



ISSN 2612-4033

Journal of Clinical & Developmental Psychology

Journal homepage: <http://cab.unime.it/journals/index.php/JCDP/index>



A Developmental Approach to Examining Well-Being in the Context of the Cancer Patient and Caregiver Relationship

Giesemann, X.,^{1,*} , Heshmati, S., DeHart, J.,

^{1*} Claremont Graduate University

ABSTRACT

The cancer patient and caregiver relationship is a pivotal aspect of caregiver well-being. Because cancer caregivers spend considerable amounts of time interacting with the patient and due to the long-standing, dynamic nature of this caregiver-patient interplay, this interaction can generate positive or dysfunctional outcomes. To date, there is relatively little research focused on caregivers' experiences in the patient-caregiver dynamic, specifically that which explores this phenomenon using a lifespan developmental approach. This review places the cancer caregiver at the center of the bioecological model (Bronfenbrenner & Morris, 2006), deeming the interaction between the caregiver and patient a proximal process--a main driver of development--in the caregiver's ecological environment. Within this interaction, how the developmental life stage--according to Erikson's (1959) stages of psychosocial development--of both the caregiver and the patient impacts caregiver well-being is investigated. Findings can inform age-appropriate interventions made to foster caregiver and patient well-being.

Keywords: *Cancer caregiver, Informal caregiver, Caregiver-patient relationship*

* *Corresponding author:* Giesemann Ximena, M.A., Division of Behavioral and Organizational Science 150 E. 10th Street

E-mail address: ximena.giesemann@cgu.edu

<http://10.13129/2612-4033/0110-3587>

© 2022 by the Author(s); licensee Journal of Clinical & Developmental Psychology, Messina, Italy.
This article is an open access article, licensed under a Creative Commons Attribution 3.0 Unported License.

Now that Joel, in the midst of adolescence, has just received his driver's license, he has been driving his single mother to and from all of her chemotherapy appointments. His role as her caregiver has left him with minimal time to socialize with his friends and do his homework, causing his grades and social life to suffer. María, who is 80 years old and a cancer caregiver to her husband, feels fortunate to be retired, having ample time to be with and take care of him. Her memory has declined with age, however, and she worries that she will forget to give her husband his chemotherapy medication.

Both María and Joel are cancer caregivers, but their caregiving experience and the ways in which it impacts their own psychological well-being differ markedly as a result of their developmental stage. Caregiving for a cancer patient is no easy feat; negative outcomes associated with cancer caregiving including but not limited to caregiver burden, psychological issues, social concerns, and physical concerns are well documented in the literature (e.g., Dumont et al., 2006; Fisher & Briggs, 2000; Lau et al., 2010; Oldham et al., 2006; Rohleder et al., 2009; Sklenarova et al., 2015). Caregiving for a cancer patient may become even more difficult if the tasks associated with caregiving prevent caregivers from meeting their own developmental needs.

There is research to suggest that the developmental stage of a cancer caregiver may differentially impact the caregiver's health, social relationships, work life, educational life, and other physical and psychological aspects of their lives and well-being (e.g., Bauman, Silver, Berman & Gamble, 2009; Dellmann-Jenkins et al., 2000; Dellmann-Jenkins et al., 2001). These distinct impacts may be due to variations in the developmental needs of the caregiver depending on their life stage (Harden et al., 2006). For example, as reflected in the vignette above, the adolescent caregiver who must juggle the developmental tasks associated with adolescence (e.g., forming close friendships, exploring their identity, etc.) with caregiving tasks is likely to have a distinct life experience in comparison to the older adult who balances caregiving with developmental tasks such as coming to terms with their own mortality, adjusting to the challenges of aging, etc. that mark their life stage (McCormick, Kuo, & Masten, 2011).

Furthermore, because of the interwoven nature of caregivers' and patients' lives (Northouse et al., 2012), the cancer patient's developmental stage may also distinctly influence the caregiving experience, and thereby the caregiver's well-being. Caregivers must be sensitive to the developmental stage of the patient and the various needs associated with it, which can be difficult, given their additional caregiving concerns (James et al., 2002). Whether or not the patient is able to continue to meet the needs associated with their developmental stage has important implications for the patient's well-being (Millar, Patterson, & Desille, 2010). This in turn inevitably impacts the caregiver's well-being, as caregiver and patient well-being are inextricably interrelated (Northouse, Katapodi,

Schafenacker, & Weiss, 2012). In fact, researchers have highlighted the reciprocal nature of the relationship between the cancer caregiver and the patient, deeming it an “emotional system” (Northouse et al., 2012, p. 237), as each individual in the relationship inevitably impacts the other over the course of the patient’s phases of illness (Northouse et al., 2012).

Thus, the developmental stage of life -- being an important factor in how one’s life as a caregiver would unfold -- will make up the central focus of this article. In this review, we aim to develop an integrated understanding of how the developmental stage of the cancer caregiver and the developmental stage of the cancer patient may both positively and negatively influence caregivers’ well-being. This is an important aim for at least two reasons. First, this information has profound implications for improving cancer caregiver interventions made to foster caregiver well-being, as developmental appropriateness of interventions helps to maximize intervention effectiveness (Haase, 2004; Nation et al., 2003). This is especially relevant for interventions made to help cancer caregivers in particular, as cancer caregivers have consistently demonstrated various negative outcomes associated with caregiving (e.g., Dumont et al., 2006; Fisher & Briggs, 2000; Lau et al., 2010; Oldham et al., 2006; Rohleder et al., 2009; Sklenarova et al., 2015). Second, this focus on caregiver well-being has meaningful implications for the cancer “patient’s” physical and psychological well-being as well. Researchers have found that when caregivers are highly distressed, cancer patients are more likely to experience anxiety themselves (Sergin et al., 2007) and caregivers face greater challenges providing optimal care for the patient (e.g., difficulty administering medications; van Ryn et al., 2011; Lau et al., 2010).

To this end, we use Bronfenbrenner’s bioecological theory and Erikson’s stages of psychosocial development -- two prominent developmental theories in the field. We center our review only on “caregiver” well-being due to the relative absence of research focus on the caregiver’s experiences in the interconnected patient-caregiver dynamic, specifically research that uses a lifespan developmental approach to explore this phenomenon (e.g., Francis, Kyriotakis, O’Toole, & Rose, 2016; Harden et al., 2008; Harden, 2005).

In this article, we will first provide a brief overview of the developmental theory informing this review. We then outline the different developmental life stages based on Erikson’s (1959) psychosocial theory of human development and review the literature on caregiver well-being based on both the caregiver and the patient’s life stages. Finally, we conclude with a synthesis of the literature and elaborate on what an integrated understanding of caregiver well-being through the lens of developmental stages affords for the improvement of this vulnerable populations’ lives.

Theoretical Approach

Developmental theory posits that whether or not an individual is able to successfully navigate and complete age-salient developmental tasks associated with each life stage has profound implications for their short and long term well-being (e.g., Erikson, 1959; McCormick, Kuo, & Masten, 2011). For example, adolescents who fail to explore and commit to an integrated identity (the major developmental task that marks adolescence; Erikson, 1959), suffer from short-term psychological impacts such as elevated levels of psychological distress, low self-esteem, and other negative outcomes (e.g., Adams et al., 2005, Luyckx et al., 2005; Schwartz et al., 2005). In the long-term, this lack of meeting their specific identity-related developmental needs leads to feelings of their life being “on hold” in young adulthood -- as if their lack of an integrated identity inhibit them from fully committing to decisions about their future (Carlsson, Wangqvist, & Frisen, 2016). In contrast, the older adult in late adulthood who does not evaluate, reintegrate, and come to terms with past events in their life (the major developmental tasks that mark late adulthood; Erikson, 1959) may experience excessive rumination, guilt, depression, and panic (Torges, Stewart, & Duncan, 2008). In the long-term, this failure to come to terms with the person they have become and lives they have lived can lead to regret for what one has done or not done in their lives, and fear of impending death (Erikson, 1959). Thus, whether or not an individual is able to successfully complete developmental tasks associated with their life stage has profound implications for their short and long-term well-being, and ability to develop optimally.

Achieving healthy, optimal development becomes more challenging for caregivers. Given the time consuming nature of caregiving, cancer caregivers may face difficulty in completing age-salient developmental tasks, leading to poorer psychological well-being. For example, given the often all-consuming nature of informal cancer caregiving (Gates & Lackey, 1998), the adolescent caregiver has less time to spend exploring issues of identity, which is crucial to development during this life stage. Thus, we need to consider every caregiver in the context of their developmental stage, for a full understanding of both short-term and long-term well-being outcomes.

In this review, we use Erikson’s (1959) psychosocial stages of development to distinguish life stages. Through ongoing observations and cross-cultural comparisons, Erikson divided the entire human life cycle into eight stages: 1) Birth to roughly one year of age, 2) roughly two years of age to three years of age, 3) roughly four years of age to five years of age, 4) roughly 6 years of age to puberty, 5) adolescence, 6) young adulthood, 7) middle adulthood, and 8) late adulthood (Miller, 2016). According to Erikson’s theory (1959), in order to develop optimally, an individual must successfully

resolve tasks that are specific to these defined life stages. Failure to resolve tasks often leads to difficulties in the subsequent life stage (Erikson, 1968).

During stages one through three, through successful resolution of these tasks, children ideally learn to develop a sense of trust that their needs will be met (stage one), a sense of autonomy (stage two), and the ability to take initiative by learning to set and achieve goals (stage three). Childhood (roughly 6 years to puberty) is largely marked by learning (in school, with peers, at home, etc.), and successful experiences in this stage give children feelings of competence and industry. Adolescence features the “trying on” of different roles, and successes in adolescence yield a well-integrated identity. Young adulthood is marked by seeking psychological intimacy with others through romantic relationships and friendships. Success in middle adulthood features a sense of generativity: that one has created a better world for future generations. Finally, individuals in late adulthood seek to integrate the previous stages, feeling a sense of acceptance for the limitations in life having acquired the wisdom of the ages. In sum, whether or not one is able to successfully navigate the developmental tasks associated with their life stage has significant implications for both short and long term well-being. Thus, in this review, we focus on the developmental stage of the cancer caregiver and the developmental tasks associated with each stage following Erikson’s psychosocial classification: childhood, adolescence, young adulthood, middle adulthood, and late adulthood. We intentionally did not include the first three stages of Erikson’s classifications as it is very unlikely that children ages five years old or younger are able to undertake the caregiving role.

Furthermore, throughout the lifespan, individuals are constantly in interaction with their surrounding ecological systems--and these interactions contribute to the individual’s development and well-being (Bronfenbrenner, 1989). Based on the bioecological theory (Bronfenbrenner & Morris, 2006) that places the individual at the very center of the bioecological surrounding systems (Figure 1), optimal development should also be taken into consideration via the bidirectional interplay of the individual and the many layers of their immediate and extended environment. Based on this model, one of the main drivers of optimal development within a person’s ecological environment are the proximal processes-- the frequent and increasingly more complex interactions that occur over an extended period of time between the individual in their immediate environment (Bronfenbrenner & Morris, 2007).

In the case of the cancer caregiver, we place the caregiver in the center of Bronfenbrenner’s bioecological model as it interacts with their ecological context, with proximal processes as a central force in this dynamic (see Figure 2). Because caregivers of cancer patients have been found to spend considerable amounts of time interacting with the patient each day (even in comparison to caregivers of patients with other chronic illnesses; Washington et al., 2015; Kim & Schulz, 2008), and due to

the dynamic, complex nature of the caregiver-patient relationship, the interaction between the caregiver and cancer patient can be identified as a proximal process in the caregiver's ecological system. Due to the frequent and long-standing nature of this caregiver-patient interplay, this interaction has the potential to both promote positive outcomes (Bronfenbrenner, 1994) or generate dysfunctional outcomes (Bronfenbrenner & Evans, 2000). Thus, because of the profound influence of the caregiver-patient dynamic as a proximal process on the caregiver's development, we will also take the cancer patient into account when considering caregiver well-being. More specifically, we will examine the differential impact of the cancer patient's developmental stage on caregiver well-being. We aim to develop a deeper understanding of this because whether or not the patient is able to complete age-salient developmental tasks has implications for the patient's well-being, which inevitably influences the well-being of the caregiver.

In sum, we place the cancer caregiver in the center of the bioecological model, considering developmental stage as a person-level characteristic of the caregiver. For each developmental stage across the lifespan, we first examine the caregiver's developmental stage specifically because whether or not the caregiver role impedes successful completion of developmental tasks likely has profound implications for caregiver well-being. Second, we examine how the cancer patient's developmental stage, according to Erikson's classifications, changes the interplay between the caregiver and patient, and the differential impacts it may have on the caregiving experience and caregiver well-being.

Childhood (Roughly 6 years to puberty)

Children as caregivers.

While literature on child caregivers of cancer patients is scarce (Gates & Lackey, 1998), much can be gleaned from research featuring child caregivers of individuals with other chronic illnesses. Children typically become caregivers when there is no one else that can help to meet the needs of an adult with a chronic illness (e.g., when a child is living with a single parent or grandparent, when both parents work and a child has to take care of an ill grandparent, etc.; Gates & Lackey, 1998). Caregiving for a patient with a chronic illness such as cancer during childhood is likely to have developmental implications for the child caregiver (Bauman, Silver, Berman, & Gamble, 2009) who, in addition to caregiving, is also trying to complete the developmental tasks associated with childhood. The period of time between roughly six years of age to puberty is marked by a child's entry into school (Erikson, 1959), where, in addition to learning class content, they learn how to follow the rules, get along with classmates and peers, and make friends (McCormick et al., 2011). In this stage, children also engage in learning outside of school with friends, at home, and in other

contexts (Erikson, 1959). In order for optimal development to occur, it is important that the child acquires a sense of competence through having successful experiences completing tasks in school, making friends and engaging with peers, and following societal rules (Erikson, 1959; McCormick et al., 2011), all of which can be difficult given the time intensive nature of caregiving (Gates & Lackey, 1998). Child caregivers may face various negative outcomes if the caregiver role does not afford them the opportunities and/or the time to develop feelings of competence at school and with peers, contexts that are integral in this stage of development.

Previous literature has provided some examples of how the caregiving role has prevented children from fulfilling their developmental needs. Child caregivers often take on roles that are typically handled by adults (Bauman, Silver, Berman, & Gamble, 2009). Child caregivers of cancer patients have reported various responsibilities associated with caregiving including running errands, assisting with feeding and daily living activities, providing emotional support and comfort, and even providing care for younger children in the household (Earley & Cushway, 2002; Gates & Lackey, 1998). Child caregivers who have taken on these responsibilities associated with caregiving have been shown to spend less time with friends, have less time for homework and extracurricular activities, have poor school attendance, and often feel more socially isolated (Becker & Dearden, 2004; Charles, Stainton, & Marshall, 2012; Gates & Lackey, 1998; Lackey & Gates, 2001; Bauman et al., 2009). Because child caregivers often have less time to spend accumulating successful experiences in contexts integral to their developmental stage (e.g., going to school and completing homework, engaging with peers, etc.), it is less likely that they will experience feelings of competency in these domains, which is crucial for healthy development (Erikson, 1959). In fact, researchers have posited that assuming the caregiving role as a child has the potential to interrupt healthy development, and even lead to clinical levels of distress and high anxiety (Armstrong, 2002; Butler & Astburg, 2005; Early, Cushway, & Cassidy, 2006; Noble-Carr, 2002). Caregiving as a child also has longer-term implications: child caregivers have demonstrated a more difficult transition into adulthood (Dearden & Becker, 2000).

While it is clear that the caregiving role can put children at risk for not completing age-salient developmental tasks thereby negatively impacting both short and long-term well-being, there is also evidence to suggest that child caregivers can also benefit from the caregiving experience. Child caregivers fare better when they feel they have the ability to successfully meet the demands associated with caregiving, some control regarding caregiving decisions, higher levels of social support from both the individual that they care for and others, and recognition by others of the value of their role (Charles, Stainton, & Marshall, 2012; Tatum & Tucker, 1998; Skovdal & Andreouli, 2011). Researchers have found that social support may be especially important for the well-being of child

caregivers. In fact, in comparison to other predictors (i.e., child's choice in caregiving, and stress and appraisal coping), social support was the strongest predictor of adjustment outcomes in young caregivers (i.e., distress, positive affect, and life satisfaction; (Pakenham, Chiu, Bursnall, & Cannon, 2007). Moreover, child caregivers are more likely to report more positive personal experience of caregiving (i.e., benefit finding), when others recognized their caregiving role and when they had more familial support (Cassidy, Giles, & McLaughlin, 2013). Thus, it is vital that greater awareness, resources, and support are developed for young caregivers in order to lessen the negative impacts associated with caregiving at a young age (Charles, Stainton, & Marshall, 2012) and make it more likely that they will be able to successfully complete developmental tasks associated with childhood. In sum, assuming the caregiving role as a child is detrimental when the role does not afford the child sufficient time to engage in contexts which are important to their development (i.e., in school and with peers). In order to ensure that the caregiving experience is not negatively impacting a young caregiver's development, it is vital that the child still be able to have successful experiences in school and with peers. The recognition by others of the child's caregiving role and adequate social support are also critical for the child's adjustment to the role and well-being, and may very well help to bolster the child's ability to develop optimally. It is important to repeat that much of the aforementioned research featured child caregivers of individuals with chronic illnesses other than cancer. In order to develop a greater understanding of how caregiving specifically for a patient with cancer impacts the young caregiver, more research must be conducted.

Caregiving for Children with Cancer. In conjunction with providing cancer-related care to a child (e.g., facilitating the child's acceptance of cancer treatment, administering medication, managing side effects from treatment, providing transportation for the child to the hospital, providing emotional support), parents -- who most often are the primary caregivers for children with cancer -- must also be sensitive to the developmental needs of the child and attend to their preexisting social, familial, and work roles (Anderson, 1990; Granek et al., 2012; Keegan-Wells et al., 2002; James et al., 2002; Young, Dixon-Woods, Findlay, & Heney, 2002; Vance & Eiser, 2004). This can become especially difficult, as the time spent caring for a child with cancer is similar or equal to a full-time job (James et al., 2002). As such, caregivers of children with cancer often demonstrate compromised levels of well-being, reporting not allocating enough time and energy to their own needs (James et al., 2002). The developmental tasks of the child with cancer enable components of the caregiver's experience to be distinct from the caregiving experience for an individual in another developmental life stage. Because successes in school are integral to healthy development in childhood, and children with cancer often miss substantial amounts of school (approximately 40-60 days during the first year after diagnosis; Brown & Madan-Swain, 1993; Christy, 1993; Fottland, 2000), caregivers often describe

the additional stressor of attending to the educational needs of their child while they are away from school (Granek, Rosenberg-Yunger, Klaassen, Sung, Cairney, & Klassen, 2012). When the child is able to return to school, caregivers also report challenges in helping the child reintegrate including poor communication and inadequate information about resources and services provided by the school (Buehler, 1999; Gayon, 1993; Prevatt et al., 2000).

In addition to school absence-related stressors, caregivers of children with cancer face negative outcomes when they perceive that the child's cancer causes them to miss out on other developmentally important experiences, such as spending time with and learning from their peers. Due to the uncomfortable side effects associated with cancer treatment and in order to avoid infection, children with cancer are often isolated, unable to interact with peers at school, in sports, or through outdoor activities (Salvador, Crespo, Martins, Santos, Canavarro, 2015), a developmental task that is crucial during childhood. When caregivers perceive that the child's cancer has enabled them to miss these important opportunities, caregivers experience higher levels of caregiver burden, and in turn poorer quality of life (Salvador, Crespo, Martins, Santos, Canavarro, 2015). Moreover, caregivers of children with cancer have also reported worrying about peers not accepting and teasing the child upon reentry into school (McCarthy, Williams, & Plumer, 1998).

Furthermore, providing care for a child with cancer may be even more difficult given the various preexisting roles that many caregivers have. Because caregivers of children with cancer often juggle the tasks associated with being a cancer caregiver with other preexisting roles, pediatric researchers have made a distinction between primary caregiving burden (i.e., meeting patient-related needs) and secondary caregiving burden (i.e., meeting other needs; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994). Primary caregiving burden occurs as a result of the responsibilities that the caregiver takes on while caring for the child with cancer (e.g., physical care and helping the child meet various social and developmental needs), while secondary caregiving burden is instigated by meeting the needs of other family members (e.g., managing the ill child's siblings emotional reactions to the child's cancer) and managing other preexisting roles (e.g., social, familial, work; Stewart et al., 1994; Svavardottir, 2005).

Due to the high level of dependency of children to caregivers for their basic needs, caregivers of children with cancer often struggle to manage their primary and secondary roles simultaneously, and report that these roles are often adversely impacted (Goldbeck, 2001; Gatz, Bengtson, & Blum, 1990). For example, caregivers have reported difficulties in managing work and organizing care for the child with cancer (Svavarsdottir, 2004), and have demonstrated higher levels of distress when they feel that their work is negatively impacted by their caregiving role (Klassen, Raina, Reineking, Dix, Pritchard, & O'Donnell, 2007). Furthermore, caregivers of children with cancer have also expressed concerns

regarding the impact of the child's illness on siblings that the child may have (Quin, 2005). It is no surprise, then, that caregivers of child cancer patients report far less leisure time (Flury, Caflisch, Bremi, & Spichiger, 2011), and less time devoted to their own needs (James et al., 2002). Single parent caregivers of child cancer patients may be especially at risk for distress (e.g., Granek, Rosenberg-Yunger, Dix, Klaassen, Sung, Cairney, & Klassen, 2012), as single marital status predicted greater caregiver stress (Sulkers et al., 2014).

While much of the research has been focused on the negative outcomes and factors associated with caregiving for a pediatric cancer patient, there is also research to suggest that the caregiving experience is not always solely negative for caregivers of child cancer patients (Fotiadou, Barlow, Powell, & Langston, 2008). Researchers have found that caregivers of children with cancer who are men experience more optimism than those who are women, and that caregivers who do not have to decrease work hours due to caregiving experience more optimism than those who do. Higher levels of optimism has been related to various positive outcomes in caregivers of children with cancer including greater satisfaction with life and less anxiety and depression (Fotiadou et al., 2008). Hope and self-efficacy may be especially important for the well-being of caregivers of children with cancer. Researchers have found that hope enabled caregivers to engage in more positive thinking, seek growth during the caregiving experience, and feel a sense of control (McCaffety, 2015). Furthermore, caregivers who demonstrated higher levels of self-efficacy about keeping children calm both before and during the child's treatment for cancer demonstrated lower levels of anxiety (Harper, Peterson, Uphold, Albrecht, Taub, Orom, Phipps, & Penner, 2013).

In sum, the caregiving experience may be especially difficult for caregivers of children with cancer as these caregivers often juggle multiple roles: providing cancer-related care to a dependent child, attending to the child's school-related and social needs, and continuing to manage other preexisting roles (e.g., career, caretaking of other family members, etc.). Thus, apart from the normative caregiving assistance that can be given, additional assistance that may be especially helpful for caregivers of children include: 1) interventions aimed towards fostering optimism, hope, and self-efficacy, 2) support from the child's school regarding educational instruction, and 3) information regarding how to provide support for siblings of children with cancer.

Adolescence

Adolescents as Caregivers. While there is a scarcity of studies that feature adolescent cancer caregivers (Gates & Lackey, 1998; Shifren & Kachorek, 2003), the literature on adolescent caregivers of individuals with a chronic illness may help to elucidate the experience of an adolescent caring for an individual with cancer. The developmental stage of adolescence is marked by various characteristics and concerns that may be interrupted by the role of being a cancer caregiver (Cournos,

2003), thereby impeding optimal development. The life stage of adolescence features the physiological changes brought on by puberty and is characterized by increased time spent with peers, cultivating a greater sense of independence and autonomy, learning about romantic relationships, and participation in secondary school (Erikson, 1959; McCormick, Kuo, & Masten, 2011). Perhaps most markedly, adolescents are also undergoing identity exploration and--according to Erikson--the basic task during this life stage is for adolescents to integrate the identities they bring from childhood into a more cohesive identity (Erikson, 1959). For healthy development to occur, adolescents must have the opportunity to explore their identity through various avenues (e.g., in school, spending time with peers, engaging in clubs, etc.) and integrate previous identifications into a more complete identity. If the caregiving role does not allow adolescents to explore and later integrate identities in contexts essential to this life stage (e.g., school, with peers), various negative outcomes may ensue.

Extant research featuring adolescent caregivers has outlined ways in which the caregiving role makes it difficult for adolescents to fulfill their developmental needs. Adolescent caregivers have reported diminished time spent in contexts integral to their identity development (e.g., in school and with peers) due to their role as a caregiver. For example, due to the time-intensive nature of the caregiving role, adolescent caregivers often report various educational difficulties, including missing significant amounts of school (Dearden & Becker, 1995; Lackey & Gates, 2001; Moore, McArthur, & Morrow, 2009; Stamatopoulos, 2018), and less time for homework and studying (Lackey & Gates, 2001; Stamatopoulos, 2018). When they were able to attend school, adolescents expressed trouble concentrating, poor school performance, bullying, difficulties finding others who understood them, and expressing negative emotions (Moore et al., 2009). Because participation in secondary school is an important developmental task of adolescence (McCormick et al., 2011), it is problematic that the caregiving role may greatly impede adolescent's ability to participate successfully. These educational difficulties have also been found to negatively impact adolescents later on in their educational lives as well (e.g., postponing secondary education; Dearden & Becker, 2002; Stamatopoulos, 2018).

In addition to difficulties balancing caregiving demands with educational responsibilities, adolescent caregivers also report trouble maintaining a social life--which results in various negative outcomes due to the importance of close friendships and time spent with peers during this developmental life stage. Many adolescent caregivers do not spend as much time with friends due to their caregiving responsibilities, often describing feelings of being different from and out of sync with their peers (Aldridge & Becker, 1993; Armstrong, 2002; Barnett & Parker, 1998; Butler & Astburg, 2005; Stamatopoulos, 2018; Noble-Carr, 2002; Price, 1996). They often experience feelings of isolation, loneliness, and missing out on social events (Dearden & Becker, 2002; Salter, 1999; Stamatopoulos, 2018). Researchers have posited that the adolescent caregiver's diminished time spent in contexts

central to their life stage (e.g., with peers and in school) can have negative ramifications for their identity development, the major developmental task associated with adolescence (Erikson, 1959; Earley & Cushway, 2002; Earley, Cushway, & Cassidy, 2007).

Because identity development is such a central task associated with adolescence, it can be problematic if the caregiving role inhibits the adolescent from undergoing identity exploration and integration. In fact, young carers have reported that their role as a caregiver inhibited them from engaging in contexts and experiences (such as spending time at school and with peers) where they could explore their identities and gain external validation (Rose & Cohen, 2010). Furthermore, young carers also often integrated caregiving into their future identity, limiting exploration of other potential identities (Earley & Cushway, 2002; Early, Cushway, & Cassidy, 2007; Rose & Cohen, 2010). In fact, researchers have found that many young caregivers often go on to adopt roles characterized by caretaking as adults (Earley & Cushway, 2002). These individuals who commit to one role rather than exploring other identities are deemed by researchers to be in a state of “identity foreclosure” (Marcia, Waterman, Matteson, Archer, & Orlofsky, 1993). Foreclosed individuals have been shown to demonstrate various negative outcomes including but not limited to homophobic and racial prejudice, more anxious or detached attachment styles, and high levels of defensive narcissism, authoritarianism, and conformity (Cramer, 1995; Fulton, 1997; Kroger, 1995).

While there are various negative outcomes associated with caregiving as an adolescent, research suggests that there are also benefits. Adolescent caregivers have reported feelings of pride, increased levels of maturity and empathy, more opportunities for fruitful sibling conversations and interactions, and feeling more nurturing due to their caregiving role (Beach 1997; Lackey & Gates, 2001; Stamatopoulos, 2018). In one study featuring adolescent caregivers ages 15-19, some of the adolescents expressed integrating caring into their career trajectories, recognizing that their early experience caregiving provided them with some of the skills necessary for a care-based profession (Stamatopoulos, 2018). However, as mentioned prior, this may be of detriment to the adolescent’s identity development if they were not afforded the opportunities to explore alternative identities.

In short, the caregiving role may be harmful to the adolescent if it does not allow them sufficient time to engage in contexts critical to their development--such as with peers and in school--and when it impedes identity exploration and integration. Researchers have found that access to both age and culturally appropriate support services may help to bolster against the negative impacts that caregiving as an adolescent can have on development (Smyth, Blaxland, & Cass, 2011). More specifically, connecting with other young carers was particularly helpful. School professionals--particularly school nurses--may be especially well-positioned to identify young carers and connect them to these support services (Siskowski, 2006). This may help ensure that adolescents are provided

with enough support to continue to participate in school, spend time with peers, and undergo identity exploration.

Caregiving for Adolescents with Cancer. Caregivers of adolescent cancer patients face the unique challenge of helping the adolescent accomplish various normative developmental tasks (e.g., identity exploration, spending time with peers, etc.) while also caring for them (Brown & Larson, 2009; Erikson, 1968; Larson, Wilson, & Rickman, 2009). For example, parents--who are often the caregivers of adolescents with cancer--may face the distinct challenge of ensuring that the adolescent has sufficient time to cultivate a greater sense of autonomy, independence, and identity exploration. Meeting adolescents' developmental needs becomes more difficult due to the adolescent with cancer's heightened dependence on their caregivers for both cancer-related and emotional support needs (Nicklin et al., 2019; Juth et al., 2015). In fact, caregivers of adolescents with cancer have reported feeling concerned about the impact that cancer had on the patient's independence while feeling strongly protective of the adolescent (Olsen & Harder, 2009). This juxtaposition between the adolescent's growing need for independence from parents and identity exploration, and their increased dependence on the caregiver may make the caregiving experience uniquely difficult (Ettinger & Heiney, 1993; Juth, Silver, & Sender, 2015).

Extant research has demonstrated that adolescents are less likely to adhere to cancer treatment, and are also concerned about issues surrounding infertility due to treatment, both of which may introduce distinct difficulties for the cancer caregiver. First, adolescent cancer patients were found to be significantly less compliant and have lower levels of adherence to treatment in comparison to younger patients (Dolgin, Katz, Shelley, & Seigel, 1986; Butow et al., 2010; Juth, 2016). Less adherence to treatment could be related to neurochemical changes in the brain due to puberty that are linked to increased risk taking (Steinberg, 2008). These lower levels of compliance and adherence may enable caregivers to play a large role in ensuring that adolescents are compliant to cancer treatment, and may exacerbate caregiver distress. Furthermore, caregivers have also reported concerns about the adolescent's fertility if infertility could be a complication of the cancer treatment--which is especially common for adolescent males who undergo treatment (Ginsberg et al., 2008). In fact, adolescent cancer patients often consult their caregivers regarding fertility preservation options which has led to caregivers expressing stress due to issues surrounding adolescent infertility. For instance, caregivers have expressed feelings of pressure from limited time to make a decision regarding fertility preservation and for potential treatment delays, and feelings of embarrassment while discussing fertility preservation options (Barlevy et al., 2016; Ginsberg et al., 2008; Quinn et al., 2011; Wyns et al., 2015).

While research has demonstrated various negative outcomes and challenges associated with caregiving for an adolescent with cancer, positive outcomes have also been identified. Namely, caregivers of adolescent cancer patients often demonstrated posttraumatic growth and reported that their experience as a cancer caregiver enabled them to think more positively about their own lives and treat other people better (Barakat et al., 2006). Furthermore, the adolescent cancer patient and caregiver relationship is often strengthened as a result of the shared cancer experience (Wu et al., 2009), as this relationship serves as the main social context in which adolescents with cancer experience and grapple with their illness (Juth et al., 2015).

In sum, caregiving for an adolescent with cancer may feature unique challenges given the adolescent's need for independence and concurrent increased dependence on the caregiver inherent to a cancer diagnosis, the adolescent's potential decreased adherence to cancer treatment, and issues of infertility resulting from cancer treatment. Thus, caregivers of adolescents with cancer are likely to benefit from educational materials and support that address the adolescent's independence, self-regulation (especially in relation to treatment compliance and adherence), and navigating issues surrounding infertility.

Young Adulthood

Young Adults as Caregivers. Due to a combination of the various stressors associated with the cancer experience (e.g., the often abrupt onset of the disease, the fact that cancer can be life-threatening, etc.) and the nature of the young adult developmental life stage, young adult cancer caregivers may be particularly vulnerable to experiencing negative outcomes (Heckel et al., 2015; Warner et al., 2020). While young adulthood is marked by numerous tasks (e.g., establishing financial independence, maintaining a household, committing to romantic relationships or marriage, caring for children, establishing oneself in the workplace or pursuing higher education, etc.; McCormick et al., 2011), developmental scholars have posited that the most salient developmental task of young adulthood is achieving intimacy (Erikson, 1968). According to Erikson (1963), intimacy is "the capacity to commit [one]self to concrete affiliations and partnerships and to develop the ethical strength to abide by such commitments, even though they may call for significant sacrifices" (p. 263). Thus, the young adult--only after achieving a well-integrated identity in adolescence--seeks to cultivate a sense of intimacy both with themselves (due to their ability to access their own intimate feelings and thoughts) and others, both romantically and platonically (Erikson, 1968). In order for healthy young adult development to occur, young adults must form intimate, mature relationships with others and themselves. If the role of cancer caregiver inhibits young adults from establishing these intimate relationships, they may face various adverse outcomes (e.g., isolation, loneliness, etc.) by

virtue of not completing the task (i.e., intimacy) integral to healthy young adult development (Erikson, 1968).

Many young adult caregivers report that the caregiving role interferes with the other relationships in their lives, often acting as a barrier to intimacy in these relationships (Associated Press & NORC Center for Public Affairs Research, 2018). In fact--because of the often time-intensive role of caregiving--young adult caregivers express regularly feeling like they have to miss out on time with loved ones, and this can be detrimental given the importance of establishing and cementing intimate relationships during this developmental life stage. Caregiving for a cancer patient as a young adult may impact intimacy across a wide range of relationships for the caregiver--romantic, familial, and platonic.

Many young adult cancer caregivers report feeling as though they do not have enough time or energy to allocate to their relationships outside of their relationship with the cancer patient (McLaughlin et al., 2019), and this is seen particularly in the context of the young adult cancer caregiver's romantic relationships. Because the development of loving, romantic relationships is particularly salient during this life stage (Erikson, 1968), young adult cancer caregivers may face various negative outcomes if their role as a caregiver thwarts their ability to develop and/or maintain these relationships. Given the time-intensive nature of the caregiving role, many single young adult caregivers have reported less time for dating (Dellmann-Jenkins et al., 2000). They express feeling as though they hardly have enough time for themselves, let alone time for social and dating relationships, which can lead to feelings of resentment in the young adult caregiver. Similarly, young adult caregivers who are married have also noted the decreased amount of time spent with their spouse (if their spouse is not the individual they are caring for). The spousal relationships of young adult caregivers are often characterized by strain and higher levels of stress--occasionally leading to separation (Dellmann-Jenkins et al., 2000; Dellman-Jenkins et al., 2001).

Research also elucidates the unique challenges that young adult couples must face if one individual in the couple is acting as a caregiver for their spouse with cancer (e.g., Innarino & Wackerly, 2021). In fact, young adult cancer caregivers are often caregivers for their spouses (Warner et al., 2020). Because cancer treatments can often lead to infertility in the patient (Oktay et al., 2018), discussions about family planning can be particularly salient and difficult for young adult cancer caregivers and their spouse with cancer. In fact, many partners of young adults with cancer admit feeling unprepared for conversations around cancer family planning (Innarino & Wackerly, 2021). These discussions around fertility can be extremely challenging and likely to feature conflict due to time constraints, cost, and the distress that cancer patients often endure as they grapple with the fact that they may no longer be able to have their own biological children (Mersereau et al., 2013; Rowen et al., 2010).

Young adult cancer caregivers who are caring for a spouse with cancer and young children also face many challenges as they try to fulfill their roles as a spouse, caregiver, and parent. Young adult cancer caregivers often struggle as they attempt to take on these various roles, and experience difficulty maintaining their parenting responsibilities while also engaging in the tasks associated with caregiving for a cancer patient (e.g., administering medication, emotional support, etc.; Waters et al., 2021). Notably, young adult cancer caregivers who are also caregivers for young children often express needs surrounding childcare, for children are either not allowed to be present for some cancer caregiver tasks (e.g., attending certain appointments) or their presence makes the task increasingly difficult (e.g., managing the patient's pain becomes exponentially more challenging while also taking care of a toddler).

Young adult caregivers have also reported that due to the time intensive nature of the caregiving role, they had less time to invest in their friendships (e.g., Dellmann-Jenkins et al., 2000; Dellmann-Jenkins et al., 2001; Frauhauf et al., 2006). In a study featuring 43 young adult caregivers caring for older relatives, almost half (47%) of the young adult caregivers expressed that since becoming a caregiver, they had less time to devote to their social lives (Dellmann-Jenkins et al., 2000). Similarly, Dellmann-Jenkins and colleagues (2001) found that over half of the young adult caregivers in their study (55%) reported that since taking on the caregiver role, they have had decreased time spent with their friends. Young adult cancer caregivers experience substantial stress as they attempt to balance tasks associated with their own developmental stage and those related to caregiving for a cancer patient (Waters et al., 2021), however, research suggests that young adult caregivers may also accrue benefits from their caregiving role. While there exists minimal research that investigates the benefits associated with caregiving for a cancer patient during young adulthood, research findings featuring young adult caregivers more generally demonstrate that young adult caregivers often experience an enhanced relationship with the care recipient, positive memories that are long-lasting, and increased levels of self-respect as a result of caregiving (Dellmann-Jenkins, Blankemeyer, & Pinkard, 2000). In sum, taking on the tasks associated with caregiving for a cancer patient may result in higher levels of stress and other negative outcomes for the young adult cancer caregiver if the caregiving role hinders their ability to develop and maintain close relationships marked by intimacy. While social support is related to more positive outcomes across all ages of cancer caregivers (Kelley et al., Kim et al., 2005; 2019; Onsworth et al., 2009), researchers have posited that it may be especially important for young adult cancer caregivers given the importance of close relationships in this particular developmental stage (Waters et al., 2021). In fact, young adult cancer caregivers fare better when they feel emotionally supported by those closest to them, and often emphasize the importance of having close relationships in which they could feel understood and vent about their feelings and

frustrations surrounding caregiving (Waters et al., 2021). More specifically, caregiver teams (teams made up of family, friends, and other loved ones) and social media may connect young adult cancer caregivers to others who can help to provide social, emotional, and/or logistical support and relational closeness to the young adult caregiver (Waters et al., 2021; Warner et al., 2020), helping to share the caregiving load.

Caregiving for Young Adults with Cancer. Caregiving for a young adult with cancer is likely to be markedly distinct from caregiving for an individual in another state of life. In comparison to middle and older adults, young adults have more recently become independent from their own parents. Furthermore—because of the salience of forming and maintaining intimate relationships in this life stage—young adults are also likely to be in long-term romantic partnerships or looking to form long-term romantic partnerships. Because of this, young adult cancer patients—even when they have a partner—may return to their parents for caregiving support through their cancer journey (Reblin et al., 2019). Thus, both the parents and partner of the young adult may take part in the caregiving tasks, and this can become challenging when the parents and partners have diverging ideas and expectations with regard to their roles.

In instances where young adult cancer patients have partner and parent caregivers, young adult cancer patients and their parent and partner caregivers described the importance of “strengths-based caregiving”, a team-based approach to caregiving where individual strengths of family members are utilized (Reblin et al., 2019). For example, a family member with healthcare training might help to make sense of diagnostic reports while a family member who is very organized may provide assistance and support with scheduling appointments.

Research demonstrates that a felt sense of support is especially critical to the caregiver-partner and young adult cancer patient’s relational well-being—so much so that young adult cancer patients with unsupportive partners report higher levels of anxiety than unpartnered young cancer patients or those with a supportive partner (Borstelmann et al., 2015). Caregiver-partners of young adult cancer patients may find that the young adult may be particularly in need of support with regard to concerns about physical/sexual intimacy and fertility. Young adult cancer patients report that the experience of cancer often impacts physical/sexual intimacy within their partnerships due to factors such as a loss of desire that accompanies depression, physical changes associated with cancer treatment, and lowered body image (Robinson et al., 2014). Furthermore, young adult cancer patients also report concerns surrounding issues of fertility and worry whether or not they will be infertile due to cancer treatment (Carpentier et al., 2011; Thompson et al., 2013; Yi et al., 2016). Issues surrounding fertility can become a major source of stress for couples who have different outlooks with regard to creating their family (Russell et al., 2016).

Young adult cancer patients who do not have partners also face difficulties surrounding sexuality and emotional intimacy (e.g., D'Agostino, Penney, & Zebrack, 2011). More specifically, young adult cancer patients often express difficulties with dating (e.g., Rabin et al., 2019). Some young adult cancer patients have expressed that changes to their physical bodies due to cancer treatment has a negative impact on their self-esteem, subsequently making it more difficult for them to date (e.g., Bellizzi et al., 2012; Carpentier et al., 2011; Ramphal et al., 2016). Others struggle with regard to when/if to tell a potential romantic partner about their cancer diagnosis (Russell et al., 2016).

While there are various stressors associated with caregiving for a young adult cancer patient, there are also positive outcomes related to caregiving for a cancer patient in this life stage. More specifically, caregiver-partners and patients have reported that their cancer experience positively impacted their relationship (Bellizzi et al., 2012). Researchers have also found that the cancer experience can increase felt emotional closeness between the patient and the caregiver-partner when the partner is emotionally supportive (Robinson et al., 2014).

In sum, young adult cancer caregivers may experience unique difficulties given the potential for diverging caregiver role expectations between partners and parents in addition to the young adults' concerns surrounding physical/sexual intimacy, emotional intimacy, and fertility. Thus, caregivers of young adults who have cancer are likely to benefit from strengths-based caregiving (if sharing the caregiving role with others), access to support to address romantic intimacy (for partner-caregivers; e.g., support groups, couples counseling), and educational materials that contain information/resources to help address the young adult's concerns surrounding intimate relationships.

Middle Adulthood

Caregivers in Middle Adulthood. Research on the “sandwich generation” may help to elucidate how the caregiving experience could impact individuals in middle adulthood. Individuals in middle adulthood are occasionally referred to as belonging to the “sandwich generation” given that they often concurrently provide care for the generation before—their adult children—and after—their aging parents—them (Raveis, Karus, & Siegel, 1998; Ward & Spitze, 1998). While individuals in middle adulthood are typically launching children and providing care for aging parents, they are also maintaining employment and long-term relationships (McCormick, Kuo, & Masten, 2009). However, according to Erikson (1950), individuals in middle adulthood are most concerned with issues surrounding generativity, or “the primary concern in establishing and guiding the next generation” (p. 267). While parenthood is highlighted as a major context in which those in middle adulthood can be generative (i.e., caring for their children), generativity can also be broader in scope. Individuals in middle adulthood may also practice generativity when they care for things that will outlast them.

Because individuals in middle adulthood often do take on multiple roles (e.g., maintaining employment and long-term relationships, caring for adult children and aging parents), the added role of becoming a cancer caregiver may impact their ability to be as involved in their preexisting roles as before. In fact, researchers have found that daughters who are a part of this “sandwich generation” often do not reduce the number of hours spent caregiving, rather, they may compensate by spending less time performing tasks relevant to their other roles (e.g., reducing work hours and eliminating leisure time) (Raveis et al., 1998). The adoption of these various roles including the cancer caregiver role may have a negative impact on caregivers in middle adulthood. One study featuring 9,555 middle-aged women from Australia demonstrated that women who were caregivers displayed poorer physical and emotional health and were less engaged in the workforce than those who were not caregivers (Lee & Gramotnev, 2006). However, it appears that perceived social support may be an important factor in determining whether individuals in middle adulthood view caregiving negatively: those who are unhappy with their social network were more likely to view caregiving negatively (Knight, Williams, McGee, & Olaman, 1998).

The outcomes associated with caregiving during middle adulthood are not all negative, in fact, there is research to suggest that the caregiving experience may be especially gratifying for individuals in middle adulthood due to the generative quality inherent to caregiving. Generative behaviors occur most often during middle age and lessen in frequency as time goes on (McAdams, 2006; Peterson, 2002). In one study, researchers compared middle-aged adults to individuals in late adulthood and discovered that the presence of caregiver involvement was related to higher levels of life satisfaction only for participants in middle adulthood but not for those in late adulthood (Ang & O, 2012), suggesting that caregiving has the potential to be especially gratifying for those in middle adulthood. In sum, caregivers in middle adulthood may experience negative outcomes if they feel overburdened by their many roles and are discontented with their social support network (Knight, Williams, McGee, & Olaman, 1998; Lee & Gramotnev, 2006). Caregivers in middle adulthood fare better not only when they are content with their social networks but when they practice role balance strategies (Evans et al., 2016). These include but are not limited to living with integrity (participating in roles that align with values), being the best one can (giving tasks one’s all), doing what one loves (embedding joy into the role), loving what one does (making an intentional effort to realize joy in the present moment), remembering why (remembering the importance of the role), searching for signs of success (looking for proof of successes within their role), time management, and nurturing social support (Evans et al., 2016).

Caring for an individual in middle adulthood with cancer. Caregiving for a cancer patient in middle adulthood may prove particularly challenging given the likelihood that the patient has various

preexisting responsibilities and roles (e.g., parent, employee, child caring for parents). As mentioned prior, middle adulthood is characterized by various developmental tasks including but not limited to maintaining work and romantic relationships, launching children, and tending to aging parents (McCormick, Kuo, & Masten, 2011). Given the likelihood that the patient has preexisting commitments—both interpersonal and work-related, the caregiver role may include the patient’s responsibilities in addition to tasks typical of the caregiving role and their own preexisting responsibilities (Francis, Kypriotakis, O’Toole, & Rose, 2016). Consequently, many caregivers of middle-aged cancer patients face interruptions in their own social, professional, and family lives (Grady & Rosenbaum, 2015). These disruptions and additional demands may have a negative impact on the caregiver—in fact, greater levels of work and family responsibilities are related to difficulties with adjusting to cancer (Northouse, Dorris, Charron-Moore, Templin, & Mood, 2001). Further, in a study of the experiences of men with prostate cancer and their partners, researchers discovered that compared to 65-74 year old couples and 75-84 year old couples, couples in the middle-aged group (50-64) demonstrated higher levels of anger and disappointment at their difficulty of reaching life goals and establishing financial security (Harden, Northouse, & Mood, 2006).

In contrast, there are also positive outcomes associated with caring for an individual in middle adulthood with cancer. Kim and colleagues (2007) found that the caregivers who report benefit finding (i.e., growth following a difficult life experience)—more specifically, acceptance of their situation and appreciation for life—are more likely to have higher levels of life satisfaction. Not surprisingly, caregivers who felt as though they had social support that was available to them if necessary engaged in benefit finding with greater frequency.

In all, caregiving for an individual in middle adulthood with cancer is distinct from caring for individuals in other life stages given the likelihood that the patient has preexisting responsibilities and roles (e.g., parent, employee, child caring for parent) that the caregiver often has to take on in addition to their own roles and the tasks associated with caregiving. Thus, caregivers of patients in middle adulthood may benefit from assistance balancing both the patients’ and their own responsibilities, in addition to the tasks associated with caregiving for a cancer patient. They are also likely to benefit from interventions geared towards fostering a sense of acceptance of their situation in addition to appreciation for life (Kim et al., 2007).

Late Adulthood

Caregivers in late adulthood. A caregiver in late adulthood must balance engaging with the developmental tasks associated with their life stage while also providing care for the cancer patient. According to Erikson (1950), the major goal for individuals in late adulthood is to achieve a sense of integrity, or a sense of self-acceptance, completeness, and satisfaction with their lives. Individuals in

late adulthood look back on their lives and engage in life evaluation and reflection, coming to terms with their own mortality. Ideally, they integrate all of their life stages and reach a sense of acceptance, wholeness, and peace before they die. However, if they are unable to achieve a sense of integrity, they feel a lack of acceptance for themselves or for events in their lives, leading to feelings of despair. Individuals in late adulthood also experience increased dependence on others, changes that occur as a result of the body and mind aging, and adjustment to the deaths of peers (McCormick et al., 2011). Extant research indicates that cancer caregivers in late adulthood are at a high risk for experiencing developmental burden, or “a sense of being trapped and out of phase with their expectations about this time in their life” (Novak & Guest, 1989, p. 801). Spatuzzi and colleagues (2020) interviewed cancer caregivers of patients receiving palliative care and divided the sample of caregivers into those aged less than 65 years and those 65 years or older. They found that the caregiver’s perception of developmental burden is positively related to caregiver age. The researchers hypothesized that older caregivers (in this case, largely spouses of the cancer patient) may mourn the loss of opportunities for the couple to engage in tasks that concern the end of life of the couple (e.g., spending time with grandchildren, having a peaceful retirement) or the pain associated with losing their partner. Studies of older caregivers of individuals with various ailments indicate that elderly caregivers may also be at an especially high risk for physical concerns and complications. Higher age was associated with worse physical health among caregivers (Neri et al., 2011; Pinguart & Sorensen, 2007). In one study featuring caregivers of friends or family members with health problems, long-term illnesses, or disabilities, caregivers aged 65 and older reported a higher prevalence of physical distress and of fair or poor self-rated health in comparison to caregivers ages 18-64 (Anderson et al., 2013). Older caregivers have also expressed various physical challenges while performing caregiving tasks, such as low grip strength (Neri et al., 2011).

Caregiving for a cancer patient in late adulthood is not only associated with negative outcomes. For example, spousal cancer caregivers ages 60 or older experienced increased positive feelings and hope after engaging in reminiscence therapy (Chen et al., 2020). The goal of reminiscence therapy (Mecloskey & Bulecheck, 1996) is to increase an individual’s quality of life by having them participate in a review of their life, recalling past experiences, ideas, and emotions. Caregivers who participated in reminiscence therapy recalled things that they had achieved in their life, as well as positive and important memories that they shared with the cancer patient (Chen et al., 2020). After a reminiscence therapy program, these caregivers in later adulthood experienced increased positive feelings and hope, in addition to decreased levels of caregiver burden.

In sum, individuals in late adulthood who are cancer caregivers may be more susceptible to poorer physical health and developmental burden. However, they are likely to experience positive outcomes

such as hope and positive feelings after engaging in reminiscence therapy. Because of this, caregivers in late adulthood may particularly benefit from this type of therapy as it encourages the caregiver to engage in a life review of sorts—a key developmental task of late adulthood. This exercise could help the caregiver to achieve a sense of integrity, which is integral to well-being in late adulthood.

Caring for an individual in late adulthood with cancer.

Caregiving for an older adult with cancer is distinct from caregiving for an individual in another life stage due largely in part to factors associated with aging. Because comorbidity becomes more common with age (Berger et al., 2005; Jorgensen, Hallas, Friis & Herrstedt, 2012) and health and functioning decline with age, researchers have suggested that caregiving for an elderly cancer patient may be especially difficult (Francis et al., 2016; Haley, 2003) as the caregiver often manages the patient's functional deficits and other preexisting health issues related to aging with factors associated with cancer treatment. In fact, caregivers of older adults with cancer report greater levels of caregiver burden if the patient needs increased functional assistance (Ge, 2017; Hsu et al., 2014). In a study featuring 100 caregivers of cancer patients aged 65 years old and over, researchers emphasized the prevalence of caregiver burden among caregivers of elderly cancer patients, noting that employed caregivers and caregivers who assist patients in daily living activities (e.g., bathing, transportation, shopping, etc) showed higher levels of caregiver burden (Hsu et al., 2014). Similarly, a review of seven studies featuring caregivers of elderly cancer patients specified that caregivers who were assisting patients with tasks associated with daily living demonstrated a higher level of caregiving burden (Ge, 2017). Caregivers of older adults with cancer also report increased caregiver burden when the patient exhibits higher levels of cognitive issues (e.g., forgetfulness, confusion, trouble recognizing others) and neuropsychiatric symptoms (e.g., depression and anxiety; Sherwood et al., 2005).

While there are negative outcomes associated with caregiving for an older adult with cancer, there is also research that suggests that cancer patients and their spousal caregivers ages 65-74 may experience better outcomes than other age groups (Harden et al., 2008). More specifically, cancer patients and their spousal caregivers ages 65-74 reported better mental health and increased self-efficacy than those ages 50-64 and better physical quality of life and a less negative assessment of the illness than those ages 50-64 and those ages 75-84 (Harden et al., 2008).

In short, caregiving for an individual with cancer in late adulthood is unique from caring for an individual in another life stage since the health and functioning of the patient is more likely to be impaired due to age (Francis et al., 2016; Haley, 2003). In fact, these caregivers experience higher levels of caregiver burden if the patient needs increased functional assistance and if they exhibit more

cognitive issues and neuropsychiatric symptoms (Ge, 2017; Hsu et al., 2014; Sherwood et al., 2005). Thus, it may be beneficial for the physician to perform a geriatric assessment on the cancer patient (a diagnostic tool used to determine the medical, psychosocial, and functional abilities of an older individual; Ellis et al., 2017) so that the medical team and the caregiver can get a better idea of the patient's needs in a way that might not be covered in a regular physical exam (Wildiers et al., 2014).

Conclusion

This review highlights the importance of taking both the cancer caregiver and patient developmental stage into account while examining caregiver well-being by delineating how the caregiver experience differs depending on both the patient and the caregiver's developmental stage. There is a relative lack of research that: 1) directly relates the age and developmental stage of the patient to the well-being of the caregiver and 2) investigates the relationship between caregiver age and caregiver well-being (Kim et al., 2010; Shahi et al., 2014). Future research should investigate the aforementioned phenomenon as findings could have valuable implications for informing and enhancing interventions geared towards cultivating caregiver well-being, making them more developmentally appropriate (Haase, 2004; Nation et al., 2003). These findings also have important implications for the well-being of the cancer patient, as caregiver and patient well-being are inextricably intertwined (Northouse et al., 2012).

Data Availability Statement

No datasets were produced or analyzed during this study.

References

- Adams, G., Munro, B., Munro, G., Doherty-Poirer, M., & Edwards, J. (2005). Identity Processing Styles and Canadian Adolescents' Self-Reported Delinquency. *Identity*, 5(1), 57-65.
- Aldridge, I., & Becker, S. (1993). *Children who care: Inside the world of young carers*. Leicestershire, England: Loughborough University, Young Carers Research Group.
- Anderson, L., Edwards, V., Pearson, W., Talley, R., McGuire, L., & Andresen, E. (2013). Adult caregivers in the United States: Characteristics and differences in well-being, by caregiver age and caregiving status. *Preventing Chronic Disease*, 10, 1-5.
- Ang, R., & O, J. (2011). Association between caregiving, meaning in life, and life satisfaction beyond 50 in an Asian sample: Age as a moderator. *Social Indicators Research*, 108, 525-534.
- Associated Press & NORC Center for Public Affairs Research. (2018, May). Younger adults' experiences and views on long-term care [Issue Brief]. Retrieved from <https://www.longtermcarepoll.org/wpcontent/uploads/2018/05/APNORC LTC 2018 bri>

[ef.pdf](#)

- Barakat, L., Alderfer, M., & Kazak, A. (2006). Posttraumatic Growth in Adolescent Survivors of Cancer and Their Mothers and Fathers. *Journal Of Pediatric Psychology*, 31(4), 413-419.
- Barlevy, D., Wangmo, T., Elger, B., & Ravitsky, V. (2016). Attitudes, Beliefs, and Trends Regarding Adolescent Oncofertility Discussions: A Systematic Literature Review. *Journal Of Adolescent And Young Adult Oncology*, 5(2), 119-134.
- Bauman, L. J., Silver, E. J., Berman, R., & Gamble, I. (2009). Children as caregivers to their ill parents with AIDS. In K. Shifren (Ed.), *How caregiving affects development: Psychological implications for child, adolescent, and adult caregivers* (pp. 37–63). American Psychological Association.
- Beach, D. L. (1997). Family caregiving: The positive impact on adolescent relationships. *The Gerontologist*, 37, 233-238.
- Bellizzi, K., Smith, A., Schmidt, S., Keegan, T., Zebrack, B., Lynch, C., Deapen, D., Shnorhavorian, M., Tompkins, B. and Simon, M. (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*, 118(20), pp.5155-5162.
- Borstelmann, N., Rosenberg, S., Ruddy, K., Tamimi, R., Gelber, S., & Schapira, L. et al. (2015). Partner support and anxiety in young women with breast cancer. *Psycho-Oncology*, 24(12), 1679-1685.
- Bronfenbrenner U., & Evans, G. W. (2000). Developmental science in the 21st century: Emerging questions, theoretical models, research designs, and empirical findings. *Social Development*, 9(1), 15–25.
- Bronfenbrenner, U. (1989). Ecological systems theory. *Annals of Child Development*, 6, 187–249.
- Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husten & T. N. Postlethwaite (Eds), *International encyclopedia of education* (2nd ed., Vol. 3, pp. 1643-1647). New York: Elsevier Science
- Bronfenbrenner, U., and Morris, P. A. (2006). “The bioecological model of human development” in *Handbook of child psychology: Theoretical models of human development*. 6th Edn. Vol. 12. eds. W. Damon and R. M. Lerner (Hoboken, NJ: Wiley), 793–828.
- Brown, B. B., & Larson, J. (2009). Peer relationships in adolescence. In R. M. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology*, Vol. 2: Contextual influences on adolescent development (3rd ed., pp. 74-103). Hoboken, NJ: John Wiley & Sons, Inc.
- Brown, R., & Madan-Swain, A. (1993). Cognitive, Neuropsychological, and Academic Sequelae in Children with Leukemia. *Journal Of Learning Disabilities*, 26(2), 74-90.
- Butler, A. H., & Astbury, G. (2005). The caring child: An evaluative case study of the cornwall young carers project. *Children & Society*, 19, 292-303.
- Butow, P., Palmer, S., Pai, A., Goodenough, B., Lockett, T., & King, M. (2010). Review of Adherence-Related Issues in Adolescents and Young Adults With Cancer. *Journal Of Clinical Oncology*, 28(32), 4800-4809.
- Carlsson, J., Wängqvist, M., & Friséén, A. (2016). Life on hold: Staying in identity diffusion in the late twenties. *Journal Of Adolescence*, 47, 220-229.

- Carpentier, M. Y., Fortenberry, J. D., Ott, M. A., Brames, M. J., & Einhorn, L. H. (2011). Perceptions of masculinity and self-image in adolescent and young adult testicular cancer survivors: Implications for romantic and sexual relationships. *Psycho-Oncology*, 20, 738–745.
- Cassidy, T., Giles, M., & McLaughlin, M. (2013). Benefit finding and resilience in child caregivers. *British Journal of Health Psychology*, 19(3), 606-618.
- Charles, G., Stainton, T., & Marshall, S. (2012). Young carers in Canada: The hidden costs and benefits of young caregiving. Ottawa, Canada: Vanier Institute of the Family.
- Chen, J., Xiao, H., Chen, Y., Sun, H., Chen, S., & Zheng, J. (2020). Effect of reminiscence therapy based on positive psychology theory (RTBPPT) on the positive feelings of the spousal caregivers of elderly patients with advanced cancer in China. *European Journal of Cancer Care*, 29(6), 1-10.
- Christy, D. S. (1993). Children with cancer: Exploring the relationship between school absenteeism and dimensions of family functioning. (The University of North Carolina at Chapel Hill, 1993). Dissertations Abstracts International, 54, 04A.
- Cournos, F. (2003). The psychological impact of being a young caregiver. Paper presented at a Young Caregivers meeting by the United Hospital Fund Foundation, New York.
- Cramer, P. (1995). Identity, narcissism, and defense mechanisms in late adolescence. *Journal of Research in Personality*, 29, 341-361
- D'Agostino NM, Penney A, Zebrack B. (2011) Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer* ;117(10):2329–2334
- Dearden, C. & Becker, S. (2000). *Growing Up Caring: Vulnerability and Transition to Adulthood—Young Carer's Experiences*. Leicester: Youth Work Press for the Joseph Rowntree Foundation.
- Dearden, C. & Becker, S., 2002. Young Carers and Education. [Online] Available at: [http://ycrg.org.uk/youngCarersDownload/yceduc\[1\].pdf](http://ycrg.org.uk/youngCarersDownload/yceduc[1].pdf)
- Dearden, C., & Becker, S. (1995). The national directory of young carers projects and initiatives. Loughborough, UK: Loughborough University, Young Carers Research Group.
- Dellmann-Jenkins, M., Blankemeyer, M., Pinkard, O. (2000). Young adult children and grandchildren in primary caregiver roles to older relatives and their service needs. *Family Relations*, 49, 177-186.
- Dellmann-Jenkins, M., Blankemeyer, M., Pinkard, O. (2001). Incorporating the elder caregiving role into the developmental tasks of young adulthood. *International Journal of Aging and Human Development*, 52,1-18.
- Dolgin, M., Katz, E., Doctors, S. and Siegel, S. (1986). Caregivers' perceptions of medical compliance in adolescents with cancer. *Journal of Adolescent Health Care*, 7(1), 22-27.
- Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C. and Vézina, L. (2006). Caring for a Loved One with Advanced Cancer: Determinants of Psychological Distress in Family Caregivers. *Journal of Palliative Medicine*, 9(4), 912-921.
- Earley, L., & Cushway, D. J. (2002). The parentified child. *Clinical Child Psychology and Psychiatry*, 7, 163-178.
- Earley, L., Cushway, D., and Cassidy, T., (2007). Children's perceptions and experiences of care giving: a focus group study. *Counseling psychology quarterly*, 20, 69-80.

- Ellis, G., Gardner, M., Tsiachristas, A., Langhorne, P., Burke, O., & Harwood, R. et al. (2017). Comprehensive geriatric assessment for older adults admitted to hospital. *Cochrane Database Of Systematic Reviews*, (9), 1-97.
- Erickson, E. (1959). Identity and the life cycle (Psychological Issues, Monograph No. 1). New York: International Universities Press.
- Erikson, E. (1968). The life-cycle: Epigenesis of identity. In *Identity: youth and crisis* (pp. 91-141). New York: W. W. Norton & Co.
- Erikson, E. H. (1950). *Childhood and society*. New York: Norton.
- Evans, K., Millsted, J., Richmond, J., Falkmer, M., Falkmer, T., & Girdler, S. (2016). Working sandwich generation women utilize strategies within and between roles to achieve role balance. *Plos ONE*, 11(6), 1-23.
- Fisher, D., & Briggs, H. (2000). Warning: Caring is a health hazard: Results of the 1999 national survey of carer health and wellbeing. Weston, ACT: Carers Association of Australia
- Flury, M., Caflisch, U., Ullmann-Bremi, A. and Spichiger, E. (2011). Experiences of Parents With Caring for Their Child After a Cancer Diagnosis. *Journal of Pediatric Oncology Nursing*, 28(3), 143-153.
- Fotiadou, M., Barlow, J., Powell, L. and Langton, H. (2008). Optimism and psychological well-being among parents of children with cancer: an exploratory study. *Psycho-Oncology*, 17(4), 401-409.
- Fottland, H. (2000). Childhood cancer and the interplay between illness, self-evaluation and academic experiences. *Scandinavian Journal of Educational Research*, 44(3), 253–273.
- Francis, L., Kypriotakis, G., O’Toole, E. and Rose, J. (2016). Cancer patient age and family caregiver bereavement outcomes. *Supportive Care in Cancer*, 24(9), 3987-3996.
- Fruhauf, C., Jarrott, S., & Allen, K. (2006). Grandchildren's Perceptions of Caring for Grandparents. *Journal Of Family Issues*, 27(7), 887-911.
- Fulton, A. S. (1997). Identity status, religious orientation, and prejudice. *Journal of Youth and Adolescence*, 26, 1–11.
- Gates, M. F., & Lackey, N. R. (1998). Youngsters caring for adults with cancer. *The Journal of Nursing Scholarship*, 30, 11–15.
- Gatz M., Bengtson V., & Blum M. (1990). Caregiving families. Cited in J.E. Birren and K.W. Schaie (Eds.), *Handbook of the Psychology of Aging* (3rd ed., pp. 404-426). San Diego: Academic Press.
- Ge, L., & Mordiffi, S. (2017). Factors Associated With Higher Caregiver Burden Among Family Caregivers of Elderly Cancer Patients. *Cancer Nursing*, 40(6), 471-478.
- Ginsberg, J.P., Ogle, S.K., Tuchman, L.K., Carlson, C.A., Reilly, M.M., Hobbie, W.L., Rourke, M., Zhao, H. & Meadows, A.T. (2008) Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. *Pediatric Blood & Cancer*, 50, 594–598.
- Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology*, 10, 325–335.
- Grady, P.A., & Rosenbaum, L.M. (2015). The science of caregiver health. *Journal of Nursing Scholarship*, 47, 197–199.

- Granek, L., Rosenberg-Yunger, Z. R. S., Dix, D., Klaassen, R. J., Sung, L., Cairney, J., & Klassen, A. F. (2014). Caregiving, single parents and cumulative stresses when caring for a child with cancer. *Child: Care, Health and Development*, 40(2), 184–194.
- Haase, J. (2004). The Adolescent Resilience Model as a Guide to Interventions. *Journal of Pediatric Oncology Nursing*, 21(5), 289-299.
- Haley, W. (2003). The costs of family caregiving: implications for geriatric oncology. *Critical Reviews In Oncology/Hematology*, 48(2), 151-158.
- Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: a review of the literature. *Cancer Nursing*, 28(2), 85-98.
- Harden, J., Northouse, L. and Mood, D. (2006). Qualitative Analysis of Couples' Experience with Prostate Cancer by Age Cohort. *Cancer Nursing*, 29(5), 367-377.
- Harden, J., Northouse, L., Cimprich, B., Pohl, J., Liang, J., & Kershaw, T. (2008). The influence of developmental life stage on quality of life in survivors of prostate cancer and their partners. *Journal Of Cancer Survivorship*, (2), 84-94.
- Harden, J., Northouse, L., Cimprich, B., Pohl, J., Liang, J., & Kershaw, T. (2008). The influence of developmental life stage on quality of life in survivors of prostate cancer and their partners. *Journal Of Cancer Survivorship*, 2, 84-94.
- Harper, F. W., Peterson, A. M., Uphold, H., Albrecht, T. L., Taub, J. W., Orom, H., ... Penner, L.A. (2013). Longitudinal study of parent caregiving self-efficacy and parent stress reactions with pediatric cancer treatment procedures. *PsychoOncology*, 22(7), 1658–1664.
- Heckel L, Fennell KM, Reynolds J, et al. (2015). Unmet needs and depression among carers of people newly diagnosed with cancer. *European Journal of Cancer*, 51:2049–2057.
- Hsu, T., Loscalzo, M., Ramani, R., Forman, S., Popplewell, L., Clark, K., Katheria, V., Feng, T., Strowbridge, R., Rinehart, R., Smith, D., Matthews, K., Dillehunt, J. and Hurria, A. (2014). Factors associated with high burden in caregivers of older adults with cancer. *Cancer*, 120(18), pp.2927-2935.
- Iannarino NT, Palmer-Wackerly AL. Fertility preservation decision-making communication between young adult cancer patients and their romantic partners: an application of the DECIDE typology. *Health Communication*. 2021: 1- 12.
- James, K., Keegan-Wells, D., Hinds, P., Kelly, K., Bond, D., & Hall, B. et al. (2002). The care of my child with cancer: Parents' perceptions of caregiving demands. *Journal Of Pediatric Oncology Nursing*, 19(6), 218-228.
- Jørgensen, T., Hallas, J., Friis, S. and Herrstedt, J. (2012). Comorbidity in elderly cancer patients in relation to overall and cancer-specific mortality. *British Journal of Cancer*, 106(7), 1353-1360.
- Juth, V. (2016). The Social Ecology of Adolescents' Cancer Experience: A Narrative Review and Future Directions. *Adolescent Research Review*, 1(3), 235-244.
- Juth, V., Silver, R., & Sender, L. (2015). The shared experience of adolescent and young adult cancer patients and their caregivers. *Psycho-Oncology*, 24(12), 1746-1753.
- Keegan-Wells, D., James, K., Stewart, J., Moore, I. M. K., Patterson Kelly, K., Moore, B., Bond, D., Diamond, J., Hall, B., Mahan, R., Roll, L., & Speckhart, B. (2002). The care of my child with cancer: A new instrument to measure caregiving demands in parents of children with cancer. *Journal of Pediatric Nursing*, 17, 201-10.

- Kelley, D., Kent, E., Litzelman, K., Mollica, M., & Rowland, J. (2019). Dyadic associations between perceived social support and cancer patient and caregiver health: An actor-partner interdependence modeling approach. *Psycho-Oncology*, 28(7), 1453-1460.
- Kim, Y., & Schulz, R. (2008). Family Caregivers' Strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging And Health*, 20(5), 483-503.
- Kim, Y., Duberstein, P., Sörensen, S., & Larson, M. (2005). Levels of Depressive Symptoms in Spouses of People With Lung Cancer: Effects of Personality, Social Support, and Caregiving Burden. *Psychosomatics*, 46(2), 123-130.
- Kim, Y., Wellisch, D., Spillers, R. and Crammer, C. (2007). Psychological distress of female cancer caregivers: effects of type of cancer and caregivers' spirituality. *Supportive Care in Cancer*, 15(12), 1367-1374.
- Sloper P (1996) Needs and responses of parents following the diagnosis of childhood cancer. *Child Care Health and Development* 22:187–202
- Knight, R., Williams, S., McGee, R., & Olaman, S. (1998). Caregiving and well-being in a sample of women in midlife. *Australian And New Zealand Journal Of Public Health*, 22(5), 616-620.
- Kroger, J. (1995). The differentiation of “firm” and “developmental” foreclosure identity statuses: A longitudinal study. *Journal of Adolescent Research*, 10, 317–337.
- Lackey, N., & Gates, M. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing*, 34(3), 320-328.
- Larson, R. W., Wilson, S. & Rickman, A. (2009). Globalization, societal change, and adolescence across the world. In R. M. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology*, Vol. 2: Contextual influences on adolescent development (3rd ed., pp. 590-622). Hoboken, NJ: John Wiley & Sons, Inc.
- Lau D.T., Berman R., Halpern L., Pickard, A.S. Schrauf, R., Witt, W. (2010). Exploring factors that influence informal caregiving in medication management for home hospice patients. *Journal of Palliative Medicine*, 13:1085-1090.
- Lee, C. & Gramotnev, H. (2007) Transitions into and out of caregiving: Health and social characteristics of mid-age Australian women, *Psychology & Health*, 22(2), 193-209.
- Marcia, J., Waterman, A., Matteson, D., Archer, S., & Orlofsky, J. (1993). *Ego Identity* (1st ed.). Springer-Verlag.
- McAdams, D. P. (2006). The redemptive self: Generativity and the stories Americans live by. *Research in Human Development*, 3, 81–100.
- McCormick, C.M., Kuo, S.I., & Masten, A.S. (2011). Developmental tasks across the life span. In K.L. Fingerman, C.A. Berg, J. Smith, & T.C. Antonucci (Eds.), *Handbook of life-span development* (pp. 117-139). New York: Springer.
- McLaughlin, J., Greenfield, J., Hasche, L., & De Fries, C. (2019). Young Adult Caregiver Strain and Benefits. *Social Work Research*, 43(4), 269-278.
- Mecloskey, J. C., & Bulechek, G. M. (1996). *Nursing intervention classification (NIC)*. St. Louis, MO: Mosby and Co. Mersereau JE, Goodman LR, Deal AM, Gorman JR,

- Whitcomb BW, Su HI. To preserve or not to preserve: how difficult is the decision about fertility preservation? *Cancer*. 2013;119:4044-4050.
- Millar, B., Patterson, P. and Desille, N. (2010). Emerging adulthood and cancer: How unmet needs vary with time-since-treatment. *Palliative and Supportive Care*, 8(2), 151-158.
- Miller, P. (2016). *Theories of Developmental Psychology*. 6th ed. New York: Worth Publishers.
- Moore T, McArthur M, Morrow R. (2009). Attendance, achievement and participation: young carers' experiences of school in Australia. *Australian Journal of Education*, 53:5-18.
- Nation, M., Crusto, C., Wandersman, A., Kumpfer, K., Seybolt, D., Morrissey-Kane, E., Davino, K. (2003). What works in prevention: Principles of effective prevention programs, *American Psychologist*, 6(7), 449-45.
- Neri, A., Yassuda, M., Fortes-Burgos, A., Mantovani, E., Arbex, F., de Souza Torres, S., Perracini, M. and Guariento, M. (2011). Relationships between gender, age, family conditions, physical and mental health, and social isolation of elderly caregivers. *International Psychogeriatrics*, 24(3), 472-483.
- Nicklin, E., Velikova, G., Hulme, C., Rodriguez Lopez, R., Glaser, A., Kwok-Williams, M., & Boele, F. (2019). Long-term issues and supportive care needs of adolescent and young adult childhood brain tumor survivors and their caregivers: A systematic review. *Psycho-Oncology*, 28(3), 477-487.
- Noble-Carr, D. (2002). *Young carers research project: Background papers*. Canberra: Carers Australia.
- Northouse L., Templin T., Mood D. (2001) Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine*, 24(2):115-136
- Northouse, L., Katapodi, M., Schafenacker, A., & Weiss, D. (2012). The Impact of Caregiving on the Psychological Well-Being of Family Caregivers and Cancer Patients. *Seminars In Oncology Nursing*, 28(4), 236-245.
- Novak, M., & Guest, C. (1989). Application of a Multidimensional Caregiver Burden Inventory. *The Gerontologist*, 29(6), 798-803.
- Oktay K, Harvey BE, Partridge AH, et al. (2018). Fertility preservation in patients with cancer: ASCO clinical practice guideline update. *Journal of Clinical Oncology*, 36:1994-2001.
- Oldham L., Kristjanson L.J., White K., Wilkes, L (2006). Female relatives' experiences of testicular cancer. *Australian Journal of Cancer Nursing*, 7:18-24.
- Olsen, P. and Harder, I. (2009). Keeping Their World Together-Meanings and Actions Created Through Network-Focused Nursing in Teenager and Young Adult Cancer Care. *Cancer Nursing*, 32(6), 493-502.
- Owensworth, T., Henderson, L., & Chambers, S. (2010). Social support buffers the impact of functional impairments on caregiver psychological well-being in the context of brain tumor and other cancers. *Psycho-Oncology*, 19(10), 1116-1122.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, 12, 89-102.
- Peterson, B. E. (2002). Longitudinal analysis of midlife generativity, intergenerational roles, and caregiving. *Psychology and Aging*, 17(1), 161-168.

- Pinquart, M., & Sorensen, S. (2007). Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 62(2), 126-137.
- Quinn, G.P., Murphy, D., Knapp, C., Stearsman, D.K., Bradley-Klug, K.L., Sawczyn, K., Clayman, M.L., (2011). Who decides? Decision making and fertility preservation in teens with cancer: a review of the literature. *Society for Adolescent Health and Medicine* 49, 337–346.
- Raveis, V. H., Karus, D. G., & Siegel, K. (1998). Correlates of depressive symptomatology among adult daughter caregivers of a parent with cancer. *Cancer*, 83(8), 1652–1663.
- Reblin, M., Stanley, N., Galligan, A., Reed, D., & Quinn, G. (2019). Family dynamics in young adult cancer caregiving: “It should be teamwork”. *Journal Of Psychosocial Oncology*, 37(4), 526-540.
- Robinson, L., Miedema, B., & Easley, J. (2014). Young Adult Cancer Survivors and the Challenges of Intimacy. *Journal Of Psychosocial Oncology*, 32(4), 447-462.
- Rohleder, N., Marin, T., Ma, R., & Miller, G. (2009). Biologic Cost of Caring for a Cancer Patient: Dysregulation of Pro- and Anti-Inflammatory Signaling Pathways. *Journal of Clinical Oncology*, 27(18), 2909-2915.
- Rose, H., & Cohen, K. (2010). The experiences of young carers: A meta-synthesis of qualitative findings. *Journal of Youth Studies*, 13(4), 473–487.
- Russell, A., Galvin, K., Harper, M., & Clayman, M. (2016). A comparison of heterosexual and LGBTQ cancer survivors’ outlooks on relationships, family building, possible infertility, and patient-doctor fertility risk communication. *Journal Of Cancer Survivorship*, 10(5), 935-942.
- Salvador, Á., Crespo, C., Martins, A. R., Santos, S., & Canavarró, M. C. (2015). Parents’ perceptions about their child’s illness in pediatric cancer: Links with caregiving burden and quality of life. *Journal of Child and Family Studies*, 24(4), 1129–1140.
- Schwartz, S. J., Pantin, H., Prado, G., Sullivan, S., & Szapocznik, J. (2005). Family functioning, identity, and problem behavior in Hispanic immigrant early adolescents. *Journal of Early Adolescence*, 25, 392-420.
- Segrin, C., Badger, T., Dorros, S., Meek, P., & Lopez, A. (2007). Interdependent anxiety and psychological distress in women with breast cancer and their partners. *Psycho-Oncology*, 16(7), 634-643.
- Sherwood, P., Given, C., Given, B., & von Eye, A. (2005). Caregiver burden and depressive symptoms: analysis of common outcomes in caregivers of elderly patients. *Journal Of Aging And Health*, 17(2), 125-147.
- Shifren, K., Kachorek, L. V. (2003). Does early caregiving matter? The effects on young caregivers' adult mental health. *International Journal of Behavioral Development*, 27,338-346.
- Sislowski, D. (2006). Young caregivers: Effect of family health situations on school performance. *Journal of School Nursing*, 22(3), 163-169.
- Sklenarova, H., Krümpelmann, A., Haun, M., Friederich, H., Huber, J., & Thomas, M. et al. (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*, 121(9), 1513-1519.
- Skovdal, M. & Andreouli, E. (2011) Using Identity and Recognition as a framework to understand promote the resilience of Caregiving Children in Western Kenya. *Journal of Social Policy* 40(4)

- Smyth, C., Blaxland, M., & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life' Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145–160.
- Spatuzzi, R., Giulietti, M., Ricciuti, M., Merico, F., Romito, F., & Reggiardo, G. et al. (2019). Does Family Caregiver Burden Differ Between Elderly and Younger Caregivers in Supporting Dying Patients With Cancer? An Italian Study. *American Journal Of Hospice And Palliative Medicine*, 37(8), 576-581.
- Stamatopoulos, V. (2018). The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child & Youth Services*, 39(2–3), 180–205.
- Steinberg, Laurence (2008). "A Social Neuroscience Perspective on Adolescent Risk-Taking." *Developmental Review* 28(1): 78-106.
- Stewart M.J., Ritchie J.A., McGrath P., Thompson, D., Bruce, B. (1994) Mothers of children with chronic conditions: supportive and stressful interactions with partners and professionals regarding caregiver burdens. *The Canadian Journal of Nursing Research* (4): 61–82.
- Sulkers E, Tissing WJE, Brinksma A, Roodbol PF, Kamps WA, Stewart RE, Sanderman R, Fler J (2015) Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. *Psychooncology* 24:318–324.
- Svavarsdottir, E. (2005). Caring for a child with cancer: a longitudinal perspective. *Journal Of Advanced Nursing*, 50(2), 153-161.
- Tatum, C., & Tucker, S. (1998). The concealed consequences of caring: An examination of the experiences of young carers in the community. *Youth and Policy*, 61, 12-27.
- Thompson, A. L., Long, K. A., & Marsland, A. L. (2013). Impact of childhood cancer on emerging adult survivors' romantic relationships: A qualitative account. *Journal of Sexual Medicine*, 10, 65–73.
- Torges, C. M., Stewart, A. J., & Duncan, L. E. (2008). Achieving ego integrity: Personality development in late midlife. *Journal of Research in Personality*, 42, 1004–1019.
- van Ryn M, Sanders S, Kahn K, et al. (2011). Objective burden, resources, and other stressors among informal caregivers: A hidden quality issue? *Psycho-Oncology*, 20:44-52
- Vance Y., Eiser, C. (2004). Caring for a child with cancer - a systematic review. *Pediatric Blood Cancer*, 42:24
- Ward, R. A., & Spitze, G. (1998). Sandwiched marriages: The implications of child and parent relations for marital quality in midlife. *Social Forces*, 77(2), 647–666.
- Warner, E., Kirchoff, A., Ellington, L., Waters, A., Sun, Y., Wilson, A., & Cloyes, K. (2020). Young adult cancer caregivers' use of social media for social support. *Psycho-Oncology*, 29(7), 1185-1192.
- Washington KT, Pike KC, Demiris G., Oliver DP. (2015). Unique characteristics of informal hospice cancer caregiving. *Support Care Cancer* 23(7), 2121-2128
- Waters, A., Gren, L., Rogers, C., Kirchoff, A., & Warner, E. (2021). Qualitative inquiry of cancer caregiving during young adulthood: responsibilities, challenges, teamwork, and social support. *Journal Of Psychosocial Oncology Research & Practice*, 3(4), 1-19.
- Wildiers, H., Heeren, P., Puts, M., Topinkova, E., Janssen-Heijnen, M., & Extermann, M. et al. (2014). International Society of Geriatric Oncology Consensus on Geriatric Assessment in Older Patients with Cancer. *Journal Of Clinical Oncology*, 32(24), 2595-2603.

- Wu, L.M., Chin, C.C., Haase, J.E., Chen, C.H. (2009). Coping experiences of adolescents with cancer: a qualitative study. *Journal of Advanced Nursing*, 65: 2358–2366.
- Wyns C, Collienne C, Shenfield F, Robert A, Laurent P, Roegiers L, Brichard B. (2015). Fertility preservation in the male pediatric population: factors influencing the decision of parents and children. *Human Reproduction*, 30: 2022–2030.
- Yi, J., Kim, M. A., & Sang, J. (2016). Worries of childhood cancer survivors in young adulthood. *European Journal of Oncology Nursing*, 21, 113–119.
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: conceptualizing mothers of children with cancer. *Social Science & Medicine*, 55(10), 1835-1847.