



# Ambiguous loss in family caregivers of loved ones with cancer, a synthesis of qualitative studies

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## Abstract

**Purpose** The purpose of this synthesis of qualitative studies is to explore manifestations of ambiguous loss within the lived experiences of family caregivers (FCG) of loved ones with cancer. Grief and loss are familiar companions to the family caregivers of loved ones with cancer. Anticipatory loss, pre-loss grief, complicated grief, and bereavement loss have been studied in this caregiver population. It is unknown if family caregivers also experience ambiguous loss while caring for their loved ones along the uncertain landscape of the cancer illness and survivorship trajectory.

**Methods** We conducted a four-step qualitative meta-synthesis of primary qualitative literature published in three databases between 2008 and 2021. Fourteen manuscripts were analyzed using a qualitative appraisal tool and interpreted through thematic synthesis and reciprocal translation.

**Results** Five themes were derived, revealing FCGs appreciate change in their primary relationship with their loved ones with cancer, uncertainty reconciling losses, an existence that is static in time, living with paradox, and disenfranchised grief. The results of this synthesis of qualitative studies complement the descriptors of ambiguous loss presented in previous research.

**Conclusions** The results of this synthesis of qualitative studies complement the descriptors of ambiguous loss presented in previous theoretical and clinical research. By understanding ambiguous loss as a complex and normal human experience of cancer FCGs, oncology and palliative care healthcare providers can introduce interventions and therapeutics to facilitate caring-healing and resiliency.

**Implications for Cancer Survivors** Untreated ambiguous loss can result in a decrease in wellbeing, loss of hope, and loss of meaning in life. It is imperative that cancer FCGs experiencing ambiguous loss are recognized and supported so that they may live well in the family disease of cancer.

**Keywords** Grief · Neoplasm · Ambiguous loss · Caregiver · Uncertainty · Qualitative research

With the advent of novel cancer treatments and increased patient survivorship rates, the impact of the cancer illness's latent outcome is often extended for patients and their family

caregivers (FCG) [1, 2]. The threshold for disease recurrence and possible death is raised, introducing a landscape of uncertainty and ambiguity for FCGs [1]. Within this space of ambiguity and heightened awareness of mortality [3], the cancer FCG may encounter emotional burdens and psychological distress such as chronic sorrow [4], heartbreaking hidden griefs [5], reduced closeness and connectedness [6], unknowns and uncertainty of the future [5, 7], emotional devastation [2, 5], and instability [6].

Ambiguous loss is defined as a situation “of unclear loss that remains unverified and thus without resolution” [8]. Ambiguous loss alludes to the ambiguity, emotional limbo, uncertainty, unfinishedness, and the circuitous and confusing nature of a physical or psychological loss as a relational phenomenon [8–10]. There are two types of ambiguous loss, the first type of ambiguous loss refers to a physically absent

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person who remains psychologically present in the family [8]. The unresolved physical absence of a family member can be due to kidnappings, disasters such as earthquakes and tsunamis, and the mysterious disappearances of airline flights. Due to the circumstances of physical ambiguous loss, families often do not know whether or not their loved ones are dead or alive. Families often describe physical ambiguous loss as “gone but not for sure” [8]. The second type of ambiguous loss is psychological and occurs when a loved one is physically present but perceived to be psychologically missing [11]. Family members describe psychological ambiguous loss as “here, but not here” [8]. A family member can be physically present yet missing psychologically due to the nature of living with chronic illnesses or disabilities, substance use disorders, and to cognitive impairment or memory loss as noted in persons with mental illness, brain injury, and dementia [8, 10].

The premise of the theory of ambiguous loss is anchored upon the assumption that ambiguous loss defies resolution as boundary ambiguities exist around who is in and out of a family, both physically and psychologically [8]. These boundaries are never absolutely clear and contribute to decreased wellbeing, loss of hope and meaning, and feelings of ambivalence. The ambiguity stems from relational processes that are frozen when a person is emotionally, cognitively, socially, or physically missing from the typical systems within a family. This loss is isolating and can be one of the most stressful losses as family members remain trapped between “hope and despair” [8].

The Clinical Practice Guidelines for Quality Palliative Care [12] call for greater attention to the FCG assessment and the support of the family in coping with uncertainty, grief, loss, and the emotional aspects of caregiving. Despite the need to understand the importance of FCG wellbeing [13], few studies exist within the literature on the phenomena of ambiguous loss and the grief reactions of family members who may be experiencing the psychological loss of their loved one. These studies are among limited family populations, including persons with dementia [14] and brain-injured intensive care unit patients [9]. Presently, health research publications lack an exploration of cancer FCGs’ lived experiences and situational understanding of ambiguous loss. A meta-synthesis of existing qualitative research moves the field of health research forward as it illuminates situations and themes that were not evident prior, thus gaining a greater understanding of ambiguous loss to guide research and clinical practice in the cancer arena.

## Research question

The research question for this review is, “How does ambiguous loss manifest in the lived experiences of FCGs of loved ones with cancer?” By extrapolating themes of ambiguous

loss through a meta-synthesis of qualitative studies on the grief and loss experiences of FCGs of cancer patients, health research and clinical practice can be guided to support FCG wellbeing and quality of life domains as they care and live with their loved one during the oncological illness trajectory and survivorship.

## Methods

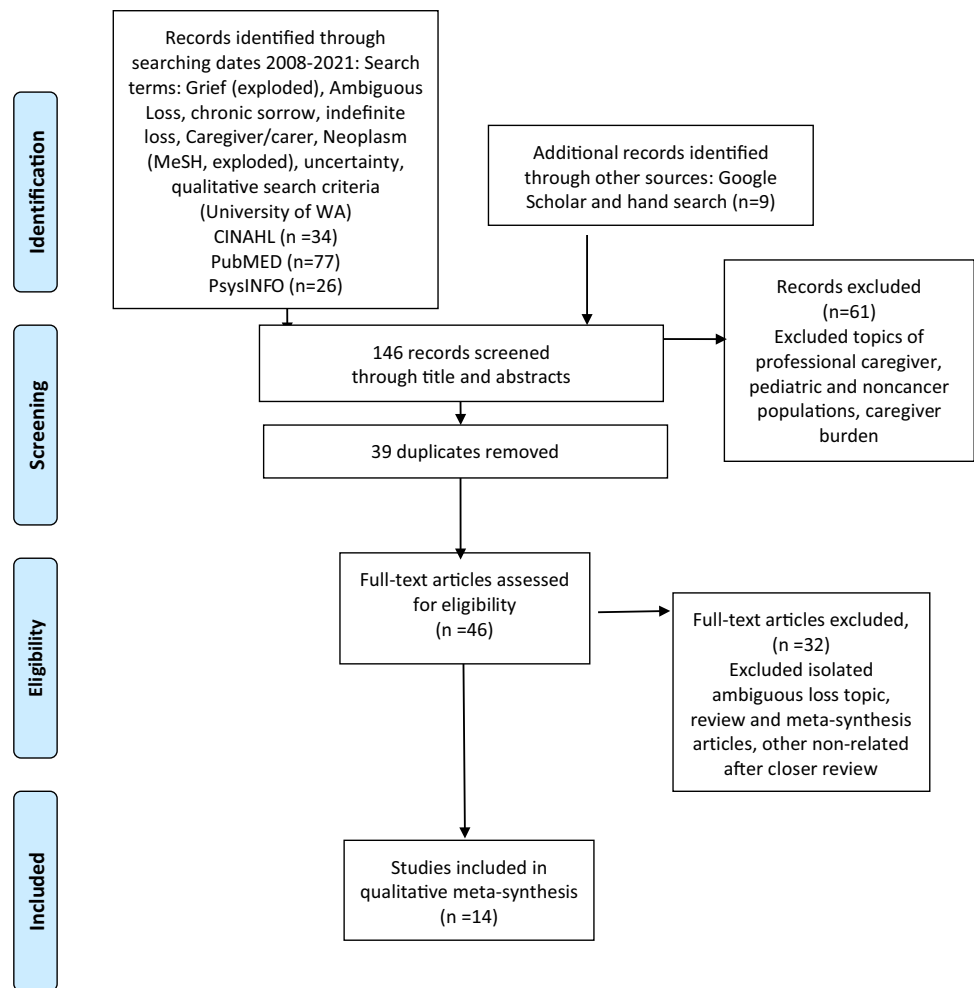
A qualitative meta-synthesis design congruent with ENTREQ international standards for reporting and conduct [15] included: a structured research question and search strategy; quality appraisal and data immersion; theme analysis and reciprocal translation; and theoretical examination. Each published research study was considered a unit for analysis and not limited to reported participant text [16].

### Procedures: search strategy, study selection, critical review, and sample

The literature search was conducted with the assistance of a large university medical campus health science librarian. Studies were identified utilizing the search engines PubMed, CINAHL, and PsycINFO. Cancer and grief were explored using PubMed MeSH terms and CINAHL “explode” option, which included the terms of loss, indefinite loss, ambiguous loss, uncertainty, and cancer and neoplasm. A combined approach of thesaurus terms and free-text terms maximized the number of potentially relevant articles. The terms caregiver, carer, and qualitative research were added to the search. The Boolean operators “and” and “or” were used to expand and narrow the search parameters (see Fig. 1). The electronic search was supplemented by data-driven manual searches using the primary reference list of the selected studies.

FCGs were defined as family members, life partners, or friends who provide and maintain a substantial level of unpaid daily care, including physical, emotional, and often financial support, to another person who cannot care for themselves without the caregiver’s assistance [12, 17]. The inclusion criteria for this study included: (a) utilized qualitative methods; (b) utilized interview data collected from cancer FCGs; (c) were published between 2008 and 2021; (d) contained the presence of cancer in the loved one of any type and stage. Recognizing the literature in cancer research is ongoing and evolving; the search for publications was initially 10 years (2010–2020) to capture significant and timely research findings. The search was expanded to 2008–2021 due to this study’s timeline extension and the decision to include multiple primary referenced articles. Exclusion criteria for the study were: (a) quantitative, mixed methods, and meta-synthesis qualitative studies, as these either did not

Fig. 1 PRISMA



utilize qualitative methodology or were involved in layers of interpretation which would limit the ability to synthesis across one method of research as used in this study's meta-synthesis technique [15]; (b) articles whose patient population focused on pediatrics, exclusive bereavement grief, or non-cancer diagnoses; and (c) articles whose caregivers were professional healthcare workers.

The PRISMA (see Fig. 1) details the article selection process in each step from identification ( $n = 146$ ), duplicate citations removed ( $n = 39$ ), and screening through titles and abstracts to reject an additional 61 articles. The process yielded a total of 46 articles for full text review. Retrieved abstracts and titles were screened for potential eligibility by two reviewers (CW, CB). After conducting a methodological critical review, 14 articles remained relevant for further analysis per our study inclusion criteria.

Research team members (CW, CB, AG) reviewed the included qualitative studies by critiquing 17 items relevant to the study's methodology, analyses, and rigor by utilizing the McMaster University method for quality appraisal [18]. The tool [18] evaluated rigor by the four components of

trustworthiness: credibility, transferability, dependability, and confirmability, as criteria initially identified by Guba and Lincoln in 1985 [19, 20]. The research team reviewed the findings of the appraisals through team discussion and jointly decided that 14 of the articles met the requirements of the methodological critical review. The findings from the critical review and characteristics of the 14 articles included in this meta-synthesis are summarized in Table 1. Articles were published between 2008 and 2019 with sample sizes ranging from 7 to 92. The total number of participants interviewed was 323 adults, composed of 204 females and 119 male FCGs. Most of the participants reported in the articles were Caucasian female spouses of a loved one with cancer, with a median age of 57 years. The principal study design utilized phenomenology methodology.

## Data analysis

The aim of a meta-synthesis is to produce from a body of qualitative research literature new knowledge beyond its primary studies [16]. The process of integrating new knowledge involves

**Table 1** Literature yield table

Authors	Purpose	Country	Study design	Methods	Participants	Summary of findings
#1: Dumont, Dumont, & Mongeau (2008) [21]	To understand the experience of the caregiver during the grieving process—to more specifically identify the factors that influence the grieving process of the family caregiver who provided care to the patient until the time of death, positive and negative	Canada	Phenomenology, descriptive	Interviews performed, using interview grid developed based on the conceptual framework chosen to guide the data collection, using open-ended questions, enabled to researcher to be guided by the participant's discourse and addressed the caregivers' bereavement experience Asked about themes according to conceptual framework	18 caregivers: age range 33–75, 11 women. 17 were Roman Catholic in faith. Recruited through 1 hospice setting	The caregiving experience of grief is complex and follows the trajectory of beginning of care till after death. Family and caregiver palliative care support throughout the trajectory is warranted to reduce risks of bereavement complications
#2: Bouchal, Rallison, Moules and Sinclair (2015) [22]	To explore the experiences of anticipatory grief of families who cared for their loved one with terminal cancer, by exploring the caregivers' retrospective understanding of grief as they lived in the midst of illness	Canada	Hermeneutic phenomenology	In person interview, tape recorded Brief notes made to comment on interviewer's observations followed by more extensive field notes to include reflections of the experiences of the interviewers Analyzed rigorously via journaling, memoing, comparison discussion between researchers	8 spousal caregivers, 6 were male, ages 55–81, all spouses of loved ones who died from cancer illnesses	The study revealed more about the complexities of grief and mourning experience of "holding on and letting go" the duality and ambiguity experience of caregivers; the study was supported by the concepts of mourning, anticipatory grief
#3: Ponto and Barton (2008) [2]	Describe the experience of ovarian cancer from the husband's perspective	USA	Descriptive, interview	Primary author conducted telephone interview in private location, semi-structured interview guide was used asking spouse to describe their experience, effects on them etc. Interviews were audiotaped, lasted an hour Reflective notes generated post interview—for author to document thoughts, summaries, reflections about the process and content	11 male Caucasians whose wives were alive with ovarian cancer, all employed and English speaking	Men experience positive and negative effectives—emotional, psychological, social, from their experience with living with their wives who have ovarian cancer

Table 1 (continued)

Authors	Purpose	Country	Study design	Methods	Participants	Summary of findings
#4: Sjolander, Hedberg, and Ahlstrom (2011) [23]	To explore management strategies that family members use when the patient is in the early stage of treatment for advanced lung and GI cancer	Sweden	Phenomenology	Tape recorded interviews conducted by first author using 2 open ended questions—regarding how the caregiver handled everyday lives, with follow questions to clarify/provide details. Coding, theme emergence	20 participants—family members of patient who had been diagnosed with lung or GI cancer 8–14 weeks prior to study. Patients actively on chemotherapy. 80% women ( $n = 16$ ), median age 60	The main function (overarching theme) of management strategies found was “striving to be prepared by the painful” with multiple subthemes: living in the present, shielding the family from grief and others
#5: Olson (2014) [1]	To explore the loss and grief experiences of a cancer spouse caregiver at various stages in the cancer journey, to provide insight into the experiences associated with potential future indefinite loss of a partner	Australia	Grounded theory	Participants were interviewed twice by the same interviewer (a sociologist)—6 months apart. First interview was narrative and semi-structured focus. Follow-up interview focused on validation of interpretations from the first interview, new questions that emerged from the analysis (themes), and any changes. Interviews were recorded digitally	Purposive sample of 14 women and 18 men, all spouses of cancer patients ages 30–89 Various types of cancers and stages, to include bereavement	Indefinite loss resonates with the type of grief that is experienced by cancer carers, providing care outside of the terminal or bereavement stage: loss of uncertainty. This is a new term and was conceptualized in this article
#6: Rodenbach, Norton, Wittink, Mohile, Prigerson, Duberstein, et al. (2019) [24]	To explore family caregivers’ emotional experiences while caring for patients with advanced cancer and navigating distressing information, awareness of dying and difficult decisions	USA	Qualitative descriptive	Audio recorded semi-structured interviews with recently bereaved caregivers—to elicit caregivers’ perspective, interviews lasted 15–45 min—1:1 with interviewer	92 family caregivers, 61 female, mean age 64, majority Caucasian with some college education, patient with cancer stage III–IV, meeting “would not be surprised if died in 6 months” question	Identification of multiple emotionally intense moments that caregivers may face, including dual stresses of advocating for patients’ needs while experiencing grief/loss, feelings of helplessness, and a sense of attainment and peace. Caregiver well-being is associated with patient-perceived quality of care

Table 1 (continued)

Authors	Purpose	Country	Study design	Methods	Participants	Summary of findings
#7: Roing, Hirsch, and Holmstrom (2008) [25]	The aim of this study was to describe oral cancer and its initial treatment as experienced by the patients' spouses—knowledge of what the spouse lives through, gaining insight into thoughts, feelings, and concerns	Sweden	Phenomenology. existential Through the lived experience of body, human relation, space, and time	Interviews with spouse (carried out by first author), included 5 main open-ended questions each starting with the word "how"	7 spouses (3 women and 4 men), median age 58. The sampling was purposeful regarding the type of cancer, recurrence, treatment given to patient	Findings give insight into the lived experience, resulting feelings of living in a state of suspension, changed life patterns and uncertainty about the future, the diagnosis and treatment of patient marked the beginning of a psychologically stressful period in the spouse's life world, even upon treatment end
#8: Pusa, Persson, and Sudin (2012) [6]	To illuminate the meanings of significant others' lived experiences of their situation from diagnosis through and after the death of a family member, because of inoperable lung cancer	Sweden	Phenomenological hermeneutic	Audio taped narrative interviews with 2 questions and then probing follow-up questions, 1 interviewer 60–120 min	11 bereaved significant others, 9 women, mean age 57. Loved ones with inoperable lung cancer	To interpret the significant others' experiences in terms of being in transition. Themes emerged included: being unbalanced, being transitional, being cared for, moving forward, reflections
#9: Shilling, Starkings, Jenkins, and Fallowfield (2017) [26]	The aim of this study was to explore how do cancer patients and their families adjust to the uncertainty that surrounds the length and quality of their survival	UK	Descriptive qualitative	In-depth semi-structured interviews with patients and their chosen informal caregivers to inform item development—and theme emergence	24 patients and 23 caregivers (Dyads) Patients diagnosed with stage 3 or 4 ovarian/lung or melanoma. 15 female participants, median age 54	20 major themes and 33 subthemes—with recurrent topic of uncertainty encompassing subthemes such as planning for future, providing for one's family, employment, and finances
#10: Mosher, Adams, Helft, O'Neil, Shahda, Rattray, et al. (2016) [27]	The purpose of this research was to identify caregivers' key challenges in coping with their family member's advanced colorectal cancer from the perspective of patients and caregivers	USA	Descriptive qualitative	Semi-structured interviews with patients and their chosen informal caregivers (separate interviews). Theme emergence	23 caregiver/patient dyads, patients with stage 3 or 4 Colorectal cancer. Living patients. 20 female caregivers, median age 56	4 cancer related challenges experienced by caregivers: emotionally processing the initial diagnosis or recurrence, managing practical and emotional aspects of patient care, facing an uncertain future, and encountering symptom-related suffering



Table 1 (continued)

Authors	Purpose	Country	Study design	Methods	Participants	Summary of findings
#11: Quinoa-Salanova, Porta-Sales, Monforte-Royo, and Edo-Gual (2019) [28]	Explore the lived experiences of primary family caregivers of myeloma patients	Spain	Hermeneutic phenomenology	In-depth semi-structured interviews with caregivers, open-ended questions around key themes guided by literature	12 main caregivers of a relative with myeloma, varied in age, 8 women, varied family relationships	4 main themes emerged with a key overarching theme of uncertainty: (a) a new life and adapting to the disease, (b) commitment, (c) the emotional sphere, (d) experiences in relation to the care and support received
#12: Olson (2014) [29]	Explore how cancer carers' experiences and support preferences vary by using the concepts of time and emotion to inform the data analysis	Australia	Grounded theory	Narrative, semi-structured longitudinal interviews with a purposive sample of spousal caregivers. Using Corbin and Strauss's grounded theory, deductive coding was completed, allowing themes to emerge	32 spousal carers of cancer patients in various stages and diseases. 18 husbands/14 wives. Most participants aged in 50's–60's	2 main coding branches emerged: informal support and support services. A subtheme within informal support was time to feel including narrative experiences of the relationship feeling stronger, emotions of guilt related to lack of time, and the view that having one's feelings are an indulgence
#13: Sutherland (2009) [30]	Explore the meaning of female partners' experiences when spouses with cancer transition to end-of-life care	Canada	Phenomenological	Purposive semi-structured face-to-face interview, using Gadamer's philosophy of understanding for analysis and theme emergence	8 female partners of persons with cancer on palliative care services, 5/8 had advanced cancer diagnosis. 6 of the women with their spouse for over 25 years	3 major themes emerged: Meaning of our lives, dying with cancer, and glimpse into the future
#14: Coelho, de Brito, Teixeira, Frade, Barros, and Barbosa. (2019) [31]	Identify the characteristics of anticipatory grief among family caregivers of terminal cancer patients	Portugal	Exploratory descriptive	In-depth semi-structured interviews in a palliative care unit, spanning 12 months. Interview script with main topics regarding perceived experiences and circumstances of caregiving. Qualitative thematic analysis guided by Braun and Clarke guidelines	26 caregiver participants, 23 were women, 14 adult children, 10 were spouses. 1/2 cohabitated with their patients. Median age 55	3 main themes emerged with subthemes: traumatic distress (uncertain of illness, image of degradation, vicarious suffering, caregiver impotence, life disruption), separation distress (anticipation of death, relational losses, separation anxiety, sense of protection, affective deprivation), emotional regulation and dysregulation

reviewing the data through the interpretive study of interpretations using thematic synthesis for systematic review [32]. We used social constructivist assumptions as the meta-synthesis framework, which situates knowledge within lived experiences, that individuals can perceive multiple realities, and that description is a process of deepening interpretation where language is the means to convey meaning through interactions [16, 33].

The collection of qualitative articles was analyzed for themes using an inductive approach, allowing for the generation of key themes [34, 35]. The articles were read in their entirety by the first researcher (CW), line by line, and reviewed for themes of grief and loss. The team then evaluated the themes and defined theme labels through group discussions. Space and time were permitted for the deconstruction and reconstruction of patterns, assumptions, and interpretations to be produced. Through our reflexive attendance to the sensitive nature of the contextual human experiences of loss and grief, new meanings, themes, and subthemes were discovered, adding credibility to this study.

## Findings

Through the process of interpretive integration adapted from Noblit and Hare [36], known as reciprocal translation, an evidentiary matrix of newly derived themes and subthemes was mapped back to the original studies from which the themes were grounded (see Table 2). The final list of themes was cross analyzed deductively with descriptors of the assumptions of the ambiguous loss theory [8, 11] to identify possible characteristics of ambiguous loss (see Table 3) within the content of this body of qualitative articles. Thus, the final analytic question was: How does ambiguous loss theory relate to the derived themes through similarities and differences? This process helped identify patterns of ambiguous loss for future study.

The themes that inform “ambiguous loss as manifested in the lived experiences of FCGs of loved ones with cancer” are: (a) changes in the primary relationship, (b) uncertainty reconciling loss, (c) living with paradox, (d) static in time, and (e) grief that is hidden. Refer to Table 4 for additional illustrative FCG participant quotes for emphasis.

*Constantly changing landscape* is the thematic thread woven throughout the patterns of ambiguous loss, as manifested in all the themes by common and unique features aggregated and interpreted within and across all 14 studies. The relational reality of these FCGs was compromised [26], and the life they knew before the cancer illness had been rearranged into an ongoing situation that lacked closure and resolution. The equilibrium of the relationship with their loved one and the life they knew together collapsed as the illness introduced a series of unpredictable changes and unknowns. This overarching theme illustrates

how FCGs were often unsure of what lay ahead while caring for their loved ones with cancer, as the landscape in front of them was constantly changing, unclear, and unpredictable [27]. They lived in the “*Day to day of not knowing...every day presents something different*” [24].

## Changes in the primary relationship

FCGs often experienced role dissonance and the development of new roles within their existing relationships with their loved ones with cancer.

*For him to become ill was like it defied all truths that we understood to be true, that he would be the leader and the protector and we would be embraced by his protection. I wanted to step in there and look after him and try to make everything better, which of course I couldn't* [25].

They took on the roles of primary emotional supporter and caregiver, both roles they had not had before the illness of cancer [6, 28, 31].

FCGs often experienced a loss of intimacy and reciprocity in the primary relationship [6, 30]. They felt unable to share their emotions with their sick loved ones, which led to a lack of connectedness [6]. The normative roles in the relationship, particularly between the spouse and partner, were often placed on hold as the partner with cancer became a patient [28]. These relationship changes often led to a shift in the balance [30] and a decrease in physical and emotional intimacy [6, 21, 30]. As their loved ones with cancer physically changed, the FCGs bore witness to the physical “wasting away” [24] and suffering [6, 25, 30], even to the extent in which they could not recognize the person for whom they loved [29].

Yet, the FCGs often maintained efforts to remain interconnected [31] and lighten the other’s burden. One participant stated, “*I come home to be there for whatever he needs*” [31]. Sometimes they noted positive changes such as increased emotional closeness, strengthened partnership, improved attitudes, and greater physical closeness [2, 6, 21, 23, 30].

## Uncertainty reconciling loss

FCGs were uncertain of their loved one’s future, including when to expect a response to treatment, recurrence of disease, or a decline of health [28]. Every day they were in a state of flux of not knowing [30, 31]. Prognostic information was often vague, and illness trajectories were unpredictable [1, 21]. Cancer was “*A cloud of metastatic possibilities hanging over them; you can see it [death] sort of looming*” [1].



**Table 2** Reciprocal translation: “manifestations of ambiguous loss in the lived experiences of family caregivers of loved ones with cancer”

Derived analytical theme and subthemes	In papers # (as listed in Table 1)	Primary study themes
<b>1: Changes in the primary relationship</b>		
Role shift	1, 2, 7, 8, 11	Characteristics of the family caregiver, being with, from spouse to supportive care-lived relation, being responsible, change in daily routines and roles negligence of self-experiences of lived body, burden of caring, uncertainty of illness feeling secluded, logistics of care, relational losses from spouse to supportive care, changes in the marital relationship, burden of caring, relational losses a restricted life-lived space a restricted life-lived space, commitment striving to be prepared for the painful, dying with cancer: burden of caring being responsible, changes in the marital relationship, time to feel, the meaning of our lives: our relationships, affective deprivation
Caregiver as witness	7, 10, 13, 14	
Loss of intimacy and reciprocity	8, 14	
Balance shift	7, 11, 13, 14	
Physical separation	3, 7	
Relationship on hold	7	
Lighten the other's burden	4, 11, 13	
Positive changes	3, 8, 12, 13, 14	
<b>2: Uncertainty reconciling loss</b>		
Uncertainty of the future of loved ones disease process and illness trajectory	2, 7, 10, 11, 14	the transition through death, negligence of self, a restricted life, facing an uncertain future, core theme: uncertainty, uncertainty of illness attempting to maintain hope a restricted life-lived space, uncertain path, looking for hope, living in the present uncertainty drives a sense of life on hold, a restricted life-lived space uncertainty and non-specific hopes and dreams, uncertainty and retirement plans, commitment: unconditionality of care ‘being the mainstay’, life disruption uncertainty and non-specific hopes and dreams, facing tomorrow uncertainty and non-specific hopes and dreams, uncertainty drives a sense of life on hold, negligence of self-experiences of lived body uncertainty and non-specific hopes and dreams, mourned for taken for granted future, separation distress negligence of self-lived body negligence of self-lived body indefinite loss, being unbalanced, uncertainty drives a sense of life on hold being unbalanced, encountering symptom-related suffering, time to feel, facing tomorrow feeling distressed, caregiver impotence
Hold on, there is hope	4	
No plans-forbidden thoughts of the future	7, 5, 13, 4	
• <b>Grief with unpredictability of fate or future</b>	9, 7	
Caregiver life suspended	9, 11, 14	
Loss of planned future dreams and hopes	10, 13	
Threat of loss of what could have been, choices	9, 5, 7	
Grief compounded	9, 5, 14	
Mourning the lost sense of a clear future	7	
• <b>Uncertainty creates negative caregiver emotions</b>	7	
Worry about the future of loved one	5, 8, 9	
Not doing enough		
Ashamed and guilt	10, 8, 12, 13	
Powerlessness to relieve suffering	8, 14	
<b>3: Living with paradox</b>		
Sacred meaning in life/death and the disease	1, 11	Spiritual suffering the paradox of holding on and letting go, burden of caring preparing for, finding gratitude-peace-and purpose, striving to be prepared for the painful, banishing thoughts about the approaching loss, living in the present, uncertainty of illness Being unbalanced/experiencing ambivalence
Meaning in memories during loss	2, 13	
Being in the present moment	2, 6, 4, 14	
Co-existence of suffering and joy	8	
<b>4: Static in time</b>		
• <b>State of suspension-emotional limbo</b>	7, 5, 4, 9, 10	altered sense of lived time, incapacitated planning, awareness of mortality, living in the present, uncertainty drives a sense of life on hold, facing an uncertain future negligence of self-experiences of lived body, banishing thoughts about the approaching loss moving into bereavement, experiencing ambivalence, significance of his life
• <b>Living in the memories</b>	7, 4	
	2, 8, 13	
<b>5: Grief that is hidden</b>		
Grief behind the veil	1, 2, 11	contradictory nature of anticipation, the emotional sphere: not airing their feelings contradictory nature of anticipation, shielding the family from grief, feeling secluded, commitment: putting on a brave face, self-regulation efforts, sense of protection
Shielding others from distress	2, 4, 10, 8, 11, 14	

**Table 3** Deductive theme table

Team-derived themes	Assumptions of ambiguous loss theory [8]
Constantly changing landscape	A phenomenon can exist even if it cannot be measured Truth is not attainable and thus is relative The stress of ambiguous loss appears to be greater for families oriented toward mastery
Change in the primary relationship	Ambiguous loss is a relational phenomenon Families can be both physical and psychological entities Ambiguity can be influenced by the family's values and beliefs
Uncertainty reconciling loss The grief with unpredictability of fate or future Living with paradox	Closure is a myth and ambiguous loss defies resolution Truth is not attainable It is still possible to find some kind of meaning in the experience Resilience has a specific meaning Naming the stressor as ambiguous loss allows for coping
Static in time State of suspension/emotional limbo Living in the memories Grief that is hidden	Closure is a myth and ambiguous loss defies resolution State of chronic mourning Truth is not attainable The source of pathology lies in the type of loss and not the type of grief People cannot cope with loss until they know what the problem is Ambiguous loss is not a problem for every family member

**Subtheme: grief with unpredictability of fate or future**

Living in constant uncertainty, FCGs stopped looking ahead as they felt as if they were living on bonus time. They experienced an inability to plan as thoughts of the future were forbidden since these thoughts conflicted with the present life of holding on to the now [37]. The FCGs were unable to reconcile the loss they were presently living. They felt like they had nothing to look forward to, and they experienced the loss of future hopes and dreams of what could have been [27, 28]. These included the loss of retirement, jobs, and plans with their loved ones [1, 27]. One participant said, “*We have a little grandchild, and she's only 15 months old. It's hard for my husband to reconcile that he's not going to see much of her growing up... I think that's the most difficult thing for him, and for me...*” [21]. FCGs mourned the lost sense of a clear mutual future, assumptions, and non-specific choices about their lives [1, 21, 27, 28].

**Subtheme: uncertainty creates negative caregiver emotions**

As FCGs experienced uncertainty, they felt shame and guilt [6, 21, 27] as they experienced moments when they considered planning for the future without their loved ones, asking, “*Why am I having these thoughts?*” [1]. They experienced guilt for doing things for themselves, as was noted by one caregiver: “*If I am earning money I feel guilty because you know, money, guilt, time*” [23].

They often lived in constant states of worry, anxiety, and fear about their loved ones' present and future health [28]. FCGs felt powerless to relieve the suffering they often witnessed [30] and, “*Stand totally helpless and alone*” [6].

**Living with paradox**

The FCGs found existential meaning in striving to be present with their loved ones while grieving the past and planning for the future [21]. They sometimes found meaning, hope, and joy [6, 31] in reflections on the meaning of the circle of life and death and in making memories [29]. The simultaneous holding space of two opposing ideologies is known as paradox [26]. FCGs noted paradoxical presence in the embodied coexistence of suffering and joy with loss and relief [6, 22]. Some FCGs could banish thoughts of a tragic looming loss to engage in being fully present while discovering peace and gratitude [25, 37]. One caregiver stated, “*I know these things are really bad, but in the face of bad things you always try to be positive, you want there to be a cure...an optimistic attitude is as important as the drugs, and that for me came first*” [31].

FCGs continually sought hope of a good outcome for their loved ones [30]. While often recognizing that their loved ones' wishes for cure were unlikely to come true, many FCGs could transition their hope into more realistic expectations [21]. “*I just said I wanted him to be comfortable, pain managed well, that his spiritual needs were met*” [21]. Additionally, the uncertainty of their loved one's disease trajectory allowed some FCGs

**Table 4** Quotes connecting to themes**Constantly changing landscape**

#9, p. 593 “And then it slowly dawns over time that it’s never going to go away. The mythical all-clear is actually never really there because you’re always looking over your shoulder again, constantly aware of what could be there.”

#2, p. 58 “You know you never knew what to expect when you come in that morning..she’d be eating and talking and the next thing you know she’d be drowsy and sleeping.”

#10, p. 2021 “Just the day to day of not knowing...you know, what’s the next text going to show...every day presents something different.”

**1: Changes in the primary relationship**

#11, p. 242 “It actually brought us really close.” “He had a really bad time..for a long time, so trying to lift his spirits was constant.”

#13, p. 427 “[He] was losing some of the control..we worked quite well as a team..and then I felt like I was..taking over more and more...But it’s just mostly that feeling of him not feeling like he’s the head of the household type thing.”

#14, p. 3 “I feel like my husband is disappearing.”

#12 p. 243 “She was in the later stage of the disease...just to be able to lie together and hug each other was, I think (crying) that was probably important for [her] too.”

**2: Uncertainty reconciling loss**

#13, p. 427 “It’s like a roller coaster..because they are up one day, down the next...You come in sometimes and he says ‘Hi’...some days I thought ‘Is this it?’ and then the next I’ve come in and he is sitting at the dining room table.”

**Grief with unpredictability of fate or future**

#7 p. 43 “I don’t know, last summer, I sat in a chair and just read all day, I don’t know..I was completely in pieces, I didn’t function, did nothing at home, or anything.”

#13, p. 428 “We would have been a very wonderful couple to be retired together. We both love to golf and we both love to walk...We would have had a wonderful time. And damn, that’s taken away from us totally.”

#14, p. 4 “Now it’s just my mother, home, and job. This is my life. Because I do not have time.”

**Uncertainty creates negative caregiver emotions**

#8 p. 36 “At the same time you are ashamed over that thing, therefore, it was so hard a period of time that I wasn’t able to be home for a few days.”

#8 p. 36 “And it was very hard on her..well you couldn’t do anything to..so to speak, take away what is hurting, you stand totally helpless and alone.”

#11 p. 243 “It seems everything I do I feel guilty. If I am taking a time out at the gym, or playing with my daughter then I am not earning money...It’s my little horrible triangle.”

#12 p. 506 “The uncertainty, the fear, is so intense that I’ve often thought about selling the house, about doing something drastic...thinking about this house for the two of us, and what I’m going to do here all alone. It’s the fear about it coming back, about whether he’ll get over it again. Ok, now he’s got over it because of his age, but in the future...”

**3: Living with paradox**

#4 p. 4 “I don’t know what it’ll be like at the end when he leaves me. So I say to myself “why go through that grief now? I mean it’s better to concentrate on the happiness we’ve got today.”

#13, p. 428 “We’ve got to have a little bit of hope and you hear everyday about these miracles...that do happen...you never want to give up hope until its gone.”

**4: Static in time**

#5 p. 558 “The future has got down to what I am doing this afternoon almost. Nevermind next week stuff.”

#5, p.556 “We are on borrowed time...I had stopped looking ahead.”

**State of suspension-emotional limbo**

#4 p. 4 “...it came as such a shock. But I suppose it’s become a bit easier to keep it a bit of a distance, so as to be able to carry on.”

#8 p. 38 “You are at some level where you can’t be upset, so much ups and downs so you try not to feel anything instead. Just in order to manage, I think.”

#7 p. 44 “The whole summer passed... and we weren’t able to do anything together...and I didn’t even try to do anything... and I didn’t even try to do anything that I could have done by myself either.”

**Living in the memories**

#2 p. 51 “It was a relationship of shared passions I would say. John was a great lover of the outdoors and he was my mentor and my guide..and my soul mate.”

**5: Grief that is hidden**

#1 p. 1053 “I couldn’t express myself.”

#4 p. 5 “I don’t want my family..to go through so much..so, I think there’s no need for me to weigh them down with all that.”

#11 p. 505 “...I’ve told them I’m better than I am. When they ask, I say ‘I’m fine, I’m fine...don’t worry, I’m managing,’ but inside I’m thinking ‘my God, how far from the truth’...”

#11 p. 505 “I prefer to cry alone...when I go to bed, or in the shower or on my own at home, I prefer that to burdening somebody else, telling them how awful I’m feeling and what an awful time I’m having. I wouldn’t feel comfortable doing that, so I haven’t let go with anybody.”

# refers to journal reference as defined in Table 1

to postpone the threat of the inevitable outcome [6, 24, 30]. This postponement gave the FCGs space to hope for alternative results such as recovery and a longer life

for their loved ones [21, 30]. “*We do not know what will happen next. He has always recovered after coming to the hospital. I’m always holding on to this hope*” [30].

## Static in time

### Subtheme: state of suspension-emotional limbo

FCGs' lives often became suspended as they did not know what the future held, and they stopped making plans for themselves [27, 28, 30]. Time stood still, and the sense of time became altered as identified by one participant: “*I do feel like life is on hold to be honest...like we're just stagnant at the moment*” [27]. Caregivers often felt immobilized or paralyzed in their life courses as they could not plan or make decisions; they could not go back or move forward [1, 27, 28]. Life around them went on autopilot as their focus shifted to their loved ones [31]. They banished thoughts of the possible loss of life and focused only on the here and now [37].

### Subtheme: living in the memories

Within the stasis of time, the FCG sometimes longed to sustain their loved one within the life and bond they shared in the past, before cancer [22]. Caregivers would reflect upon the significance of their loved one's contribution to their families and communities by telling stories [21]. They desired to live in the past life of happier, healthier days as they remembered and reconstructed memories of their loved ones [22]. One participant reflected upon her alcoholic spouse, whom she wanted to be seen as a good person:

*He's had a hard life. He was taken into the army when he was 14 years old. He didn't find his parents for two years afterwards in Europe. Then he came to Canada and worked a double contract so that when his parents and his brother came they wouldn't have to. So life has not been easy for him [21].*

As their relationships with their loved ones continued but changed [22], FCGs found an internal grounding, peace, and appreciation for life by reflecting upon the good times and memories [25].

### Grief that is hidden

The FCGs in these studies often expressed feeling the emotional burden of bearing their grief alone [6, 29, 31], without witness or social support [22]. It was understood that, “*People do not want to talk about things that are sick*” [6]. Mourning occurred behind the veil in private moments, after meeting the patients' and family members' needs [22]. Grief was often held inward, “*Trying to create that sense of I would be okay, that we would all be okay*” [22], to protect and spare others, including the loved one with cancer, their children, and the elderly from experiencing distress and further emotional pain [30, 31, 37].

## Discussion

This study introduces an unknown aspect of cancer FCGs lived experiences of grief and loss by illuminating themes of ambiguous loss. The family theory of ambiguous loss has multiple underlying theoretical assumptions [8] and propositions [11], which have been identified over time by social scientists working with populations across many cultural contexts. These assumptions were deductively explored in relation to the team derived themes to further contextualize and develop new knowledge of ambiguous loss (see Table 3). The first theme *change in the primary relationship* reveals the significance of ongoing change and transformation in the cancer FCG's lived experience of ambiguous loss. FCGs experience significant relationship alterations secondary to changes in their loved ones due to the nature of the cancer illness and its oncological treatment regimens. There is potential for loss of connection and support vital to the relationship, resulting in a psychological absence, “*here but not here,*” referred to as psychological ambiguous loss [8]. While this meta-synthesis noted the presence of positive changes in some of the primary relationships, we consider these findings counter stories to the dominant stories of cancer FCGs. Yet these findings may speak to the reconstruction of identities within relationships as a means for people to overcome the trauma and loss introduced by cancer and remain resilient and healthy through relational connections [26].

The second theme of *uncertainty reconciling losses and the grief with unpredictability of fate or future* reveals the presence of not knowing and the unattainable nature of truth, essential assumptions of ambiguous loss. With ambiguous loss, the loss and grief remain open and without resolution. The expectations surrounding the illness of cancer, including the prognosis and treatment trajectory, often remain unclear. Grief accompanies the uncertainty of not knowing what will happen to their loved ones or themselves. Truth is not attainable, and closure is a myth. There lacks the mastery of finding answers to a problem [38] regarding the expected illness outcome of the FCG's loved one [31]. Cancer FCGs can be encouraged to re-define their hopes as hope-in-the-moment, accept truth as truth-in-the-moment [39], and reorient away from the urge to control and master outcomes.

The third theme, *living with paradox*, unveils the mystery of opposite qualities contained within the whole [8]. Paradox signifies the cancer FCG's experience of simultaneous holding on and letting go while riding the “*emotional roller coaster*” [6, 40]. Ambiguous loss manifests in a chaotic pattern of “*up and down, back and forth*” [38], by which FCGs create new ways of rationalizing and making sense of the world around them through the regulatory

oscillating process of balancing conflicting demands [30]. This theme recognizes the need for individuals to hold space for conflicting thoughts without the pressure and tension to label and define their experiences and thoughts dualistically. Healthcare providers can encourage FCGs to manage the tensions of polarity thinking by allowing and nurturing space for both-and thoughts, such as “my loved one is both sick and well, or both dying and alive.”

The process of ambiguous loss is understood to be circular and continuous, resulting in immobility, both socially and psychologically [8], as manifested in the fourth theme of *static in time*. The FCG feels trapped in their inability to find closure to their losses, poignantly described in this participant population as being paralyzed in time, living day-by-day [27, 30]. FCGs related to putting life on hold, delaying decisions, and implementing previously made plans for the future. As a consequence of ambiguous loss, FCGs can experience a state of *emotional limbo* while *living in the memories*, which can be misunderstood and mislabeled as depression, post-traumatic stress disorder, and complicated grief [10, 38]. This theme also speaks to the need for healthcare providers to accept the normality of ambiguity present in the cancer loss experience and avoid the urge to label the grief in the loss as a stage of grief to overcome or a mental health crisis. These diagnoses and labels are reductionist and overlook, misunderstand, and minimize the complex lived experience of ambiguous loss. Additionally, misunderstanding this loss can delay acceptance and the delivery of interventions that are vital to a person’s healing.

The final theme, *grief that is hidden*, also known as disenfranchised grief [41], is a common finding of ambiguous loss [10]. Society often does not know how to legitimize loss and grief and provide the support required to grieve when these losses are non-death-related [42], as experienced in palliative and survivorship trajectories. Disenfranchised grief can occur when a loss is not acknowledged, there is an exclusion of the griever, and when society fails to recognize the relationship of the loss to the griever [41]. When grief is hidden and disenfranchised, FCGs lack opportunities to share their loss, and therefore they suffer alone in silence, without social and empathetic support required to heal [43]. This theme is supported in a recent study that found cancer FCGs were co-afflicted but invisible and felt not seen or heard by healthcare providers, friends, and family members [44]. Cancer FCGs need safe spaces to be seen, carry their sadness, and openly grieve as they search for and create meaning when the cancer disease itself is meaningless. Empathetic and compassionate human connections are required for healing. The social recognition of ambiguous loss can promote individual resiliency required for FCGs to tolerate a life of uncertainties.

## Implications for research and practice

By integrating what is known about ambiguous loss from work completed within the social science paradigm [8, 11, 26] with a human science person-centric dynamic framework, FCGs’ humanity and lived experiences of loss can be further contextualized to evolve the constraining and reductionist bio-medical models of care. A collaborative theoretical framework that lends itself to intradisciplinary endeavors may assist oncology nurses and healthcare providers in supporting FCGs’ experiences of ambiguous loss as an acceptable and normal human response to health and the environment. The Resilience Framework for Nursing and Healthcare [45] can guide nurses and healthcare providers in assisting cancer patients and FCGs in identifying and using coping mechanisms that build resilience. The process of becoming resilient is active and incorporates strategies and therapeutic programs intending to acquire a state of equanimity defined as personal acceptance of the impact of the current health situation.

Ambiguous loss theorists and clinicians have identified therapeutic practices and modalities to include those which strengthen resiliency [46], normalize uncertainty [13], reframe meaning [43], create and redefine hope, facilitate the reconstruction of identity, and reorient away from mastery and control when closure is not an option [8, 26, 38, 47]. The Resilience Framework for Nursing and Healthcare identified common coping concepts for illness caregivers including: acceptance, knowledge, mastery, meaning finding, optimism, resourcefulness, self-care, social support, and spirituality [45]. An evolved and intradisciplinary theoretical model of care that incorporates and builds upon the concepts introduced in this framework may provide oncology nurses and healthcare providers in research and clinical practice with language, new patterns of knowing [48], and a holistic lens to introduce practices of care for FCGs across all quality of life domains [13]. Facilitating practices and therapies which promote resiliency can strengthen FCGs to carry the not-knowing and live well in the ambiguity and loss introduced by the cancer illness.

## Strengths and limitations

This meta-synthesis utilizes an international body of qualitative literature on the lived experience of oncology FCG grief and loss within the context of uncertainty. While the findings identified in this study may not represent all cancer FCGs, they provide a situational understanding of the manifestations of ambiguous loss in FCGs of cancer patients with various cancer diseases and stages. Individual differences may exist in experiences of ambiguous loss in relation to the type and stage of the cancer of the family member and other factors not described in this review. A strength



of a meta-synthesis is the interpretation of themes second-hand through a review of data and synthesis of information previously obtained by another researcher, which increases the confidence that themes identified across studies are pertinent. We recognize that a meta-synthesis does not offer researchers access to the full data sets of the original qualitative research. As the data analysis in a meta-synthesis is inherently subjective, we acknowledge that our knowledge and experience of ambiguous loss, grief, and the oncology arena are reflected in this research's data analysis, discussion, and results. Although participants were not excluded based on age, ethnicity, or gender, we noted the lack of ethnic and racial representation. The predominant gender represented was women, while common among caregiver populations for elective studies, was reported to be a limitation in multiple articles. We consider the inclusion of bereaved caregivers as a limitation [1, 6, 21, 22, 25, 27, 29, 30], as bereavement grief could alter the stories of the FCG's loss experience while caring for their loved one while they were living.

## Conclusion

This meta-synthesis of qualitative literature provides new insight into the patterns of ambiguous loss that may underpin FCGs' lived experiences while caring for their loved ones with cancer. Ambiguous loss is a unique type of loss and can contribute to an individual's decrease in wellbeing, loss of hope and meaning in life. We invite oncology nurses and other healthcare providers to accept the normality of ambiguity present within the ongoing loss experiences of cancer FCGs and encourage practices of care that foster resiliency and tolerance of uncertainties.

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## Declarations

**Conflicts of interest** The authors declare that there are no conflicts of interest.

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