patterns and continuing bonds. This model recognizes and challenges the critical importance of the grief work hypothesis. Indeed, it underlines all the processes implicated in coping with loss (loss-oriented coping), which directly refer to this hypothesis, but it also suggests the prominence of restoration-oriented coping. Certain characteristics of cancer-related spousal bereavement have also emerged in the present review. They include the caregiving experience, symptoms of the disease, the patient’s care and treatments, and perceptions of cancer. First, findings suggest that the literature concerning the nature of anticipatory grief reactions among family caregivers, with corresponding protective and nonprotective factors, remains controversial. Second, the process of adaptation to loss is usually decontextualized, removing any consideration of the
relationship of attachment to the deceased, the circumstances of the death, or the bereaved individuals’ personal history. Specifically, only 20 of the 76 studies (26%) included in this review investigated the specific characteristics of spousal bereavement. The remaining studies assessed grief without distinguishing the relationship with the deceased person. Finally, the majority of these 20 used quantitative methodologies to detect emotional distress in the bereaved spouse.

Discussion

Theoretical trends in spousal bereavement after cancer

When looking at theoretical foundations of studies, it was observed that two models tended to be dominant in recent grief literature: (i) attachment theory [46]; and (ii) socio-cognitive models of coping [93].

The various theoretical models described in the literature present certain limitations in relation to the reactions to loss of the loved one from cancer. First, assessing attachment style has the advantage of being particularly useful in describing the characteristics of the relationship to the spouse (e.g., dual process model of coping with bereavement [122]). However, attachment theory does not take into account the characteristics related to illness nor the experience of the caregiving spouse at the end of life. The failure to take into account these characteristics is also true in coping models of bereavement [e.g., 40], which remain decontextualized.

Trends in prolonged/complicated grief

When considering the literature investigating reactions to loss after the death of a loved one as either normal or pathological, we observed that the attempts to empirically validate the relevance of the classification of PGD tend to focus on the following: (i) discrete factors; and (ii) intensity of grief-related symptoms. Among the 25 studies targeting these issues, only three examined spousal bereavement. Studies by Holly Prigerson and colleagues on prolonged grief/PCB-RD have identified predisposing factors for PGD including burden of the caregiving experience, separation distress, and attachment styles [e.g., 52]. Prigerson’s studies also have the advantage of proposing treatment modalities for bereaved individuals such bereavement support groups whose objective is to reduce participants’ separation distress [45].

Lack of empirical studies

As noted earlier, results show that among studies dealing with the grieving reaction of relatives following cancer, only 20 focused on bereaved spouses. Several hypotheses can be proposed to explain this lack. First, bereaved spouses may constitute a population that might be difficult to recruit for research purposes. For instance, in the context of bereavement, participating in research may be perceived as too burdensome or harmful [124–126]. For instance, the qualitative methodologies are thought to be likely to cause more psychological pain than responding to a questionnaire because talking about the experience of grief is believed to induce emotional distress. These arguments contrast sharply with recent studies emphasizing that approaching and studying partners and spouses is feasible and can even be highly beneficial for them [127]. In addition, there are very few outcome measures in terms of questionnaires that integrate the spousal experience, with the exception of the Inventory of Daily Widowed Life [128].

Directions for future research

We propose that future research might address the following three core issues. First, because of the lack of literature concerning the intersections of spousal bereavement and cancer death, it appears crucial to investigate the characteristics of the spousal experience at the end of life and during bereavement to develop specific mixed methods [e.g., 128,129]. To address the specific nature of grieving through cancer, specific comparative methods can be developed.

Second, in order better to inform grieving models, an important objective for bereavement research is to ensure ongoing investigation of the psychological processes, for instance, anticipatory grief, involved before and after death. Longitudinal studies, such as the Prigerson’s Coping with Cancer study [e.g., 99], that span the time both before and after death could permit the evaluation of the spouse’s experience of the disease and the end of life.

Finally, it may be important to address the lack of empirical data about cultural variations in the grief process [e.g., 130–133] or about grief reactions in gay communities [134].

Implications for clinical practice

The present review suggests two possible consequences for clinical practice. The literature clearly indicated that there is no scientific consensus concerning the protective or deleterious nature of anticipatory grief reactions in the emotional adjustment of the close friends or relatives of terminal cancer patients [9,61]. This finding should promote a less normative attitude regarding spousal adjustment.

Some clinicians may use outmoded models that fail to integrate spousal experience in bereavement. Particular attention may need to be paid to core features of spousal grief, especially the attachment styles to the deceased partner [123].

Limitations of the present study

One important limitation of this review is that the majority of the literature was largely restricted to Western,
English-speaking countries. Given the cultural aspects of grieving and mourning, the findings may not be generalizable across culturally diverse populations.

A second limitation is related to the methodology. Emerging themes discussed in the previous texts were deemed sufficiently explicit to warrant acceptable reliability and face validity. Nevertheless, the exclusion criteria of this review may have been too rigid and did not permit inclusions of potentially relevant studies on the topic. For example, some studies were not specific to the cancer context but underlined interesting findings regarding grief trajectories, which readers are invited to review at their discretion [e.g., 135,136]

Conclusion

This review underlined several limitations of main models of grief reactions. Nevertheless, all these models tend to highlight the same critical point: it is crucial to consider adjustment to loss as a phenomenon that derives from elements present prior to the patient’s death. To identify and to prevent complicated grief or extreme psychological distress, as well as to more clearly identify the needs of bereaved individuals, the present review suggests that researchers and clinicians pay particular attention to both end-of-life and the subjective experience of spousal grief. The identification of prevention factors, both empirically and theoretically derived, may allow for assessing and treating spouses at greater need of psychological support following the death of their partner.

Acknowledgements

Léonor Fasse wishes to acknowledge the following funding source: the French National Cancer Institute SHS 2011 (INCa). Christopher J. MacKinnon wishes to acknowledge the following funding sources: The Canadian Institutes of Health Research (CIHR); the CIHR/Canadian Cancer Society Strategic Training Program in Palliative Care Research, McGill Graduate Studies, and the Family Caregiving at End of Life New Emerging Team (CIHR). Appreciation is also extended to S. Robin Cohen (McGill University).

Notes


2. For purposes of this manuscript, a spouse is defined as an intimate-romantic partner of the cancer patient who has shared the same residence (as the majority of the literature, we have surveyed has defined it).

3. Stress proliferation phenomenon is defined as the spread of stress related to the illness and caregiving experience (for instance, fear of loved one’s death), to other areas of daily life (for example, fear of losing one’s job) [7].

4. The recently published DSM5 suggests the new term PCB-RD and places it in a category for Conditions for Further Study. It does not yet acknowledge PCB-RD as a fully accepted diagnosis but does allow bereavement to be an acceptable cause of adjustment disorder.

5. The DPM integrates attachments styles as predictors of adjustment [123].

References

64. Mystakidou K, Tsilika E, Parpa E, et al. Demographic and clinical predictors of
Models of spousal grief after cancer


Addington-Hall J, O’ Callaghan A. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliat Med* 2009;23(3):190–199. *


Stajduhar KI, Martin W, Cairns M. What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative and Supportive Care* 2010;8(3):277–89. *

Gordon TA. Living in the memory of loss: Exploring the impact of aggressive, palliative, and hospice care and surviving loved ones. *Dissertation Abstracts International Section A The Sciences and Engineering* 2010;70:4854. *


