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Youth Psychosocial Adjustment in the Context of Parental Illness: Risk and Protective Factors

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Abstract

Young carers might experience both psychological distress and positive changes from living with their chronically ill parent. Herein, little is known about why some young carers do well with their situation and experience positive outcomes, whereas others do not. In this regard, this dissertation aims to investigate how parental chronic illness affects young carers' psychosocial adjustment through risk (i.e., unmet needs) and protective factors (i.e., benefit finding, emotion regulation). This main goal has been addressed by conducting three empirical studies presented in Chapters 2–4. Chapter 2 has examined the mediating role of unmet needs on the relationship between illness unpredictability and youth psychosocial adjustment (i.e., quality of life and internalizing problems). Accordingly, it has been found that levels of unmet needs significantly mediated the relationship between illness unpredictability and offspring health-related quality of life. In the systematic review with meta-analysis presented within Chapter 3, it has been sought to investigate the mediating role of the protective factors (i.e., benefit finding and emotion regulation) in the relationship between caregiving components and youth psychosocial adjustment (i.e., quality of life and internalizing and externalizing problems) in young carers. This study has shown the significant associations between caregiving components (i.e., caregiving responsibilities and tasks) and psychosocial adjustment in young carers not only directly, but also indirectly through benefit finding. Finally, to expand on previous findings, a qualitative study conducted in Chapter 4 has examined the lived experiences of young carers, as well as the effects of the COVID-19 global pandemic. This study has yielded a deeper understanding of how protective factors may be operated during young carers' lived experiences before and during the COVID-19 global pandemic. These findings have provided crucial insights into the key dimensions that shape the caregiving experiences in the context of parental chronic illness as well as shed light on the effects of the pandemic on the experiences and well-being of young carers. Overall, this dissertation has shed light on the pivotal role played by risk and protective factors in caregiving components that serve as key determinants that can enhance positive psychosocial outcomes as well as concurrently mitigate adverse psychosocial consequences among young carers.

Keywords: Young Carers; Parental Illness; Caregiving Components; Youth Adjustment; Benefit Finding; Risk Factors; Protective Factors

Astratto

I giovani caregiver possono sperimentare sia la sofferenza psicologica che cambiamenti positivi vivendo con un genitore affetto da malattia cronica. Tuttavia, si sa poco sul motivo per cui alcuni giovani caregiver si adattano bene alla loro situazione e vivono esperienze positive, mentre altri no. A tal riguardo, questa tesi si propone di studiare come la malattia cronica del genitore influisce sull'adattamento psicosociale dei giovani caregiver attraverso fattori di rischio e di protezione e come possono trarre benefici dal loro ruolo di caregiver. Questo obiettivo principale è stato affrontato attraverso tre studi. Il Capitolo 2 ha esaminato il ruolo mediatore dei bisogni non soddisfatti sulla relazione tra imprevedibilità della malattia e l'adattamento psicosociale (in termini di qualità della vita e problemi internalizzanti) dei giovani caregiver (cioè qualità della vita e problemi internalizzanti). A tal riguardo, il Capitolo 2 ha indicato che i livelli di bisogni non soddisfatti rappresentano un mediatore significativo della relazione tra imprevedibilità della malattia e qualità della vita correlata alla salute dei figli. Nella revisione sistematica con meta-analisi presentata nel Capitolo 3, si è cercato di indagare il ruolo mediante dei fattori protettivi (cioè ricerca del beneficio e regolazione delle emozioni) nel rapporto tra componenti dell'assistenza e l'adattamento psicosociale dei giovani caregiver (qualità della vita e problemi internalizzanti ed esternalizzanti). Questo studio ha mostrato sia l'associazione diretta tra i componenti del caregiving (cioè responsabilità e compiti del caregiving) e l'adattamento psicosociale dei giovani caregiver, sia quella indiretta attraverso meccanismi protettivi. Infine, per ampliare i risultati precedenti, uno studio qualitativo nel capitolo 4 ha esaminato le esperienze uniche dei giovani assistenti, nonché gli effetti della pandemia globale di COVID-19. Questo studio ha prodotto una comprensione più profonda di come i fattori protettivi possono essere gestiti durante le esperienze vissute dai giovani assistenti prima e durante la pandemia globale di COVID-19. Questi risultati hanno fornito approfondimenti cruciali sulle dimensioni chiave che modellano le esperienze di assistenza nel contesto della malattia cronica dei genitori, oltre a far luce sugli effetti della pandemia sulle esperienze e sul benessere dei giovani assistenti. In generale, questa dissertazione ha fatto luce sul ruolo fondamentale svolto dai fattori di rischio e protettivi nelle componenti dell'caregiving che fungono da determinanti chiave che possono migliorare i risultati psicosociali positivi e contemporaneamente mitigare le conseguenze psicosociali avverse tra i giovani caregiver

Parole chiave: Giovani caregiver; Malattia genitoriale; Componenti del caregiving; Adattamento giovanile; Ricerca del beneficio; Fattori di rischio; Fattori di protezione.

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CHAPTER 1

General Introduction

General Introduction

Diagnosis and treatments of parental illness significantly impact the lives of children and other family members. More than 25% of children and adolescents are living with a parent who has a serious physical or mental illness (Jørgensen et al., 2021). This prevalence is rising globally as a result of improved medical techniques extending ill parents' life expectancies, as well as current demographic trends, including an ageing population, the rising numbers of children born to older parents, and a tendency towards multigenerational living, which, in turn, is associated with a higher vulnerability to developing a severe illness when parenting their young offspring (Morley et al., 2016; Stamatopoulos, 2015). In the broader literature, "young carers" refer to people, typically under the age of 25, who provide significant unpaid caregiving for another person that exceeds what is typically anticipated of someone their age (Aldridge & Becker, 1993; Becker, 2007; Remtulla et al., 2012; Rose & Cohen, 2010). However, identifying young carers may be difficult, as they often do not self-identify as carers, and some caring tasks may be invisible.

Children living with parental illness are at risk of psychosocial adjustment problems such as affective dysregulation, stress-related somatic disorders, lower school performance, and fewer opportunities for personal pursuits compared to their peers with healthy parents (e.g., Chikhradze et al., 2017; Morley et al., 2016; Pakenham & Cox, 2014b). Young carers are still mainly unrecognized or ignored by the public, healthcare providers, researchers, academics, and policymakers, even though they are a high-risk group that needs particular attention (Pakenham et al., 2006; Smyth et al., 2011). As youth caregiving is a "hidden" phenomenon, mainly because many young carers do not self-identify themselves as caregivers, many are unwilling to share their experiences because of fear of stigma connected with it (Aldridge & Becker, 2003; Bolas et al., 2007; McDougall et al., 2018; Rose & Cohen, 2010).

Parental illness is related to a significantly higher risk of mental and physical health problems, poorer health-related quality of life, and social, educational and employment difficulties that persist well into adulthood in young carers (Armistead et al., 1995, Chikhradze et al., 2017; Nagl-Cupal et al., 2014; Pakenham & Cox, 2015; Sieh et al., 2010). These youth with chronically ill parents are also at higher risk for emotional dysregulation, stress-related somatic disorders, and weakened immune responses than their peers (Morley et al., 2016; Sieh et al., 2012). Moreover, adverse effects on mental health, such as low self-esteem and life satisfaction, significant worries, increased risk of depression and anxiety, restricted peer networks and social withdrawal, and failure in education, can be considered among the adverse outcomes that can be associated with youth caregiving (Barry, 2011; Collins & Bayless, 2013; Landi, Duzen, et al., 2022; Landi, Pakenham, Crocetti, et al., 2021; Pakenham & Cox, 2014b).

While caregiving activities make young carers a particularly vulnerable group of young people, current studies have indicated that caregiving activities can have not only negative but also positive consequences (e.g., Gough & Gulliford, 2020; Leu et al., 2019; Pakenham & Cox, 2018; Wepf et al., 2021, 2022). Extant literature has pointed out potential growth and some other positive aspects of growing up with parental illness, including strengthened family relations, increased maturity, and giving a sense of worth from caring activities (Fives et al., 2013; Gough & Gulliford, 2020; Pakenham & Cox, 2018; Wepf et al., 2021, 2022). These positive outcomes indicate that young individuals might benefit from the challenging caregiving process. Indeed, the process of positive growth in the face of challenges has been conceptualized as *benefit finding* (Gough & Gulliford, 2020; Pakenham & Cox, 2018; Wepf et al., 2021, 2022), while adaptive strategies in response to adverse internal or external experiences has been conceptualized as *emotion regulation* (Aldao et al., 2010; Penela et al., 2015).

Given that young carers often derive positive aspects from living with an ill parent and attribute specific meanings to their caregiving roles (Pakenham et al., 2007), *benefit finding*, and *emotion regulation* have been conceived as potential protective factors (Pakenham & Cox, 2018; Troy & Mauss, 2011; Wepf et al., 2022). Alongside such protective factors that may mitigate the detrimental impact of parental illness on youth psychosocial adjustment, there are also risk factors, such as *unmet needs*, which can further exacerbate psychosocial adjustment problems among young carers (e.g., Chikhradze et al., 2017; Pakenham & Cox, 2015). However, the broader literature has largely neglected the factors that could potentially alleviate the negative psychosocial consequences of having ill parents (Jørgensen et al., 2021). Hence, the set of studies presented in the current dissertation aimed to draw a clearer picture of the effect of living with at least one ill parent on the positive (i.e., quality of life) and negative (i.e., internalizing and externalizing problems) psychosocial adjustment of young carers by underlying the roles of the potential risk (i.e., unmet needs) and protective factors (i.e., benefit finding and emotion regulation).

Theoretical Background

Who Are Young Carers?

Caring for a close person who has health issues can be demanding and is frequently accompanied by the experience of potentially traumatic events such as a medical emergency or the death of a loved one, or ongoing family tension (Wepf et al., 2021). Application of the label “young carer” is applied based on intricate, frequently unstated assumptions about what constitutes a carer and what age range qualifies as "young" (Heyman, 2013). The terms ‘young carers’ was first defined by Aldridge and Becker (1993) as young people aged 18 years and younger who "*provide important or important care tasks and take on a level of responsibility often associated with an adult*" (Becker, 2000, p.378). In broader literature, young carers are defined as young people, typically under the age of 25, who provide significant unpaid caregiving for another person that exceeds what is typically expected of someone their age (Becker, 2007; McDougall et al., 2018; Remtulla et al., 2012). However, what is typically expected varies greatly when taking into account socio-cultural differences in understanding of caregiving responsibilities (Andreouli et al., 2013; Skovdal & Andreouli, 2011). Moreover, young carer specifically refers to young people who take on the responsibilities of caring for a parent with an illness or disability (Pakenham et al., 2006; Pakenham & Cox, 2014a). Furthermore, in defining young carers, there are relevant differences between countries regarding the age range included. Namely, in the United States, the age limit for young carers is up to 18 years, in the UK up to 17 years old, and in Australia up to 24 years (Cass et al., 2009; Cunningham et al., 2017). All these definitions together suggest that young carers are a particularly vulnerable group of young people, as they are internationally referred to (Leu & Becker, 2017). Even though, neither Italy nor Turkey has specified the age range for young carers, based on broader literature this dissertation has included young people, those who are

10–25 years, living with one’s families and providing ongoing support and/or care to at least one parent with chronic mental or physical illness.

Also, professionals experience difficulties in identifying young carers, not only because of differences in definitions of young carers but also because many young carers still do not recognize themselves as a caregiver because society does not attribute this ability and role to children and does not support their self-definition, and if they do, many of them prefer to keep their role to themselves and their families for fear of stigma, ridicule, bullying, or even separation from their families (Frech et al., 2021; Leu et al., 2022). Consequently, the comprehensive inclusion of children and young people in the broader caregiving literature has often been delayed by social norms or expectations about what constitutes a "caregiver" and what is regarded outside the social structure of the role children and young people have in families (Kavanaugh & Stamatapoulos, 2021).

Prevalence of Young Carers

Even though a significant proportion of youth grows up with a family member with health problems, the accurate prevalence of those who undertake caring tasks for this person (i.e., young carers) is uncertain (Wepf et al., 2022). International estimates indicate that around 6-22% of all children and adolescents are young carers (e.g., Joseph et al., 2009; Leu et al., 2019; Metzing et al., 2020; Robison et al., 2020). This number is likely to be an underestimation, given the existence of “hidden” carers who undertake caregiving roles but do not identify themselves as carers (Aldridge & Becker, 1993; Smyth et al., 2011). Indeed, the prevalence of young carers is rising worldwide as a result of improved medical techniques extending ill parents' life expectancies and people deciding to have children at an older age which, in turn, is led to a higher vulnerability to developing a serious illness when parenting their young offspring (Morley et al., 2016; World Health Organization, 2020).

Moreover, it should be underlined that when the definition of young carers includes care for siblings and the elderly with needs, the prevalence of young carers is much higher (Stamatopoulos, 2015). Considering there is no clear definition of young carers, studies indicating prevalence rates often use different descriptions, different methods of research, different outcome measures, and samples to estimate prevalence rates, resulting in outcomes often not being comparable (Aldridge, 2018; Kavanaugh et al., 2015; Stamatopoulos, 2015).

Awareness of Young Carers

Young carers have historically been ignored in research, scholarship, and policy development worldwide (Lewis et al., 2022). The reason why young carers have only recently emerged in the public arena might be explained by the fact that some young carers may not regard their situation as socially acceptable and feel compelled to hide their caregiving role from outside sources. Indeed, young carers indicated experiencing difficulties in talking openly about their caregiver role (Banks et al., 2002). Moreover, some young caregivers are unwilling to disclose their caring roles due to concerns about the stigma associated with illness or disability or the possibility that authorities may intervene to the extent that it separates the family (Pakenham et al., 2006). The terms “hidden” or “hard to reach” have been applied by academics to refer to the situation of young carers who are not in contact with official support services but whose caregiving role is also 'unknown' to others in their daily life (Aldridge & Becker, 1993).

Before 2019, only one nonprofit association (JADE) worked to raise awareness and give young carers some respite, but before that, by the 1990s, young carers had received virtually no academic or policy recognition. Since 2020, awareness has increased slightly, and some services are provided by other organizations, though mainly on a local level. According to one study indicating that professionals do already provide support for young carers and their families while not being aware of the situation and specific needs of young carers, especially as children grow older during ‘childhood’ and transition into ‘adulthood’ (Frech et al., 2021).

A first global review of the awareness and support for young carers was carried out in 2017, detailing the level of awareness and response of young carers in each country: (1) incorporated/sustained, (2) advanced, (3) intermediate, (4) preliminary, (5) emerging, (6) awakening, or (7) no response (Leu & Becker, 2017). Based on this classification, no country achieved the status of incorporated/sustained (Leu et al., 2022), with the exception of the United Kingdom (UK) demonstrated an advanced ranking. Nevertheless, many young carers in all countries (even in UK) are still left behind and do not have access to formal health and social care support provided by the government, the market, or charities, making many young carers hidden and unsupported (Lewis et al., 2022).

More attention is needed for the strengths and weaknesses of those policy and service frameworks, including the evaluation of interventions, because research activities on young carers are recognized as one of the key drivers for increasing awareness and developing policy and service frameworks (Leu et al., 2022). Furthermore, regardless of geographic location, young carer research is still understudied (Hendricks et al., 2021). Considering young carers are at risk of psychosocial adjustment problems, it should be underlined that there is a need for increasing awareness of young carers in terms of policies and professionals.

Although the impact of parental illness on youth psychosocial adjustment outcomes has been widely acknowledged (e.g., Chikhradze et al., 2017; Pakenham et al., 2006; Pakenham & Cox, 2015), the lack of a clear conceptualization and functionalization of youth caregiving in the context of parent illness has led to the ambiguity of the definition of youth caregiving (Landi, Pakenham, Crocetti, et al., 2021). Families often meet parental illness needs by redistributing roles among family members, often resulting in young people undertaking more family caregiving tasks (Pakenham et al., 2006). Herein, Family Ecology Framework (FEF;

Pedersen & Revenson, 2005) has underlined an important pathway linking parental illness to youth well-being is the redistribution of caregiving that happens when a parent is diagnosed serious medical condition. Taking a step further from FEF, recent advancements (Landi, Pakenham, Crocetti, et al., 2021; Pakenham & Cox, 2015) have indeed proposed an alternative youth-oriented tripartite model of youth caregiving and combined distinct but firmly related caregiving components (i.e., caregiving responsibilities, experiences, and tasks). Given that the studies in this dissertation aim to fully understand and empirically test how parental illness affects youth's psychosocial adjustment, each of these studies has been built upon the FEF (Pedersen & Revenson, 2005) and tripartite model of youth caregiving (Landi, Pakenham, Crocetti, et al., 2021).

Family Ecology Framework

Chronic illness affects the whole family system (Faulkner & Davey, 2002) because the whole family has to readjust themselves when one of the family members has been diagnosed with a chronic illness, such as cancer (Rolland, 1996). As a result, disruptions in family life occur, and the family dynamics consisting of family relationships, interactions, daily routines, and recreational habits change accordingly (Yang et al., 2016). In a nutshell, the parental illness context requires families often provide for illness needs by redistributing roles among family members, which often involves youth taking on more family caregiving responsibilities (Pakenham et al., 2006). Therefore, it is of utmost importance to gather deeper insight into how young people handle such a challenging process.

Herein, the FEF (Pederson & Revenson, 2005) provides essential baseline by emphasizing a mediating pathway that links the characteristics of parental illness and youth well-being through proximal factors. More particularly, the FEF indicates that there is a set of mediating and buffering mechanisms linking parental illness to youth adjustment (i.e., well-being) and family functioning (i.e., cohesion and parenting), assuming that parental illness indirectly affects youth and family functioning through interpersonal (e.g., daily hassles, youth stress and stigma) and family-levels (e.g., role redistribution) mediators. The FEF has also conceptualized such a mediational pathway as can be affected by additional buffering mechanisms such as coping style, and psychological resources such as resilience and self-efficacy (Pederson & Revenson, 2005).

Tripartite Model of Youth Caregiving

Building upon the FEF, Pakenham and Cox (2015) have innovatively proposed a tripartite model of youth caregiving to examine the comparative impact of seriously ill non-parental family members on youth caregiving and investigate health conditions beyond physical illness, such as mental illness and alcohol and drug problems to physical illness. Afterwards, Landi, Pakenham, Crocetti, et al. (2021) has recently refined the conceptualization of youth caregiving by testing the tripartite model of youth caregiving and reported that caregiving responsibilities, experiences, and tasks represent empirically distinct but related to youth caregiving components. *Caregiving responsibilities* refer to the psychological sense of duties or responsibilities associated with caregiving activities. *Caregiving experiences* correspond to a set of positive and adverse psychosocial experiences related to caregiving responsibilities (Cox & Pakenham, 2014; Pakenham et al., 2006; Pakenham & Cox, 2015). *Caregiving tasks* indicate specific caregiving activities undertaken by youth, such as shopping and cleaning (Ireland & Pakenham, 2010; Pakenham & Cox, 2012b). Overall, concerning youth caregiving, parental illness often demands altering household routines that require a redistribution of roles among family members, while this role shift often involves children taking on a range of potentially demanding caregiving tasks, including instrumental, social, emotional, intimate, and domestic duties (Ireland & Pakenham 2010; Pakenham and Cox 2012b).

Impact of Parental Chronic Illness on Psychosocial Adjustment of Young Carers

Variable amounts of care and maintenance tasks can create different situations for children; some children may provide hours of care per day that includes housekeeping and practical tasks, while others provide less care, and these duties may also include personal or emotional care being (Cunningham et al., 2017). As such, these tasks may affect the child's psychological well-being. Although youth care has often been functionalized over the behavioral component (i.e., involvement in specific caregiving activities; Kallander et al., 2018; Metzing et al., 2020; Nagl-Cupal et al., 2014), the psychological components of caregiving have been largely neglected. However, a growing body of studies embraced a more holistic approach to study youth caregiving and aimed to capture a more nuanced picture of how parental illness influences the psychosocial outcomes of young people (Chikhradze et al., 2017; Landi, Pakenham, Benassi, et al., 2021; Pakenham et al., 2006; Pakenham & Cox, 2012a, 2015) because intensive youth caregiving hinders normative development in youth and is often associated with adverse outcomes (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Landi, Duzen, et al., 2022; Landi, Andreozzi, et al., 2020; Pakenham & Cox, 2014b; Waters et al., 2021).

More specifically, young carers are at increased risk of internalizing (e.g., depressive symptoms, anxiety, and somatic symptoms) and externalizing problems (e.g., aggressive and delinquent behaviors) as well as lower life satisfaction and poorer quality of life (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Landi, Duzen, et al., 2022; Landi, Pakenham, Crocetti, et al., 2021). Compared to their peers with healthy parents, they report feelings of shame, guilt, and loneliness due to parental illness, and they are at risk of affective dysregulation, stress-related somatic disorders, weakened immune responses, lower school performance, higher unemployment rates, and fewer opportunities for personal pursuits (Chikhradze et al., 2017; Morley et al., 2016; Pakenham & Cox, 2014a). In addition, given that they may have trouble managing the competing demands that take up their time, young carers might also experience poor occupational functioning, a decline in academic performance, difficulty in social interactions, and poor physical and mental health (Fives et al., 2015).

Furthermore, young carers often experience social exclusion as a consequence of higher rates of absenteeism, a dropout from education, and lower employability than their peers (Kaiser & Schulze 2015; Stamatopoulos, 2018). Besides, young carers may experience stigma that leads to secrecy and social withdrawal and may struggle with bullying at school (Bolas et al., 2007; Lloyd, 2013; Moore et al., 2009), and limited participation in recreational and social activities, while they are less likely than most children to be visited by friends at home because of parental illness (Aldridge & Becker, 1993; Lackey & Gates, 2001). Over and above this, academic difficulties such as problems concentrating in class, inability to complete homework, absenteeism, and dropping out of school in young carers have also been reported (Dearden & Becker, 2004).

Apart from these disruptive effects, recent studies have systematically underlined that many young carers might benefit or gain from such adversity. Indeed, it has been shown that youth caregiving might lead to positive outcomes, such as perceptions of personal growth, the strengthening of relationships, and changes in priorities and goals (e.g., Gough & Gulliford, 2020; Landi, Pakenham, Crocetti, et al., 2021; Pakenham & Cox, 2018; Wepf et al., 2021). Taken together, one might conclude that the effects of caregiving are variable. Some young carers may be particularly vulnerable to adverse life outcomes due to the nature of their caregiver roles, relationship factors, or other variables within or outside the caregiver relationship, while other caregivers may thrive beyond these roles (Areguy et al., 2019). Hence, it is of utmost importance to identify ways of maximizing the benefits of such a challenging situation for youth in these vulnerable group and, in turn, protect them against the negative outcomes, including psychological distress, lower self-esteem, and increased isolation (Jarrige et al., 2020).

Risk and Protective Factors

There is a need for additional research to obtain more insight into protective and risk factors for the high-risk group of youth with chronically ill parents in order to mitigate the detrimental effects of parental illness on youth psychosocial adjustment (Pakenham & Cox, 2015; Patterson et al., 2017). In fact, additional risk factors might further trigger psychosocial adjustment among youth with an ill parent, most likely because of the intensive caregiving activities, on the one hand, (e.g., Chikhradze et al., 2017; Nagl-Cupal et al., 2014; Pakenham & Cox, 2012a, 2012b, 2015), and on the other, having troubles to fully meet their psychosocial needs, (Patterson et al. 2013). As such, these youth may become more vulnerable and open to experiencing highly adverse psychosocial adjustment outcomes, especially their needs cannot be fully met in families (McDonald et al., 2016).

Herein, *unmet needs* can be conceived as one of the risk factors for young carers and is described as the lack of information about parental illness, feeling not supported by their families, lack of information and assistance, lack of sports and social activities, difficulties with dealing with feelings, lack of support from friends and from others (Patterson et al., 2013). Considering the extant body of knowledge indicating that unmet needs have often increased the risk of improving internalizing and externalizing problems as well as decreasing youth positive psychosocial outcomes (e.g., Ghofrani et al., 2019; McDonald et al., 2016; Patterson et al., 2011; Patterson et al., 2017), it is pivotal to address the additional factors that might increase unmet needs among these youth. Hence, an initial empirical study of this dissertation specifically aimed to disentangle to what extent unpredictability may trigger both unmet needs and, ultimately, psychosocial adjustment among young carers.

Apart from the risk factors causing increased psychosocial adjustment problems, protective factors, might mitigate the detrimental impact of parental illness on youth psychosocial adjustment. Considering that youth tend to benefit from living with an ill parent and tend to attain specific meanings to their roles (Pakenham et al., 2007), *benefit finding* has been conceived as the potential protective factor (Pakenham & Cox, 2018; Wepf et al., 2022). Indeed, it has initially been defined as identifying benefits in difficulties and conceptualized as a meaning-making construct (Janoff-Bulman & Yopyk 2004; Tennen & Affleck 2002). In other words, it refers to obtaining benefits from experienced adversities and appears to be a critical factor that may ensure positive mental health outcomes, especially in young carers (Cassidy et al. 2014). So far, little empirical attention has been given to the specific types of benefits that care may prompt. However, several suggestions have been made to explain how care leads to positive changes among young people, such as that care tasks can lead to experiences of closeness and reciprocity in relationships, promote a positive self-concept, and develop skills in terms of a real-world learning environment (Bolas et al., 2007; Earley et al., 2007; Janes et al., 2021). Research showed that any young person could report some level of experience of benefit finding related to adverse events in their life in each of these six dimensions: acceptance, family bonds, relationships, growth, reprioritization, and empathy (Pakenham & Cox, 2018; Wepf et al., 2021; Cassidy et al., 2014). Finding benefits in these dimensions might enable these youth to reduce the potential negative impacts of being ‘young carers’ and inevitably improve their positive psychosocial adjustment.

In fact, limited evidence highlighted the relationships between benefit finding and greater psychosocial adjustment among young carers (Gough & Gulliford, 2020; Pakenham & Cox, 2018; Wepf et al., 2022). For instance, a study conducted in Australia (Pakenham et al., 2007) showed that benefit finding appeared to be associated with greater positive affect but not with higher life satisfaction and lower distress (Pakenham et al., 2007). However, in another study, it was related to higher life satisfaction and positive effect, on the one and lower distress and somatization, on the other hand (Pakenham & Bursnall, 2006). Besides, benefit finding was also linked to lower caregiver burden and fewer adverse caregiving impacts on school, family, and social life (Cassidy & Giles, 2013; Pakenham & Cox, 2018). Taking all these findings together, it might be worthwhile to help young carers picture their strengths in coping with difficulties, promoting their self-efficacy and well-being (Wepf et al., 2021). Searching for and identifying benefits in the caregiving experience might be helpful to carers to find meaning in their role and, thereby, help to gain meaningfulness.

Herein, *benefit finding* is a possible protective mechanism that can mediate the effects of caregiving components on youth psychosocial adjustment because it has been highly correlated with caregiving demands and participation (Pakenham & Cox, 2018). However, in particular, benefit finding has been neglected by researchers in the youth caregiver field (Pakenham & Cox, 2018). Recent studies have underlined that caregiving components might also be associated with positive outcomes, with many young carers reporting benefits or gains from their adversity, including perceptions of personal growth, the strengthening of relationships, and changes in priorities and goals (Jørgensen et al., 2021; Landi, Pakenham, Benassi, et al., 2021; Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2018; Wepf et al., 2021). For instance, the indirect effect of increased benefit findings has ameliorated the association between caregiving responsibilities and adverse youth psychosocial adjustment (Pakenham & Cox, 2018). In addition to such findings derived from the quantitative studies, qualitative studies have also highlighted that many young carers experience positive consequences of their caring role, including pride, stronger family ties, learning new skills, and personal development (e.g., Boyle, 2020; McDougall et al., 2018; Stamatopoulos, 2018). Several studies report similar benefits associated with caregiving roles, while few studies indicate that the benefit finding structure has not been well developed in the context of parental illness (Earley et al. 2007; Pakenham et al. 2006; Pakenham & Cox, 2018). Although the subjective experience of positive changes following negative events has been referred to as a benefit finding which has also been noted as an essential characteristic and resource among young carers (Cassidy & Giles, 2013; Gough & Gulliford, 2020; Lechner et al., 2009; McDougall et al., 2018; Pakenham & Bursnall, 2006). Also, recent research has also indicated that more perceived caring responsibility is associated with a higher level of benefit findings in young carers (Landi, Boccolini, et al., 2022; Pakenham & Cox, 2018). In this sense, providing occasions for young carers to maximize the positive psychosocial adjustment outcomes is important because benefit finding is linked to positive psychosocial adjustment outcomes and diminishes adverse psychosocial adjustment outcomes in relation to caregiving components.

Emotion regulation might be another protective factor that is likely to reveal the positive aspects of being a young carer, such as finding benefits, and minimizing its negative effects, because it can be helpful for acquiring psychological resilience, especially in stressful situations (Troy & Mauss, 2011). It indicates the awareness and understanding of emotions, acceptance of emotions, ability to control impulsive behaviors and behave in accordance with desired goals when experiencing negative emotions, and ability to use situationally appropriate emotion regulation strategies flexibly to modulate emotional responses as desired in order to meet individual goals and situational demands (Gratz & Roemer, 2004). At the broadest level, emotion regulation addresses cognitive and behavioral strategies individuals use in response to an internal or external experience (Gruhn & Compas, 2020). From this point of view, similar to the benefit finding, emotional regulation might act as a protective factor that may diminish the risks related to undesirable psychosocial adjustment outcomes by fostering adaptive coping in young carers (Kliewer et al., 2004). Moreover, protective factors against the adverse effects related to the caregiving role have been associated with positive adjustment outcomes among young carers, including lower levels of internalizing and externalizing problems, higher levels of quality of life, and more adaptive coping strategies (Cassidy et al., 2014; Cassidy & Giles, 2013; Pakenham & Cox, 2018; Wepf et al., 2021). In light of these considerations, emotion regulation can be conceived as an alternative protective factor (together with benefit finding) in fostering better psychosocial adjustment among young carers.

Little is known about why some young carers do well with their situation and experience positive outcomes, whereas others do not. It has been underlined that this may have some benefits for psychological well-being while conveying a more positive message about how the conditions of youth caregiving can lead to the development of skills to overcome future challenges and, if not, lessen the difficulties encountered (Newman, 2002). From this point of view, it should be underlined the importance of finding benefit from caregiving activities, as well as the ability to use situationally appropriate emotion regulation strategies to better positive psychosocial adjustment outcomes. Therefore, the distinction between negative and positive care outcomes requires further research on the conditions that support some young carers to develop more positive growth in the face of challenges than other young carers. (Abraham & Aldridge, 2010). Hence, further research is needed to determine factors associated with adverse and positive psychosocial outcomes through risk and protective factors to mitigate adverse effects of caregiving components in young carers.

Supplemental research is needed to gain deeper insights into the protective and risk factors pertaining to the vulnerable group of young carers. Risk factors may exacerbate psychosocial adjustment difficulties among young carers primarily due to the demanding nature of caregiving activities (e.g., Chikhradze et al., 2017; Nagl-Cupal et al., 2014; Pakenham & Cox, 2012a, 2012b, 2015), coupled with challenges in adequately meeting their psychosocial needs (Patterson et al., 2013). Conversely, protective factors have the potential to mitigate the detrimental effects of parental illness on the psychosocial adjustment of youth. Notably, benefit finding has been recognized as a potential protective factor, as young carers tend to derive personal growth and benefits from their roles as caregivers (Pakenham et al., 2007; Pakenham & Cox, 2018; Wepf et al., 2022). Additionally, emotion regulation has been identified as another protective factor that can facilitate the identification of positive aspects of being a young carer, such as benefit finding, while minimizing the negative effects that play a pivotal role in fostering psychological resilience, particularly in the face of challenging circumstances (Troy & Mauss, 2011). Consequently, an in-depth exploration of these protective and risk factors holds promise for enhancing our understanding of the psychosocial adjustment process among young carers.

Overview of the Dissertation

In light of these considerations, this dissertation aimed to investigate how parental chronic illness affects young carers' psychosocial adjustment through risk (i.e., unmet needs) and protective factors (i.e., benefit finding, emotion regulation). This main goal has been extensively addressed by conducting three separated studies presented in empirical Chapters 2–4 within this dissertation. Considering that the number of young carers living with parental cancer has been steadily increasing due to cancer being the second leading cause of death worldwide (Landi, Andreozzi, et al., 2020; Landi, Duzen et al., 2022; Morley et al., 2016; Weaver et al., 2010), and these particular group of young carers are at risk of increasing internalizing and externalizing problems (Morris et al., 2016; Morris et al., 2018; Chan et al., 2020), Chapter 2 specifically focused on the young carers with parents who diagnosed with cancer and aimed to address potential risk (i.e., unmet needs) factors influencing their psychosocial adjustment. More precisely, Chapter 2 sought to investigate the mediating role of unmet needs in the relationship between illness unpredictability and psychosocial adjustment (i.e., quality of life and internalizing problems). After focusing on the crucial risk factors on young carers' psychosocial adjustment, accounting that caregiving roles can lead to both positive and negative outcomes (e.g., Gough & Gulliford, 2020; Leu & Becker, 2017; Pakenham & Cox, 2018; Wepf et al., 2021), a systematic review with meta-analysis presented in Chapter 3 has taken a closer look at the protective factors. More particularly, a study conducted with the meta-analytic structural equation model (MASEM) examined the associations between caregiving components (i.e., caregiving experiences, caregiving tasks, caregiving responsibilities) and psychosocial adjustment (i.e., quality of life, internalizing and externalizing problems) by underlying the potential mediating effects of the certain protective factors (i.e., benefit finding and emotion regulation). Finally, considering that the COVID-19 pandemic is a new crisis for young carers who are already facing demanding caregiving tasks and/or challenging caregiving experiences, Chapter 4 is aimed at developing a deeper understanding of how protective factors may be operated during young carers' lived experiences before and during the COVID-19 global pandemic. In this regard, a qualitative study has been conducted to examine the lived experiences of young carers as well as the effects of the COVID-19 pandemic on this vulnerable population by underlying how these youth operate benefit finding.

CHAPTER 2

Illness Unpredictability and Psychosocial Adjustment of Adolescent and Young Adults Impacted by Parental Cancer: The Mediating Role of Unmet Needs

Landi, G., Duzen, A., Patterson, P., McDonald, F. E., Crocetti, E., Grandi, S., & Tossani, E. (2022). Illness unpredictability and psychosocial adjustment of adolescent and young adults impacted by parental cancer: The mediating role of unmet needs. *Supportive Care in Cancer, 30*(1), 145-155. https://doi.org/10.1007/s00520-021-06379-3

Abstract

Objective: Given the large number of adolescents and young adults (AYAs) impacted by parental cancer and the potential for negative psychosocial outcomes in this vulnerable population, this study examined the mediating role of offspring unmet needs with regard to parental cancer and the relation between AYAs psychosocial adjustment and perceived illness unpredictability.

Methods: A total of 113 AYAs (aged 11–24 years) living with a parent diagnosed with cancer completed a questionnaire assessing illness unpredictability, offspring unmet needs, and psychosocial adjustment (i.e., health-related quality of life and internalizing problems).

Results: Higher offspring unmet needs were associated with lower health-related quality of life ($r = -0.24^{**}$) and higher internalizing problems ($r = 0.21^{*}$). Offspring unmet needs mediated the relation between illness unpredictability and health- related quality of life (standardized indirect effect = -0.100^{*} [–0.183, –0.018]) but not internalizing problems (standardized indirect effect = 0.067 [–0.015, 0.148]). In particular, higher illness unpredictability was related to higher unmet needs ($\beta = 0.351^{**}$) which, in turn, predicted lower health-related quality of life ($\beta = -0.286^{**}$).

Conclusion: These findings identify offspring unmet needs and illness unpredictability as implicated in AYAs positive psychosocial adjustment to parental cancer. Given that AYAs are at greater risk of elevated psychosocial difficulties, interventions should target offspring unmet needs and perception of illness unpredictability to mitigate the adverse effects of parental cancer.

Keywords: Adolescents and young adults, Health-related quality of life, Illness unpredictability, Internalizing problems, Offspring unmet needs, Parental cancer

Introduction

In 2018, around 2–2.2 million cancer cases were diagnosed worldwide (de Martel et al., 2020). About 45% of these people are aged between and 64 years; therefore, childbearing and parenting years are widespread periods to receive a parental cancer diagnosis (Center for Disease Control and Prevention, 2017). Given that cancer is the second leading cause of death worldwide with high rates of new cases increasing each year, the number of offspring affected by parental cancer is likely to steadily rise (Landi, Andreozzi, et al., 2020; Morley et al., 2016; Weaver et al., 2010). Furthermore, worldwide, the prevalence of offspring affected by parental cancer is increasing, not only because cancer survival rates have increased by about 20% rise in the last 5 years (Shah et al., 2017), but also because parents are conceiving children at an older age. In turn, older parental age may be associated with raises in the number of offspring impacted by parental cancer (Morley et al., 2016).

A Lancet commission further identified the age range 11–24 years as the highest priority target for youth health and well-being research (Patton et al., 2016), and studies show that having a parent with cancer during this period can adversely affect the psychosocial adjustment of adolescents and young adults (AYAs) (Krattenmacher et al., 2012; Morris et al., 2016, 2018; Philips, 2014; Walczak et al., 2018). In comparison with their peers with "healthy" parents, AYAs living with a parent diagnosed with cancer are at increased risk of internalizing (e.g., depressive symptoms, anxiety and somatic symptoms) and externalizing problems (e.g., aggressive and delinquent behaviors) (Chan et al., 2020; Edwards et al., 2008; Kennedy & Lloyd-Williams, 2009; Krattenmacher et al., 2012; Morris et al., 2016, 2018), poorer quality of life, and lower life satisfaction (Krattenmacher et al., 2016; Morris et al., 2016, 2018; Philips, 2014; Walczak et al., 2018). Parental cancer is also associated with higher emotional dysregulation, stress-related somatic disorders, lower school performance, and higher unemployment rates in offspring (Morris et al., 2016, 2018; Walczak et al., 2018). According to one longitudinal study, AYAs experiencing parental cancer consulted psychiatric services with greater frequency and at an earlier age than offspring of "healthy" parents (Niemela et al., 2012).

Another indicator associated with increased anxiety and depression in family members affected by parental cancer is their levels of cancer related unmet needs (Patterson, Pearce & Slawitchka, 2011) with higher unmet needs related to increased anxiety and depression (McDonald et al., 2016; Patterson et al., 2011, 2013, 2017; Sklenarova et al., 2015). The Offspring Cancer Needs Instrument (OCNI) (Patterson et al., 2013) is a self-report measure that specifically assesses the unmet psychosocial needs of AYAs who have a parent with cancer. It is divided into seven areas of unmet needs (see Table 1 for OCNI domain descriptions). Higher unmet needs were reported in older offspring and in families characterized by poorer family functioning, as well as when parental cancer treatment was current or a relapse had occurred (McDonald et al., 2016). Furthermore, the need for information regarding parental cancer diagnosis, treatment implications, and prognosis has been highlighted as the strongest psychosocial need reported by AYAs (Ghofrani et al., 2019; Patterson et al., 2017).

In addition, compared to objective indicators of severity of parental cancer (e.g., stage or prognosis), higher perceived parental cancer severity is associated with increased distress in AYAs (Compas et al., 1996). One qualitative study corroborated these findings indicating that AYAs who perceived their parental cancer with greatest feelings of fear, uncertainty, and loss of control toward the illness experienced the highest negative emotional reactions (Fletcher et al., 2019). Also, AYAs reported more anxiety, depression, and stress compared to a group of pre-adolescents impacted by parental cancer (Compas et al., 1996; Fletcher et al., 2019; Houck et al., 2007). AYAs living in families impacted by parental cancer may be particularly vulnerable to the negative psychosocial consequences of illness unpredictability (i.e., fear of recurrence, unpredictable symptoms and side effects), as they may be more aware of the seriousness and consequences of their parental cancer diagnosis but may not yet have developed their ability to cope with this unpredictable condition (Andreozzi, et al., 2020; Karlsson et al., 2013; Landi, Boccolini et al., 2022; Pakenham et al., 2006).

In line with previous research pointing to unmet needs as relevant predictors of psychosocial adjustment in AYAs (Compas et al., 1996; Fletcher et al., 2019; Ghofrani et al., 2019; Patterson et al., 2017) the primary focus of this study was to further disentangle the relationship between offspring unmet needs and their psychosocial adjustment. In particular, we expanded on previous findings by further examining the mutual relationship of illness unpredictability and unmet needs and their link with positive (i.e., health-related quality of life) and negative (i.e., internalizing problems) outcomes in offspring of parents with cancer. We supposed that unmet needs would be a mechanism through which illness unpredictability exerts its effect on AYAs psychosocial adjustment. This prediction is line with one of the most promising model of youth adjustment in the context parental illness, the FEF, which indicates that parental illness severity affects youth adjustment indirectly through various youth responses to parental illness (Pedersen & Revenson, 2005). Therefore, the aims of this study were as follows: (1a) to analyze the relationship between levels of unmet needs in AYAs and their psychosocial adjustment (i.e., health-related quality of life and internalizing problems) as well as (1b) to explore the impact of demographic (offspring age and gender, and parental gender) and cancer variables (time since diagnosis and illness unpredictability) on level of offspring unmet needs and (2) to investigate the mediating role of unmet needs in the relationship between illness unpredictability and psychosocial adjustment in AYAs. We expected that (H1a) higher unmet needs would be associated with worse psychosocial adjustment (i.e., poorer health-related quality of life and greater internalizing problems) and (H1b) higher levels of illness unpredictability, which is one of the cancer variables, would be related to higher levels of unmet needs; (H2) illness unpredictability would increase unmet needs which, in turn, would be associated with worse psychosocial adjustment in AYAs.

Table 1

Unmet Needs in Adolescents and Young Adults (AYAs) Impacted by Parental Cancer.

Dimensions of the Offspring Cancer Needs Instrument (OCNI)	
Information about my parent’s cancer	This domain refers to offspring having access to information about their parent’s cancer and the need for conveying this information in a way understandable to them (e.g., “To get information about my parent's cancer in a way that I can understand”).
Family issues	This domain refers to the need for offspring to feel supported by their families and to communicate openly and honestly with them about parental cancer (e.g., “To feel that I can talk openly with my family about my parent's cancer”).
Practical assistance	This domain refers to the need for information and assistance with the caring of the ill parent and household duties as well as practical support for staying on tasks at school or work. It also includes having access to professional support services (e.g., “Assistance with looking after my parent with cancer”).
‘Time out’ and recreation	This domain refers the need for offspring to be involved in sport and social activities along with the need for occasional escapism and ‘time out’ from the pressures of having a parent with cancer (e.g., “Need to be able to have fun”).
Dealing with feelings	This domain refers to the need for offspring to be able to express how they are feeling about their parent’s cancer along with the need for help when dealing with these feelings (e.g., “Help dealing with feelings of anxiety and feeling scared about my parent's cancer”).
Support from my friends	This domain refers to the need to feel supported by one’s own friendship group who share a similar experience about having a parent with cancer (e.g., “My friends to understand what I am going through”).
Support from other young people	This domain refers to the need to supported by other young people who share a similar experience about having a parent with cancer (e.g., “To talk to someone my own age who has been through a similar experience with cancer”).

Notes. Adapted from Patterson et al. (2013).

Method

Participants and Recruitment Procedure

We conducted this study in Italy, where it is estimated that about 3.5 million people are currently living with an oncological disease, with more than 1,000 new cases of cancer diagnosed every day (AIOM, 2019). Eligibility criteria included AYAs aged between 11 and 24 living with a parent affected by cancer. Exclusion criteria were insufficient command of Italian, cognitive impairments, and severe medical conditions in youth themselves, siblings, or other family members apart from parents. Data was collected between November 2018 and May 2019. Because there is a lack of official statistics describing the characteristics of Italian AYAs of parents with cancer, we could not directly compare the characteristics of our sample with the characteristics of the overall population of youth in the context of parental cancer. Nevertheless, in order to collect a sample that could be as representative as possible, we used multiple recruitment strategies such as information brochures and posters in primary and secondary schools, universities, and groups of youth (e.g., library, music, and sports groups); cancer-related local community organizations (e.g., self-help and family support groups); and waiting rooms of health facilities (i.e., general practitioner, hospital, and cancer specialist clinics). Potential participants who showed interest in taking part in the study contacted the researchers by telephone or email. Subsequently, a researcher conducted an initial interview collecting some socio-demographic and qualitative data and then gave AYAs a booklet of questionnaires to fill out, usually at the family home, after obtaining active informed consent from both parents or legal guardian if youth were under the age of 18 years or from youth themselves if they were ≥ 18 years. The administration procedure was pencil and paper based. The variation in recruitment methods precluded the calculation of an overall response rate. The study was approved by the University of Bologna ethics committee.

Measures

Demographics and family structure variables

AYAs indicated their age (via the date of birth), gender, studying status, and employment status. AYAs also indicated the number of family members, including siblings as well as whether they were living in a dual or single-parent family.

Parental cancer variables

AYAs indicated which parent had cancer (mother, father, or both) as well as the type of parental cancer. If both were selected, participants were asked to answer the remaining questions concerning the parent with the more severe type. Participants also indicated the time in years since their parent's cancer diagnosis.

Perceived illness unpredictability

Perceived illness unpredictability was evaluated with a scale developed by Pakenham and colleagues (Pakenham et al., 2006) and used in prior published research in the field of youth caregiving (e.g., Landi, Andreozzi, et al., 2020; Pakenham et al., 2006). AYAs indicated the extent to which they agreed with 5 items (e.g., "My parent's condition could change at any time with little warning" or "It's not clear to me when my parent's condition is getting better or worse" or "It is difficult to plan ahead because my parent's condition is unpredictable") rated on a 5-point scale (0 strongly disagree to 4 strongly agree) (Pakenham et al., 2006). Items scores were averaged with higher scores indicating higher illness unpredictability (Pakenham et al., 2006). The internal consistency ($\alpha = 0.68$) in the current sample was adequate.

Offspring unmet needs

The Offspring Cancer Needs Instrument (OCNI) (Patterson et al., 2013) assesses the unmet psychosocial needs of offspring who have a parent with cancer. It is composed of 47 items clustered into 7 domains. Scores are summed, with higher scores indicating higher offspring unmet needs. The OCNI has evinced good psychometric properties (Patterson et al., 2013). A multistep approach was selected for the translation of OCNI into Italian (Acquardo et al., 2008). The original version of the instrument was firstly independently translated by two authors and a bilingual translator. Ambiguities of these versions were identified, and a reconciled forward version was created. This preliminary version was back-translated by one bilingual translator whose native language was English. This back-translated version was sub mitted to the original authors for approval. After applying a few suggested changes, the Italian version of the OCNI was administered to a pilot group of 30 offspring to evaluate the extent to which the instrument was clear and understandable. Final modifications were carried out according to this pilot study. Because the OCNI has not been validated in Italian, as a preliminary step, we ran a confirmatory factor analysis (CFA) of the translated version. The final Italian OCNI used in this study demonstrated excellent internal consistency (α = 0.95).

Psychosocial adjustment

The following positive and negative psychosocial adjustment outcomes were assessed in AYAs: health-related quality of life and internalizing problems.

Health-related quality of life. The Kidscreen-27 (Ravens-Sieberer et al., 2007) is a self-report questionnaire composed of 27 items assessing youth quality of life in five subscales: physical well-being, psychological well-being, autonomy and parent relations, peers and social support, and school environment. Total scores were computed by summing all items, with higher scores indicating greater health-related quality of life. Kidscreen-27 has been validated in a large population-based youth sample from several European countries, including Italy, and demonstrated good psychometric properties (Ravens-Sieberer et al., 2007). The internal consistency of Kidscreen-27 in this study was excellent (α = 0.82).

Internalizing problems. The internalizing problem scale of the youth self-report (YSR) was used to assess emotional and behavioral functioning of AYAs (Achenbach & Resorta, 2001). The YSR internalizing problems scale reflects three dimensions: anxious/depressed, withdrawn/depressed scale, and somatic complaints. Items are summed to obtain a total score for internalizing. The original YSR has demonstrated sound psychometric proprieties including test–retest reliability ($r = 0.79$ to 0.88), internal consistency ($r = 0.67$ to 0.83) and good content, and criterion-related and construct validity (Achenbach & Resorta, 2001). The Italian version of YSR has been validated and showed good psychometric properties (Frigerio et al., 2001). The internal consistency ($\alpha = 0.88$) in the current sample was excellent.

Data Analysis

Data analyses were performed using statistical software SPSS and M*plus* 8.3 (Muthén & Muthén, 1998-2017). Multiple linear regression was used to examine the impact of demographic and cancer variables on the level of offspring unmet needs. Cronbach's alpha was used to estimate the internal reliability of all measures, with values greater than 0.60 considered to be acceptable, more significant than 0.70 satisfactory, and above 0.80 excellent (Berger & Hanze, 2015).

The structural validity of the Italian translation of the OCNI was tested by confirmatory factor analyses (CFA) with maximum likelihood robust (MLR) estimator. To estimate the structural associations between the study variables, structural equation modelling (SEM) analyses were conducted with MLR. In particular, we tested models including a combination of latent (i.e., unmet needs, health-related quality of life, internalizing problems) and observed (i.e., illness unpredictability) variables. Demographics significantly correlated with youth adjustment outcomes were controlled for in the mediation analyses. Finally, to test the mediating effects of offspring unmet needs in the relationship between parental cancer unpredictability and psychosocial adjustment, indirect effects were tested. The model fit was evaluated by means of the comparative fit index (CFI), with values higher than 0.90 indicative of an acceptable fit, and values higher than 0.95 demonstrating an excellent fit, and the standardized root mean square residual (SRMR) and the root mean square error of approximation (RMSEA), with values below 0.08 representing an acceptable fit and values lower than 0.05 indicative of a very good fit (Marsh et al. 2005). The 90% confidence interval (CI) of the RMSEA was also examined (i.e., a good fit is indicated by the upper bound lower than 0.10) (Marsh et al., 2005).

Results

Participants' Characteristics

One hundred and thirteen AYAs impacted by parental cancer took part in the study. The participants ranged in age from 11 to 24 years (*M* = 17.97, *SD* = 3.79), with 61.1% female and an average parental time since diagnosis of 3.07 years (*SD* = 2.98), ranging from just diagnosed to 5 years since diagnosis. Further demographic characteristics of young people and their parents with cancer are depicted in Table 2.

Preliminary Analyses

Factor analysis of Italian Offspring Cancer Needs Instrument

To test the original factor structure of the OCNI (Patterson et al., 2013), a CFA was conducted using MLR estimator. Because there was variability in the number of items forming each of the OCNI dimensions (ranging from four to thirteen items), we used a parceling approach (random assignment of items to parcels) (Little et al., 2002). In this condition, the parceling technique has several advantages, such as a more optimal sample size ratio indication and a greater likelihood of achieving a good model solution (Crocetti et al., 2016; Marsh et al., 1998). Specifically, we used three parcels for each of the OCNI dimensions, as reported in Fig. 1.

Table 2

Demographic Characteristics of the Adolescents and Young Adults (AYAs) and Their Parents with Cancer

Variable	%	*M (SD)*	Range
Demographics			
Age years		17.97 (3.79)	11.59-24.79
Gender			
Male	38.9		
Female	61.1		
Currently studying	87.6		
Currently working	28.3		
Family structure variables			
Family size		4.19 (1.21)	
Number of siblings		1.01 (0.07)	
Single parent family	8.8%		
Parent with Cancer			
Mother	87.6		
Father	12.4		
Time since cancer diagnosis (years)		3.07 (2.98)	1-5
Illness unpredictability		1.6 (0.8)	0-3.6
Cancer types[1]			
Breast cancer	66.4		
Colon cancer	12.4		
Skin cancer	4.4		
Brain cancer	2.7		
Uterine cancer	2.7		
Thyroid cancer	1.8		
Kidney cancer	1.8		
Soft tissues tumor	1.8		
Lymphoma cancer	1.8		
Ovarian cancer	0.9		
Bone cancer	0.9		
Liver cancer	0.9		
Laryngeal cancer	0.9		
Auditory nerve tumor	0.9		

Notes. [1]Some people had more than one type of cancer.

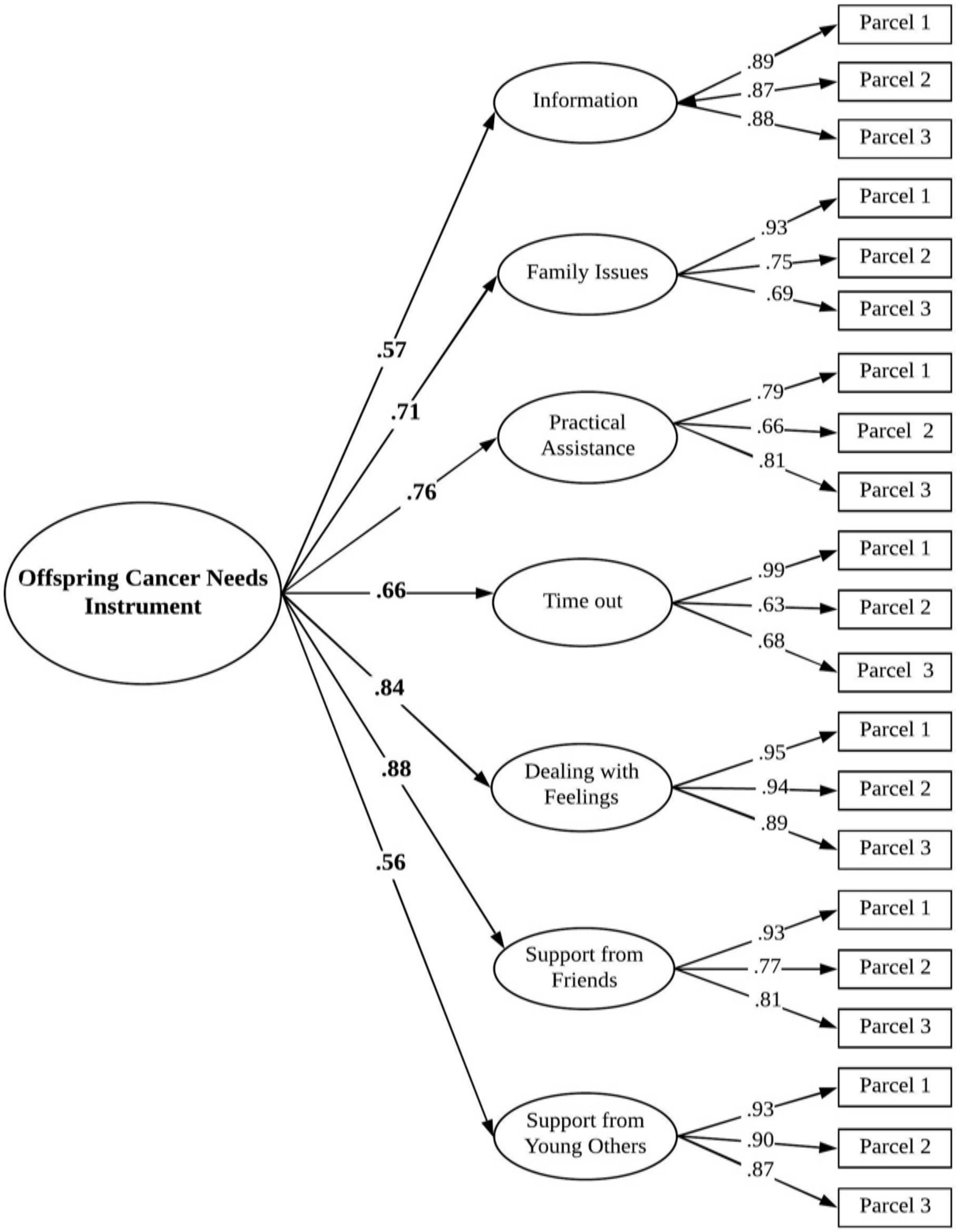
Fit indices indicated that the original factor structure of the OCNI, with seven first-order latent factors and one second-order latent factor (i.e., total score of OCNI), fit the data very well also in this Italian sample ($\chi^2 = 1828.745$, $df = 210$, CFI = 0.925, RMSEA [90% CI] = 0.077 [0.061, 0.092], SRMR = 0.065). Cronbach's alpha for each subscale were good (information about my parent's cancer = 0.92, family issues = 0.82, practical assistance = 0.79, "time out" and recreation = 0.82, dealing with feelings = 0.92, support from my friends = 0.88, support from other young people = 0.94). Figure 1 displays standardized solution for the Italian OCNI factor structure.

Levels of unmet needs and AYAs psychosocial adjustment and the relationship between demographic and cancer variables on level of unmet needs

In line with the first study aim, we conducted Pearson's correlations to analyze the relationship between levels of unmet needs in AYAs impacted by parental cancer and their psychosocial adjustment (operationalized with health-related quality of life and internalizing problems). As reported in Table 3, results indicate that higher unmet needs were negatively related to health-related quality of life ($r = –0.24$, $p < 0.001$) and positively related to internalizing problems ($r = 0.21$, $p < 0.05$). Illness unpredictability was positively associated with offspring unmet needs ($r = 0.35$, $p < 0.01$) and with internalizing problems ($r = 0.22$, $p < 0.05$), but was not associated with health-related quality of life. Health-related quality of life was negatively and strongly correlated with internalizing problems ($r = −0.60$, $p < 0.01$). All study variables were normally distributed, and their means, standard deviations, skewness, kurtosis, and bivariate correlations are displayed in Table 3.

Figure 1

Standardized Solution of the Original Factor Model of the Offspring Cancer Needs Instrument (OCNI)



Note. All factor-loadings and correlations are significant at p < .001.

Table 3

Study Variables. Means (M), Standard Deviations (SD), Skewness, Kurtosis and Bivariate Correlations among Study Variables

	M (SD)	Skewness, Kurtosis	1	2	3
1. Offspring Unmet Needs	104.76 (26.84)	−.15, −. 81			
2. Illness Unpredictability	1.60 (0.80)	.10, −.52	.35**		
3. Internalizing Problems	13.93 (9.13)	.85, .32	. 21*	.22*	
4. Health-related Quality of Life	97.14 (15.38)	−.51, −.18	−.25**	−.14	−.60**

Notes. $N = 113$. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

We further explored the impact of demographic variables (offspring age and gender, and parental gender) and cancer variables (time since diagnosis and illness unpredictability) on the level of offspring unmet needs. We fitted a multiple linear regression model with total unmet needs as the dependent variable and demographic and cancer variables as predictors. As shown in Table 4, among all included predictors, only illness unpredictability ($\beta = 0.333$, $p < 0.01$) was significantly positively associated with unmet needs. As expected, illness unpredictability was positively related to unmet needs in AYAs. The total model accounted for 15% of the variance in offspring unmet needs which represents a medium effect size (Landi, Pakenham, Benassi, et al., 2021).

The mediating role of offspring unmet needs in the relationship between illness unpredictability and offspring psychosocial adjustment

In line with the second study aim, to examine the mediating role of offspring unmet needs in the relationship between illness unpredictability and offspring psychosocial adjustment, we conducted two SEM analyses in which illness unpredictability was set as the independent variable, offspring unmet needs as the mediator, and internalizing problems and health-related quality of life as dependent variables, respectively. Of the demographics, gender and age were significantly associated with internalizing problems and health-related quality of life; therefore, we controlled for them in mediation analyses. Specifically, being female positively related to internalizing problems ($r = -0.30$, $p < 0.01$), while being older was associated with poorer health-related quality of life ($r = -0.21$, $p < 0.001$). The two models fit the data well: $\chi^2 = 113.724$, $df = 83$, CFI = 0.941, RMSEA [90% CI] = 0.057 [0.027, 0.082], and SRMR = 0.060 for the model with health-related quality of life and $\chi^2 = 87.781$, $df = 58$, CFI = 0.935, RMSEA [90% CI] = 0.067 [0.036, 0.095], and SRMR = 0.063 for the model with internalizing problems as outcomes.

Table 4

Linear Regression Examining the Impact of Demographic and Cancer Variables on the Level of Offspring Unmet Needs

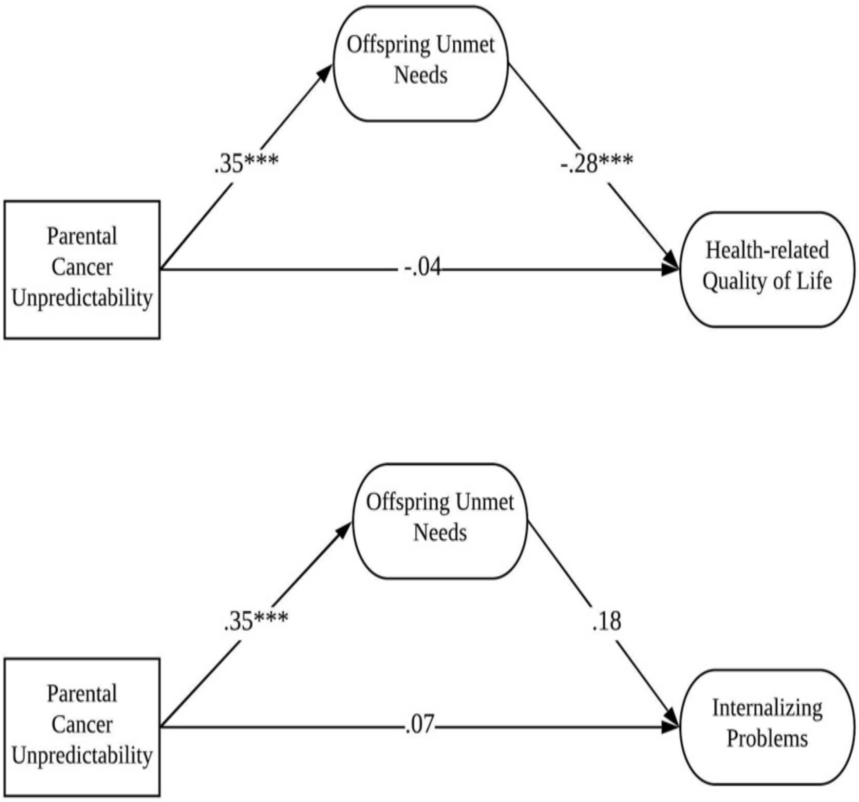
	Offspring Unmet Needs	
	Coeff. (*SE*)	95 % CI
Offspring Age	.006 (.656)	−1259, 1.343
Offspring Gender	−.011 (5.052)	−10.601, 9.434
Parental Gender	.095 (7.310)	−6.838, 22.149
Time Since Diagnosis	.122 (.820)	−0.534, 2.716
Illness Unpredictability	$.333^{**}$ (3.180)	4.952, 17.564
		$R^2 = .153^{**}$
		$F\ (5,105) = 3.805$

Note. $^{**}p < .01$

Results of the mediation analyses are displayed in Fig. 2. Illness unpredictability had no direct effect on health-related quality of life ($\beta = -0.048$, $p > 0.05$) nor internalizing problems ($\beta = 0.071$, $p > 0.05$). As expected, offspring unmet needs significantly mediated the relationship between illness unpredictability and health-related quality of life: standardized indirect effect = –0.100 [–0.183, –0.018], $p = 0.017$. In particular, illness unpredictability was positively associated with offspring unmet needs ($\beta = 0.351$, $p < 0.001$), which in turn were negatively related to health-related quality of life ($\beta = –0.286$, $p < 0.01$). However, contrary to our hypothesis, offspring unmet needs did not significantly mediate the relationship between illness unpredictability and internalizing problems: standardized indirect effect = 0.067 [–0.015, 0.148], $p = 0.111$.

Figure 2

Mediation Role of Offspring Unmet Needs in the relation between Parental Cancer Unpredictability and Health-related Quality of Life, and Internalizing Problems



Note. $^{***}p < .001$

Discussion

This study analyzed the relationship between levels of unmet needs in AYAs impacted by parental cancer and their psychosocial adjustment (i.e., health-related quality of life and internalizing problems) and explored the impact of demographic variables (offspring age and gender, and parental gender) and cancer variables (time since diagnosis and illness unpredictability) on level of unmet needs. In line with our first hypothesis, we found that higher unmet needs were negatively associated with health-related quality of life and positively related to internalizing problems. These results are consistent with previous studies indicating that parental cancer in AYAs is associated with higher unmet needs and distress (McDonald et al., 2016; Patterson et al., 2011, 2013, 2017) and significantly impacts their psychosocial adjustment (Chan et al., 2020; Ellis et al., 2017; Krattenmacher et al., 2012; Morris et al, 2016; Walczak et al., 2018). We expanded these findings by highlighting an association not only with negative psychological outcomes but also with health-related quality of life which is a positive psychological outcome. This is, thus, the first study highlighting a negative relationship between unmet needs and health-related quality of life.

Furthermore, results of this study indicate that among demographics and parental cancer variables, only perceived illness unpredictability was significantly positively associated with offspring unmet needs. That is, higher levels of illness unpredictability were related to greater unmet needs in AYAs. These results are consistent with previous studies indicating that parental cancer relapse, which is related to the unpredictability of the illness, is associated with higher unmet needs in AYAs (McDonald et al., 2016). Also, results of this study might be explained by previous literature in which stronger subjective beliefs in AYAs toward the negative consequences of their parents' illness were associated with the perception that the illness was unpredictable and with lower psychosocial adjustment, regardless of objective indicators of severity of parental illness (Pakenham et al., 2006). The demographic and parental cancer variables included in our regression model explained 15% of the variance in offspring unmet needs, which indicates a medium effect size (Ellis, 2017). Other variables not assessed in this study might be also associated with offspring unmet needs. In fact, because parental cancer modifies family dynamics, decreasing the ability of the ill parent to fulfill familiar roles and responsibilities and increasing demands on other family members (Landi, Andreozzi, et al., 2020; Landi, Pakenham, Benassi, et al., 2021; Pakenham et al., 2006, 2007; Pedersen & Revenson, 2005), AYAs might take on more caregiving responsibilities resulting in less time for social and activities and more unmet needs (Justin et al., 2021). The quality of the relationship between family members might also affect the assumptions of caregiving responsibilities within the family and be associated as well with offspring unmet needs (Pakenham et al., 2006, 2007). Future studies should investigate how family role redistribution impacts on the levels of offspring unmet needs.

The second aim of this study was to examine the mediating role of unmet needs in the relationship between illness unpredictability and offspring psychosocial adjustment. A mediating effect of unmet needs was found between illness unpredictability and health-related quality of life. In particular, higher levels of illness unpredictability were related to higher levels of unmet needs which, in turn, were associated with lower levels of health-related quality of life. This finding is in line with the broader literature in which offspring of parents with cancer reported poorer quality of life as a result of parental cancer diagnosis (Inbar et al., 2013; Krattenmacher et al., 2012; Morris et al., 2016; Walczak et al., 2018). We clarified that lower levels of health-related quality of life were mediated by higher levels of offspring unmet needs due to greater illness unpredictability.

Unexpectedly, offspring unmet need did not mediate the relationship between illness unpredictability and internalizing problems. According to the broader parental cancer literature, AYAs of parents with cancer are at more risk of internalizing problems (Edwards et al., 2008; Kenndey & Lloyd-Williams, 2009) and offspring unmet needs were associated with higher levels of internalizing problems in this study. Nevertheless, we did not find that higher levels of internalizing problems were mediated by higher offspring unmet needs via higher levels of illness unpredictability. The lack of a significant mediation of offspring unmet needs in the link between illness unpredictability and internalizing problems might be explained by the fact that our sample had a mean parental time since diagnosis of three years while most other studies on the psychosocial adjustment of AYAs have been conducted with shorter mean parental time since diagnosis (Krattenmacher et al., 2012; McDonald et al., 2016). Future research should further explore the association between illness unpredictability, offspring unmet needs, and internalizing problems in AYAs.

Results of this research highlighted perception of illness unpredictability as a factor implicated in psychosocial adjustment and unmet needs among AYAs over and above other demographic and cancer variables (i.e., offspring age and gender, parental gender, and time since diagnosis). Understanding this can assist in identifying at risk AYAs with higher perception of parental illness unpredictability and unmet needs and providing tailored interventions to improve their psychosocial adjustment to parental cancer. These interventions could include the following: (1) increasing AYAs understanding of, and active involvement in, their parents' cancer treatment and care through psychoeducation and attending medical appointments with their ill parent (Maynard et al., 2013); (2) encouraging discussion about cancer within the family and the participation of AYAs in peer recreation/therapeutic camps which provide an opportunity for psychosocial support, skill development, and time out from the daily stresses of living with a parent affected by cancer (Konings et al., 2020) and (3) using acceptance and commitment therapy based therapeutic approaches that facilitate having a different relationship with the realities of uncertainty and unpredictability while focusing the young person’s energy on living their life in line with their values (Landi, Pakenham, Benassi, et al., 2021; Patterson et al., 2015).

This study has several methodological limitations. First, the non-random sampling increases the risk of volunteer response bias and limits the generalizability of findings. However, participants were recruited from various cancer-related local community organizations as well as other recruitment strategies targeting youth (e.g., schools and youth groups) in order to obtain a sample as representative as possible of the Italian population of AYAs in the context of parental cancer. Nonetheless, our sample had an unbalanced distribution in terms of parents’ cancer type and gender of AYAs—as frequently reported in psycho-oncology research (Wakefield et al., 2017), there were over-representations of parents with breast cancer and of female AYAs. Furthermore, because of the cross-sectional design, inferences about causal directionality among illness unpredictability, offspring unmet needs and their psychosocial adjustment remain unclear. As mediation consists of causal processes that unfold over time, further research should examine longitudinally the mediational role of unmet need as a mechanism through which illness unpredictability exerts its effect on AYAs psychosocial adjustment.

Conclusion

Our study has underlined that higher offspring unmet needs are associated with lower levels of health-related quality of life and internalizing problems and that higher levels of illness unpredictability are related to higher unmet needs. Finally, we showed that levels of unmet needs significantly mediated the relationship between illness unpredictability and offspring health-related quality of life (but not internalizing problems). These results enhance our understanding of offspring psychological adjustment by providing novel insight into the relationship between offspring unmet needs and positive (health-related quality of life) and negative (internalizing problems) offspring adjustment outcomes. Our findings also indicate that illness unpredictability is positively associated with offspring unmet needs and that it is the only significant predictor of unmet needs over and above demographics (gender, age, parental gender) and parental time since diagnosis. Perception of illness unpredictability may be a clinically relevant variable to target in supporting these young people given the greater risk of elevated levels of unmet needs and psychosocial difficulties.

CHAPTER 3

The Mediating Role of Protective Factors in Relationship Between Caregiving Components and Psychosocial Adjustment Among Young Carers: A Meta-Analysis

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Duzen, A., Landi, G., Bilici, Z., Pakenham, K. I., Oort, F., Jak, S., Agostini, F., Grandi, S., & Tossani, E. (2023**).** The mediating role of protective factors in the relationship between caregiving components and psychosocial adjustment among young carers: A meta-analysis. [Manuscript in preparation].

Abstract

Objective: In order to fulfill the needs of young carers for support and recognition, a better understanding of the conditions and ways that permit positive outcomes is necessary. This systematic review with meta-analysis examined the relationship among the caregiving components and youth psychosocial adjustment (i.e., quality of life, internalizing, externalizing problems), and protective factors (i.e., benefit finding and emotion regulation), as well as the mediating role of the protective factors in the relationship between caregiving components and youth psychosocial adjustment.

Methods: Three electronic databases have been searched until December 2021, identifying 6,876 unique publications that were further screened by title and abstract, resulting in 254 publications being fully screened. A total of 57 quantitative studies yielded at the end of the search process.

Results: The results showed that caregiving experiences were positively associated with internalizing and externalizing problems. Furthermore, caregiving tasks were positively associated with quality of life not only directly but also indirectly through benefit finding. However, there was no statistically significant indirect effect of the caregiving components on psychosocial adjustment outcomes through emotion regulation.

Conclusion: These findings established within an innovative meta-analytic mediation model expand the available knowledge by indicating not only direct but also indirect associations of caregiving components and psychosocial adjustment through protective factors. Overall, the present study provides novel insights by suggesting that it may be valuable to support young carers in reflecting on their way of finding benefits and promoting positive psychosocial adjustment.

Keywords: Young Carers; Parental Illness; Caregiving Components; Youth Adjustment; Benefit Finding; Emotion Regulation; Meta-analysis

Introduction

Diagnosis and treatment of parental illnesses significantly impact the lives of their children and other family members. More than 25% of children and adolescents live with a parent who has a serious physical or mental illness (Jørgensen et al., 2021). The prevalence of parental chronic illness is increasing worldwide due to advancements in medical techniques that extend the life expectancies of ill parents (Stamatopoulos, 2015). Additionally, current demographic trends, such as an aging population, an increase in children born to older parents, and a tendency towards multigenerational living, contribute to a higher vulnerability of parents developing severe illnesses while raising their young offspring (Morley et al., 2016). Children living with parental illnesses are at risk of psychosocial adjustment problems such as affective dysregulation, stress-related somatic disorders, lower school performance, and fewer opportunities for personal pursuits compared to their peers with healthy parents (e.g., Chikhradze et al., 2017; Morley et al., 2016; Pakenham & Cox, 2014a). Even though children at risk are now considered a distinct social group, the term "young carer" explicitly represents a diverse and heterogeneous group of young people (Gough & Gulliford, 2020). However, young carers are still mainly unrecognized or ignored by the public, healthcare providers, researchers, academics, and policymakers, even though they are a high-risk group that needs particular attention (Pakenham et al., 2006; Smyth et al., 2011). Youth caregiving is a "hidden" phenomenon, mainly because many young carers do not self-identify themselves as caregivers, and many are unwilling to share their experiences because of fear of stigma connected with it (Aldridge & Becker, 2003; Bolas et al., 2007; McDougall et al., 2018; Rose & Cohen, 2010).

In the broader literature, young carers are referred to as young people, typically under the age of 25, who provide substantial unpaid care to another person, often beyond what would be expected of someone their age (Aldridge & Becker, 1993; Becker, 2007; Remtulla et al., 2012). While caregiving processes make young carers a particularly vulnerable group of youth, extended studies have also stated that caregiving activities could have either positive or negative consequences (Leu & Becker, 2017; Joseph et al., 2009). Based on the literature, caregiving processes may lead to personal growth and, as a protective factor, provide the youth with a meaningful and contributing role during challenging times in the family (Gough & Gulliford, 2020). However, little is known about the role of protective factors in the psychosocial adjustment of young carers. Therefore, it is becoming progressively important to understand the role of protective factors on the impact of caregiving components on youth psychosocial adjustment.

In order to clarify the role of protective factors in the relationship between caregiving components and youth psychosocial adjustment, the present study examines the mediating roles of protective factors between caregiving components and psychosocial adjustment, which is derived largely from the mediational model proposed by Pakenham and Cox (2018). In their study, reported the mediating role of benefit finding in relationships between social support satisfaction, network size, caregiving responsibilities and mental health, and it has been reported that benefit finding mediates the effects of social support and caregiving on youth adjustment, which fully aligns with what this study has proposed. In this regard, the mediational model may explain the interrelations among caregiving components, protective factors, and their effects on youth psychosocial adjustment.

Family Ecology Framework (FEF) points out that an essential pathway that links parental illnesses to youth well-being is the redistribution of the caregiving role that happens when a parent has a serious medical condition (Pedersen & Revenson, 2005). This study has built upon the concept of the tripartite model of youth caregiving proposed by Pakenham and Cox (2015), which extended the FEF and refined by Landi, Pakenham, Crocetti, et al. (2021). This model comprises caregiving responsibilities, experiences, and tasks to refer to all caregiving components together and each of them has been found to be related to youth psychosocial adjustment. In this way, using the concept of the tripartite model of youth caregiving has the potential to advance our understanding and research into the links between parental illnesses and youth well-being (Landi, Pakenham, Crocetti, et al., 2021).

Given that some types of caregiving are also a source of meaning-making and enrich benefit finding, this study has considered the studies that only conceptualized caregiving as an adverse life event, and therefore, we omitted those studies that conceptualized caregiving components as positive. Caregiving responsibilities refer to the psychological sense of the duties or responsibilities related to caregiving activities that promote family functioning, while caregiving tasks correspond to specific caregiving activities that youth undertake (Cox & Pakenham, 2014; Ireland & Pakenham; 2010a; Pakenham et al., 2006; Pakenham & Cox, 2012a). Caregiving experiences, on the other hand, represent the potential experiences of all youth with parental illnesses, such as perceived maturity anxiety about their parents, work/study activity restrictions, and isolation (Bursnall & Pakenham, 2013; Cox & Pakenham, 2014; Pakenham & Cox, 2015; Pakenham et al., 2006). Extant body of qualitative and quantitative research has highlighted that caregiving roles are associated with adverse psychosocial adjustment outcomes, such as internalizing and externalizing problems in young carers that might continue into adulthood (e.g., Chen & Panebianco, 2020; Ireland & Pakenham, 2010; Landi, Pakenham, Crocetti, et al., 2021; Landi, Pakenham, Benassi et al., 2021; McGibbon et al., 2019; Nagl-Cupal et al., 2014; Pakenham & Cox, 2012a, 2012b; 2014a, 2014b, 2015).

Nonetheless, it has been highlighted that intensive caregiving roles might negatively impact the normative development of young carers (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Cox & Pakenham, 2014; Landi, Andreozzi et al., 2020; Waters et al., 2021). Hence, they are more at risk of internalizing (e.g., depressive symptoms, anxiety, somatic symptoms) and externalizing problems such as aggressive and delinquent behaviors in terms of psychosocial adjustment (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Landi, Boccolini, et al., 2022; Landi, Duzen, et al., 2022; Landi, Pakenham, Crocetti, et al., 2021; Landi, Pakenham et al., 2022). Furthermore, young carers are more at risk for a poor quality of life, which refers to a multidimensional construct that includes caregivers' self-reported well-being in various, such as physical well-being, psychological well-being, autonomy, and parental relationships (Landi, Boccolini, et al., 2022; Landi, Duzen, et al., 2022; Ravens-Sieberer et al., 2007; Ravens-Sieberer et al., 2014).

The impacts of caregiving are variable; while youth caregiving might be associated with vulnerability to adverse life outcomes due to the nature of their caregiving role, or other internal and external variables, it might also be associated with positive psychosocial adjustment outcomes such as quality of life through the development of protective factors that enhance resilience by reducing the negative outcome of risk factors and enhance positive outcomes (Zimmerman et al., 2013). However, while many studies have highlighted risk factors in this vulnerable population, only a few focused on protective factors (Gough& Gulliford, 2020; Jørgensen et al., 2021; Landi, Pakenham, Benassi et al., 2021; McDougall et al., 2018; Pakenham & Cox, 2018; Wepf et al., 2021, 2022; Wepf & Leu, 2022). Recent studies underlined that many young carers report benefits or gains from their adversity, including perceptions of personal growth, the strengthening of relationships, increased perceived maturity, willingness to seek social support, and changes in priorities and goals (e.g., Jørgensen et al., 2021; McDougall et al., 2018; Pakenham et al., 2006, 2007; Pakenham & Cox, 2018; Wepf et al., 2021; Wepf et al., 2022). For instance, the indirect effect of increased benefit findings has ameliorated the association between caregiving responsibilities and adverse youth psychosocial adjustment (Pakenham & Cox, 2018). In addition to such findings derived from the quantitative studies, qualitative studies have also highlighted that many young carers experience positive consequences of their caring role, including pride, stronger family ties, learning new skills, and personal development (e.g., Boyle, 2020; McDougall et al., 2018; Stamatopoulos, 2018). These benefits have been highlighted as protective factors against the adverse effects related to the caregiving role, indicating that young carers find ways to manage and adapt to living with a parent affected by a severe illness (e.g., Cassidy & Giles, 2013; Gough & Gulliford, 2019; Pakenham & Cox, 2012a; Pakenham & Cox, 2018).

Emotion regulation might also be conceived as another protective factor for young carers to acquire psychological adjustment, especially in stressful situations (Troy & Mauss, 2011). Emotion regulation has various definitions from different perspectives, such as an integrated mechanism that manages goal achievement and organizes emotions through circumstances and a conscious or nonconscious mechanism that contains emotions (Rottenberg & Gross, 2003). From the perspective of behavioral adaptiveness, emotion regulation involves the awareness and understanding of emotions, the acceptance of emotions, the ability to control impulsive behaviors, and the capacity to flexibly use emotion regulation strategies to modulate emotional responses to meet individual goals and situational demands (Cole et al., 2017; Gratz & Roemer, 2004). In other words, emotion regulation refers to the flexible, adaptive, and socially appropriate strategies in which individuals express and manage their emotional experiences (Morris et al., 2007). It encompasses cognitive and behavioral strategies in response to internal or external experiences and can act as a protective factor against long-term internalizing and externalizing problems (Aldao et al., 2010; Penela et al., 2015).

Contrary, emotion regulation difficulties refer to the frustrations or lack of modulation of arousal with emotional experiences and expressions toward events that individuals encounter (Cole et al., 1994), which can be maladaptive and associated with adverse long-term outcomes (Aldao et al. 2010). Given that this study examines emotion regulation as an adaptive strategy with a potentially protective role for young carers facing negative experiences that cause stress, it may also be suggested that emotion regulation plays a mediating role in adapting to stress

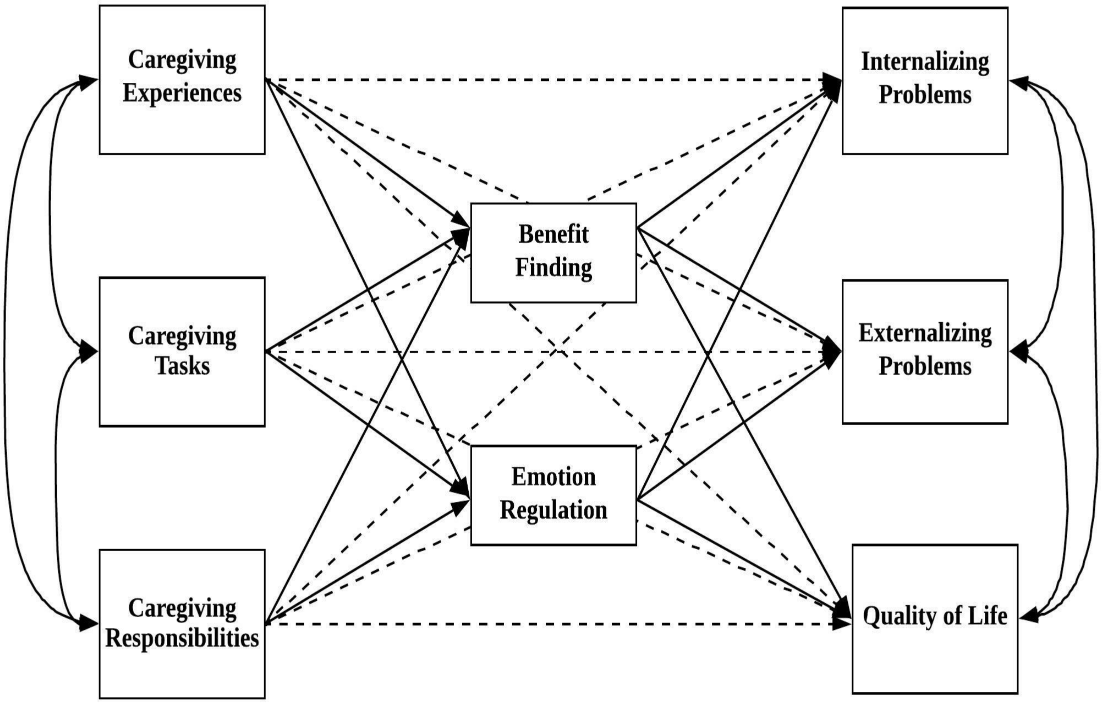
(Schwartz & Protoctor, 2000; McCarthy et al., 2006; Morris et al., 2007). Therefore, it is crucial to understand how emotion regulation influences an individual's ability to adapt to stress, especially in high-risk populations such as young carers. From this point of view, emotional regulation might mitigate risks related to internalizing and externalizing problems by fostering adaptive psychosocial adjustment processes in young carers (Kliewer et al., 2004).

Protective factors against the adverse effects related to the caregiving role have been associated with positive adjustment outcomes among young carers, including lower levels of internalizing and externalizing problems, higher levels of quality of life, and more adaptive coping strategies (Cassidy et al., 2014; Cassidy & Giles, 2013; Joseph et al., 2009; Pakenham & Cox, 2018; Wepf et al., 2021, 2022). Besides, young carers who can manage the caregiving process have social support, are able to use coping strategies, experience fewer psychosocial adjustment problems, and have better well-being than children who lack protective factors (Chikradze et al., 2017; Pakenham et al., 2007; Wepf & Leu, 2022). In this sense, it can be anticipated that protective factors may be underlying mechanisms for facilitating the mitigation of potential negative impacts on young carers' psychosocial adjustment and promoting their quality of life.

By using a meta-analytic structural equation model (MASEM), this study aimed to test the relationship between caregiving components and youth psychosocial adjustment (i.e., quality of life, internalizing, externalizing problems) and protective factors (i.e., benefit finding and emotion regulation). Furthermore, it has investigated whether the protective factors can mediate the association between caregiving components and youth psychosocial adjustment. In this respect, it is expected that the caregiving components are positively associated with psychosocial adjustment problems, but negatively related to the quality of life (H1a, *direct effect hypothesis*). Next, it is anticipated that caregiving components are negatively associated with benefit finding and emotion regulation as well as benefit finding, and emotion regulation is negatively associated with psychosocial adjustment problems while positively related to the quality of life (H1b, *direct effect hypothesis*). Finally, it is hypothesized that caregiving components are associated with youth psychosocial adjustment and this link is mediated by protective factors (H2, *mediational hypothesis*). Figure 1 provides an overview of the hypothesized model.

Figure 1

Hypothesized mediation model



Note. Dotted lines indicate the direct effects related to H1a, whereas straight lines indicate the direct effects related to H2a.

Method

This review has been registered in PROSPERO, an online register for systematic reviews under registration number CRD4202234508. Registration allows for transparency in research by publicly stating the aims and methodology of the research.

Literature Search

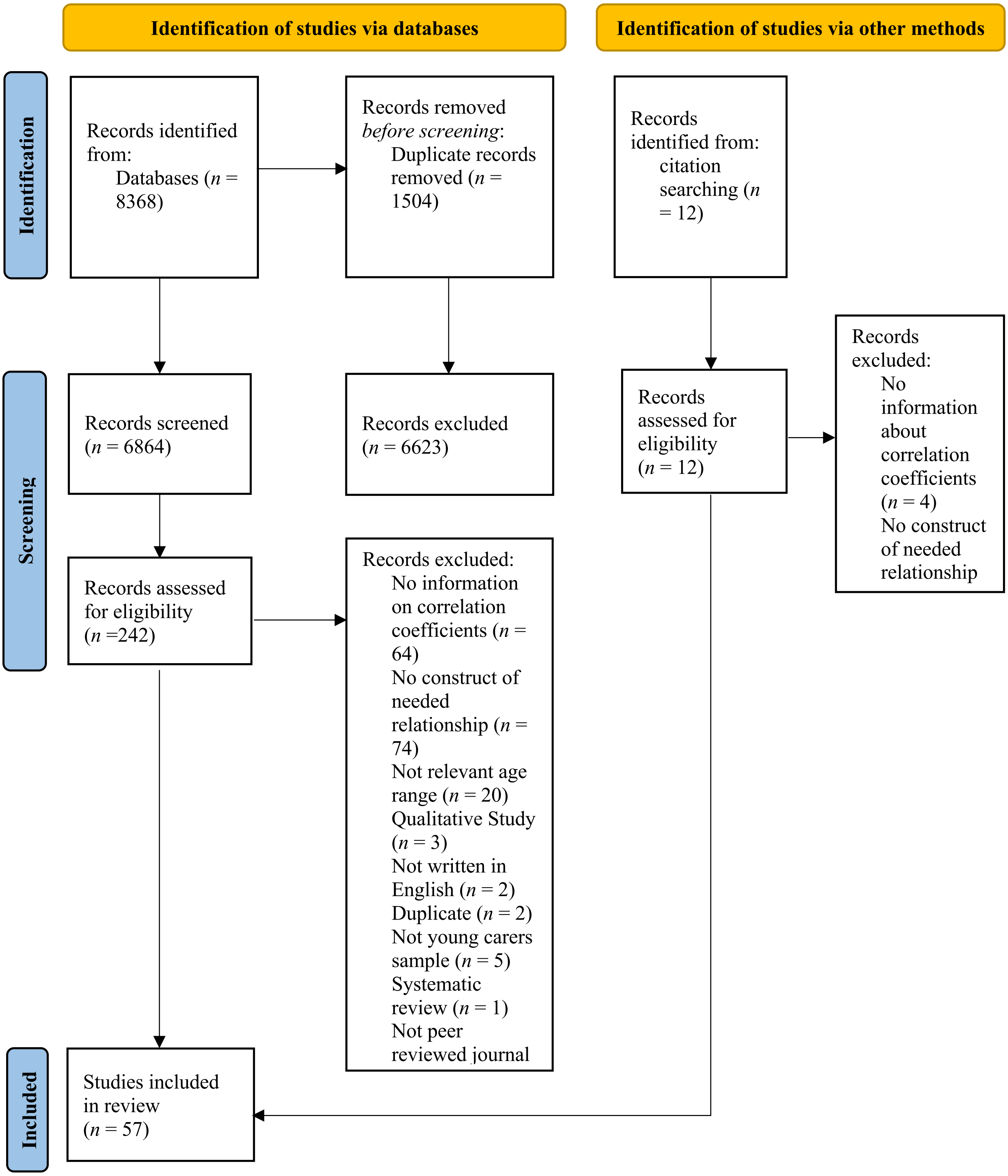
Following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria (http://www.prisma-statement.org), quantitative studies, published until December 2021, were jointly identified by systematic searches in three electronic databases: PsycINFO, MEDLINE, and Scopus. It has been used the following search terms in various combinations: *young carer, parental illness, psychosocial problem or well-being, emotion regulation or benefit finding, and caregiving experiences*. Studies were also identified through citation tracking using reference lists through identified studies. Finally, experts in the field were e-mailed inquiring about published literature that was not identified using the first two search strategies.

Selection of Studies

Our search process yielded a total of 57 publications, as detaliled in Figure 1. More precisely, the electronic database searching and other search techniques (e.g., checking the reference lists of studies) provided a total of 8,378 citations, of which 6874 unique publications were identified and screened by title and abstract. Of these, 254 publications were examined in more detail as full text. Two team members independently screened each abstract and excluded studies that did not adhere to our inclusion criteria (%90 agreement). Disagreements were resolved through discussions until consensus was reached.

Figure 2

Study selection following PRISMA guidelines



Studies were included if they (1) studied young carers with chronically ill mothers and/or fathers; (2) focused on young carers' mean age between 8–25; (3) were quantitative studies; (4) were peer-reviewed; and (5) published in English. Studies were excluded if (1) studied young carers with other ill family members; (2) young carers' mean age over 25; (3) were not quantitative studies; (4) were not peer-reviewed; and (5) were not published in English. Titles and abstracts of the found studies were filtered based on a predefined list of inclusion and exclusion criteria. The summary of studies included based on these criteria which can be found in Table 1.

Data Extraction

Effect sizes. After coding the study characteristics, effect sizes were extracted. Effect sizes were bivariate correlations between all variables included in the model (see Figure 1). When data for effect size computations were not reported in primary studies, study authors were contacted by email to request missing data. Authors were also contacted when data published in the study were collected in both majority and minority groups. In this case, study authors were asked to provide disaggregated data computed only in the majority subsample.

Table 1

Summary of Included Studies

Author & Year	*N*	Country	Mean age	Female %	Mother %	Type of Illness
Abraham & Stein (2010)	53	USA	19.61	%75	%62	Depression, bipolar disorder, schizophrenia, other mental illnesses
Abraham & Stein (2013)	52	USA	19.79	%82	%100	Depression, bipolar disorder, schizophrenia, schizoaffective disorder, other mental illnesses
Annunziato et al. (2007)	812	USA	12.06	%46	%100	Maternal chronic illnesses
Bursch et al. (2008)	409	USA	15.25	%53	%83	HIV
Cai et al. (2019)	164	China	12.23	%51,2	-	Schizophrenia, mood disorder
Cassidy et al. (2014)	203	UK	13.4	-	-	Chronic illnesses
Cassidy & Giles (2013)	152	UK	13.4	-	%92	Chronic illnesses
Champion et al. (2009)	34	USA	12.24	%56	%100	Depression
Chan et al. (2020)	120	Australia	18.5	%57	%100	Breast cancer
Chen & Panebianco (2020)	132	USA	14.38	%39,4	%49	Multiple sclerosis, diabetes, chronic pain, cancer, other chronic illnesses
Costas-Muniz (2012)	51	USA	15.5	%55	-	Breast cancer, vaginal cancer, other cancer types

Deloney (2015)	94	USA	23.34	%86,9	%100	Mental illnesses
Du et al. (2017)	518	China	12	%51	-	HIV
Egberts et al. (2021)	175	Netherlands	11.98	%52	%87	Cancer types
Gazendam-Donofrio et al. (2010)	221	Netherlands	15.5	%52	%81	Breast, gynecological skin, hematological, urological, sarcoma/bone, head/neck, gastrointestinal, central nervous system cancer
Hauken, Senneseth et al. (2018)	35	Norway	12.6	%60	%60	Breast cancer, gynecological, lymphomas, gastrointestinal, testis/prostate cancer
Hauken, Pereira et al. (2018)	35	Norway	12.6	%60	%60	Breast cancer, gynecological, lymphomas, gastrointestinal, testis/prostate, other cancer
Huizinga et al. (2005)	284	Netherlands	16.4	%58	%82	Breast, gynecological, skin, hematological, sarcoma/bone, urological cancer
Iacono et al. (2018)	77	Sweden	8.38	%48	-	Bipolar disorder
Jaser et al. (2007)	73	USA	12.74	%57,9	%92	Depression
Karayağmurlu et al. (2021)	50	Turkey	11.38	%44	%22,4	Breast, head/neck, gastrointestinal, other cancer types
Kothick et al. (1996)	75	USA	12.88	%55	-	HIV

Krattenmacher et al. (2013)	214	Germany	12.4	%43.2	%79.9	Breast, gynecological, colorectal, other cancer
Kühne et al. (2012)	86	Germany	13.78	%55.8	%57.1	Breast, gynecological, digestive organs, other cancer types
Lakman &Chalmers (2019)	124	Canada	12	%58,1	-	Chronic illnesses
Landi, Boccolini et al. (2022)	386	Italy	17.78	%59,6	%64,2	Cancer, diabetes, substance use, neurological, rheumatic diseases, mental illnesses, auto-immune, cardiovascular, gastrointestinal, respiratory, musculoskeletal diseases, physical disabilities, infectious, Kidney and genitourinary system, others
Landi, Pakenham, Crocetti et al. (2021)	325	Italy	17.92	%61,5	-	Cancer, diabetes, substance use, mental illnesses, neurological, rheumatic, autoimmune, cardiovascular, gastrointestinal, respiratory, infectious, physical disabilities and musculoskeletal diseases, diseases of the liver, kidney and genitourinary system, others
Landi, Pakenham, Benassi et al. (2021)	387	Italy	17.71	%59,2	%63,3	Diabetes, neurological, cardiovascular, gastrointestinal, respiratory, infectious, autoimmune, liver, rheumatic, physical disabilities and musculoskeletal diseases, mental illnesses, others
Landi, Duzen et al. (2022)	113	Italy	17.97	%61,1	%87,6	Breast, colon, skin, brain, uterine, thyroid, kidney, lymphoma, ovarian, bone, liver, laryngeal cancer, soft tissues tumor, auditory nerve tumor cancer
Lau et al., 2018	90	Australia	15.56	%52,2	-	Bipolar disorder
Leu et al. (2019)	307	Switzerland	12.6	%50,7		Parental Illness

Loechner et al. (2020)	74	Germany	12	%52,7	%62,7	Depression
Malcarne et al. (2020)	40	USA	10.13	%37,5	%100	Depression
Malhotra et al. (2015)	30	India	10.73	%56,7	%100	Schizophrenia
McDonald et al. (2016)	255	Australia	16.1	%74	%67.8	Digestive, leukemia, lung, bone/soft tissue, head and neck reproductive, Non-Hodgkin's brain, liver, other cancer
Morris et al. (2020)	244	Australia	18.8	%82	%68	Parental cancer
Nicholls et al. (2017)	107	UK	18.22	%69	%74,9	Epilepsy, arthritis, multiple sclerosis, diabetes, myalgia encephalopathy, asthma
Ostiguy et al. (2012)	65	UK	8.43	%46	-	Bipolar disorder
Pakenham et al. (2006)	100	Australia	16.38	%72	%76	Chronic illnesses
Pakenham & Bursnall (2006)	48	Australia	15.6	%56	%92	Multiple sclerosis
Pakenham et al. (2007)	100	Australia	16.38	%72	%76	Chronic illnesses
Pakenham & Cox (2014b)	126	Australia	14.04	%54	%83	Multiple sclerosis
Pakenham & Cox (2012a)	124	Australia	14.22	%54	%84	Multiple sclerosis

Pakenham & Cox (2012b)	90	Australia	14.22	%54	%84	Multiple sclerosis
Pakenham & Cox (2018)	428	Australia	12.77	%63,3	%47.43	Chronic illnesses
Patterson et al. (2011)	18	Australia	16	%66	-	Breast, Non-Hodgkin's, bowel, bone/tumor, leukemia, lung, gastrointestinal, other cancer
Patterson et al. (2013)	256	Australia	16.1	%73	%68	Breast, bowel, leukemia, lung, Non-Hodgkin's, lymphoma, reproductive, other cancer
Patterson et al. (2017)	256	Australia	16.1	%73	%68	Breast, bone, bowel, brain, leukemia, lung, Non-Hodgkin's, lymphoma, reproductive, other cancer
Rodriguez et al. (2019)	40	Ireland	16.78	%77,5	%100	Breast, colon, gastrointestinal, bowel cancer
Schrag et al. (2004)	17	UK	-	-	-	Chronic illnesses
Sell et al. (2021)	295	Germany	9.99	%52,2	-	Mental illnesses
Sieh et al. (2012)	160	Netherlands	15.1	%51,9	%67.6	Multiple sclerosis, rheumatoid arthritis, brain damage, neuromuscular disease, spinal cord injury, inflammatory bowel disease, Parkinson disease, diabetes
Stoeckel (2015)	70	USA	19	%48	-	Arthritis, blood disorder, cancer, chon's disease, diabetes, epilepsy, fibromyalgia, genetic disease, heart disease, hepatitis, kidney disease, lung disease, lupus, multiple sclerosis, Parkinson's, stroke, thyroid problem, other chronic illnesses
Van Loon et al. (2014)	124	Netherlands	13.4	%51	%72	Mental illnesses

Van Loon et al. (2015)	112	Netherlands	13.44	%50	%66	Mental illnesses
Van Loon et al. (2017)	118	Netherlands	13.47	%50,8	%70.3	Mental illnesses
Wepf & Leu (2022)	405	Switzerland	17.91	%70,4	-	Chronic illnesses

Meta-analysis Procedure

For the purposes of the current study, a meta-analytic structural equation modeling (MASEM) analysis was performed to test the hypotheses (Bergh et al., 2016; Combs et al., 2019). MASEM is a relatively new statistical technique that allows for synthesizing relationships between multiple variables, which goes beyond investigating the effect size between two variables in the traditional meta-analysis (Jak, 2015; Jak & Cheung, 2022). The main advantage of MASEM is that it allows for the test of relationships that the primary studies do not report by combining data from multiple individual studies. (Jak, 2015; Jak & Cheung, 2022). This study followed Cheung's (2015) two-stage structural equation modeling (TSSEM) approach to MASEM. TSSEM employs multivariate random-effects meta-analysis to pool correlation matrices at the first stage. Then, the hypothesized SEM model is fitted to the pooled correlation matrix at the second stage (Cheung & Chan, 2005; Jak & Cheung, 2017). We tested a mediation model where we hypothesized that protective factors would mediate the association between caregiving components and youth psychosocial adjustment.

MASEM allows for the inclusion of multiple effect sizes from each individual study, provided that they give information about different bivariate relationships. This way, we extract correlation matrices from each study that reports multiple effect sizes, and MASEM merges and pools all these effect sizes before fitting the SEM model whilst taking into account this dependency between the effect sizes coming from the same primary study. However, within the context of MASEM, there is another source of dependency. It is not uncommon to see studies reporting multiple effect size values for the same bivariate relationships, which also happens frequently in the current study. This happens when the same variables are measured across different time points or using different operationalizations (Van den Noortgate et al., 2013). MASEM cannot deal with this source of dependency, and the current strategies in dealing with these dependent effect sizes lead to different conclusions, as evidenced in Stolwijk et al. (2022). The results of a preliminary simulation study carried out by the second author comparing the performance of six different strategies in dealing with dependent effect sizes in MASEM shows the simple averaging approach to show the best performance (Bilici & Jak, 2022). This approach entails simply averaging of the effect sizes reported for the same bivariate relationship in each individual study before the MASEM analysis can be carried out. In the simulation study, the simple averaging approach had the lowest relative bias in parameter estimates and standard errors. It also showed acceptable power and efficiency (defined by low mean squared error (MSE) values). Hence, for the current study, we chose to use the simple averaging approach to deal with dependent effect sizes.

Results

Descriptive Statistics

A total of 373 effect sizes extracted from 57 studies were included in the meta-analysis (see Table 2). The average sample size of the included effect sizes was n = 160 (range 18–812). From the 57 articles, 54 originated from peer-reviewed journals, and 3 were dissertations. Some studies contained multiple effect sizes on the same relationship or effect sizes on multiple relationships.

Publication Bias

Studies with larger samples and studies with significant results are more likely to be published than those with smaller samples and those with non-significant results (Borenstein et al., 2009). This results in publication bias, which may lead to bias in the sample set selected for inclusion in a meta-analysis. As there is no formal statistical test to determine the presence of publication bias and its effect, it is advised to combine several analyses (Banks et al., 2012; Borenstein et al., 2009).

Table 2

The number of studies and the number of effect sizes (in parentheses) extracted for each bivariate relationship.

Variables	**CE**	**CT**	**CR**	**BF**	**ER**	**IP**	**EP**	**QL**
CE	-							
CT	5 (10)	-						
CR	3 (11)	1 (1)	-					
BF	4 (8)	2 (3)	3 (3)	-				
ER	3 (7)	2 (2)	3 (3)	7 (10)	-			
IP	17 (61)	13 (27)	10 (15)	12 (23)	13 (23)	-		
EP	4 (16)	4 (5)	5 (7)	1 (8)	4 (12)	19 (34)	-	
QL	8 (14)	7 (13)	6 (6)	6 (6)	8 (12)	17 (21)	9 (12)	-

Notes: CE, caregiving experiences, CT, caregiving tasks; CR, caregiving responsibilities; BF, benefit finding; ER, emotion regulation; IP, internalizing problems; EP, externalizing problems; QL, quality of life.

Currently, there are no existing techniques within the MASEM framework to check this assumption simultaneously for all the bivariate relationships; however, we can make use of traditional publication bias detection methods, specifically those designed for three-level meta-analysis. The methods we use to detect whether there is selection bias in the current study are Egger's regression test (Egger et al., 1997), Funnel-plot test and the Trim and Fill method (Duval & Tweedie, 2000). The first test looks into whether the magnitude of the effect sizes depends on their standard errors, while the second looks into their relationship with the sample size. The trim and fill method gives us the number of suppressed effect sizes on either side of the funnel plot.

We conducted each of these tests for each of the 28 correlations we had in our model, except for CT-CR, as there was only one entry for this effect size. In terms of the Trim and Fill test, according to the rules-of-thumb given by Fernandez-Castilla et al. (2021), we had three problematic correlations, all for the left side of the plot. The CE-IP, CR-IP, and BF-IP effects all suggested that the number of suppressed effect sizes on the left side of the plot was high enough in number to point to some form of selection bias. Egger's regression test presented some evidence of selection bias in 12 of the 27 correlations. The Funnel-plot test indicated a significant relationship between sample size and effect size magnitude for 7 correlations, 6 of which were also commonly identified in Egger's regression test.

Overall, it could be said that there was evidence of some sort of selection bias in the current study. However, we cannot speak to whether this selection bias was the result of publication bias, in the sense that only significant findings were published. The mechanism from which the selection bias resulted could also be the simple case of limited resources, where researchers who were using more advanced and reliable methods could only recruit a smaller sample of participants.

What is also important to note here is that none of these methods have the desired performance in terms of having high enough power to detect selection bias while controlling for Type I error rate. Fernandez-Castilla et al. (2021) show in their simulation study that for most cases, the mean power is around 0.30, which is nowhere near the desired number. This means that even though our analyses did not find evidence of selection bias, in reality, there could still be some form of selection bias.

MASEM Analysis

In Stage 1 of the MASEM analysis, a pooled correlation matrix between the eight variables was estimated. The correlation coefficients demonstrated that each of caregiving components (i.e., caregiving experiences, tasks, responsibilities) was related to more internalizing problems ($r = .36, p < .001$; $r = .16, p < .05$; $r = .20, p < .001$), while caregiving experiences and responsibilities were related to more externalizing problems ($r = .24, p < .001$; $r = .12, p < .001$). In addition, benefit finding was related to less internalizing problems ($r = –.20$, $p < .01$) as well as more quality of life ($r = .33$, $p < .001$). Emotion regulation was negatively correlated with externalizing problems ($r = –.20, p = .06$). Finally, caregiving tasks and responsibilities were significantly associated with benefit finding ($r = –.17$, $p < .05$; $r = 20$, $p < .001$), while none of the caregiving components was significantly associated with emotion regulation ($r = –.17$, $p > .05$; $r = –.81$, $p > .05$; $r =.25$, $p > .05$). The degree of heterogeneity is evaluated using the I^2 of the correlation coefficients (Higgins & Thompson, 2002). The I^2 can be interpreted as the percentage of total variance in observed effect sizes that is due to between-studies variability as opposed to (typical) within-study variability. Higher I^2 values indicate higher heterogeneity, which supports using the random-effects model. The average correlation coefficients from the Stage 1 TSSEM analysis are presented in Table 3.

In Stage 2 of TSSEM, we fitted the hypothesized partial mediation model to the pooled correlation matrix from Stage 1. The reported direct effects (regression coefficients) represent the unique effects of the predicting variable on the outcome, controlled for the effects of the other predictors of the outcome. The model with parameter estimates is shown in Figure 2.

Direct effects of each caregiving components on benefit finding and emotion regulation. There was a statistically significant negative effect of caregiving tasks on benefit finding ($\beta = -.51$, $p < .05$), and a statistically significant positive effect of caregiving responsibilities on benefit finding ($\beta = .69$, $p < .05$). Caregiving experiences did not significantly affect benefit finding ($\beta = -.30$, $p > .05$). There were no statistically significant direct effects of any of the caregiving components on emotion regulation (caregiving experiences: $\beta = -.26$, $p > .05$; caregiving tasks: $\beta = -.16$, $p > .05$; caregiving responsibilities: $\beta = .27$, $p > .05$).

Direct effects of benefit finding and emotion regulation on psychosocial adjustment. As expected, benefit finding is positively related to the quality of life, there was a statistically significant direct effect of benefit finding on quality of life ($\beta = .59$, $p < .05$), while unexpectedly there were no significant direct effects on internalizing ($\beta = -.23$, $p > .05$) or externalizing problems ($\beta = .17$, $p > .05$). In addition, there were no statistically significant direct effects of emotion regulation on any of the youth psychosocial adjustment outcomes (internalizing problems: $\beta = .04$, $p > .05$; externalizing problems: $\beta = -.24$, $p > .05$; quality of life: $\beta = -.17$, $p > .05$).

Indirect and direct effects of caregiving components on psychosocial adjustment. Of the 18 indirect effects that are included in the path model, only two of them were statistically significant. Consistent with the hypothesis H2, *mediational hypothesis*, there was a statistically significant indirect effect of caregiving tasks on quality of life, mediated by benefit finding ($\beta = -.30$, $p < .05$). That is, an increase in caregiving tasks leads to lower levels of benefit finding, which decreases the quality of life. Although the indirect effect was negative, caregiving tasks had a positive direct effect on quality of life ($\beta = .65$, $p > .06$). This indicates inconsistent partial mediation.

Considering the other direct effects of caregiving components on psychosocial adjustment outcomes, there were only statistically significant direct effects of caregiving experiences on internalizing ($\beta = .29$, $p < .001$) and externalizing problems ($\beta = .23$, $p = .05$). There was no statistically significant direct effect of caregiving responsibilities on any youth psychosocial adjustment outcomes (quality of life: $\beta =-.51$, $p > .05$; internalizing: $\beta = .12$, $p > .05$; externalizing problems: $\beta = .00$, $p > .05$).

Table 3

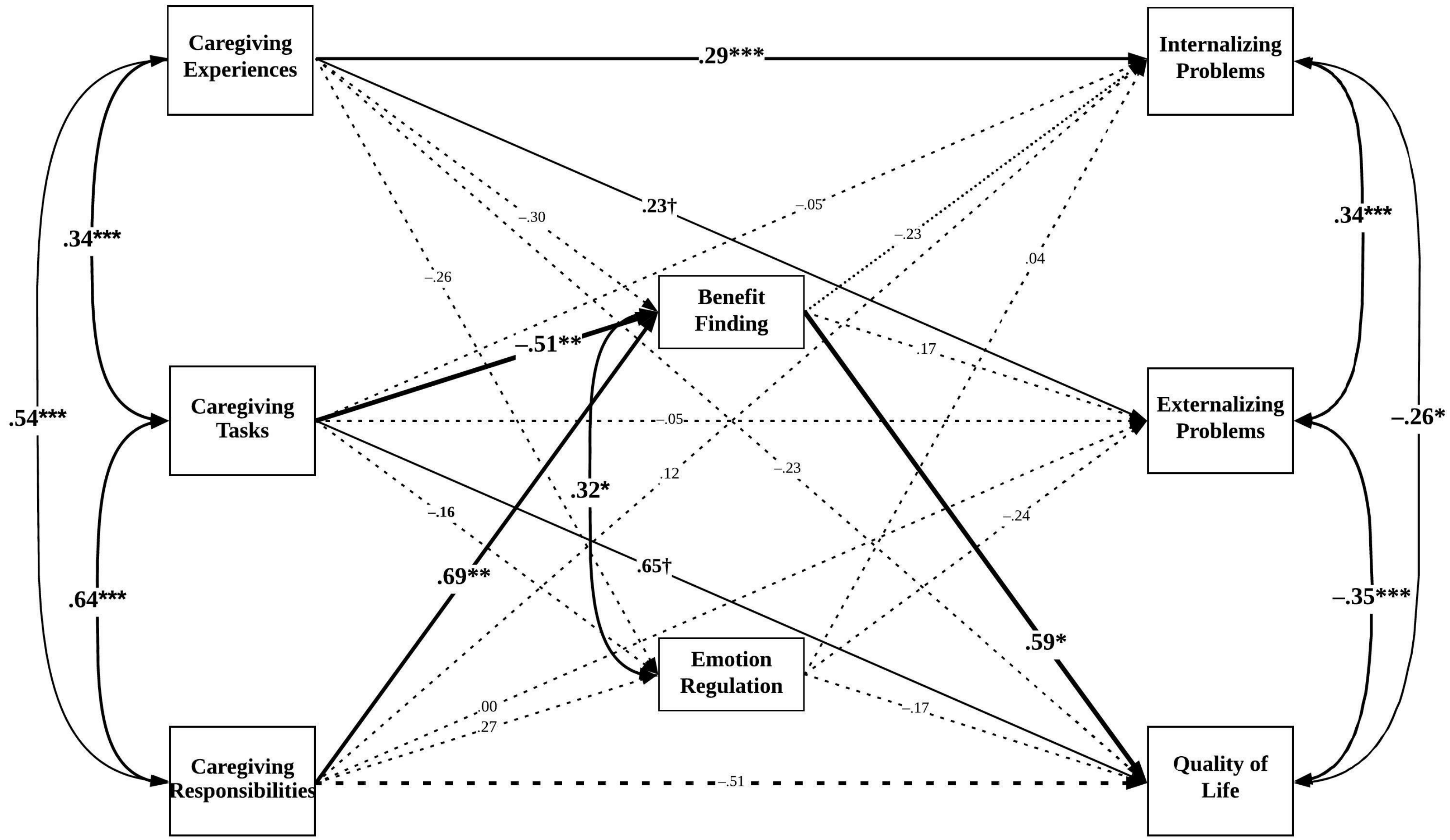
Pooled Correlations (and I^2) of the Variables

Variables	**CE**	**CT**	**CR**	**BF**	**ER**	**IP**	**EP**	**QL**
CE	-							
CT	.34*** (.81)	-						
CR	.54*** (.48)	.64*** (.00)	-					
BF	–.10 (.96)	–.17* (.57)	.20*** (.00)	-				
ER	–.17 (.92)	–.81 (.00)	.25 (.82)	.43*** (.80)	-			
IP	.36*** (.68)	.16* (.91)	.20*** (.09)	–.20** (.91)	–.10 (.91)	-		
EP	.24*** (.00)	.18 (.79)	.12*** (.00)	.56 (.00)	–.20† (.87)	.40*** (.88)	-	
QL	–.32*** (.61)	.14 (.95)	–.11** (.41)	.33*** (.78)	.61 (.95)	–.45*** (.83)	–.39*** (.00)	-

Note: I^2, degree of heterogeneity; CE, caregiving experiences; CT, caregiving tasks; CR, caregiving responsibilities; BF, benefit finding; ER, emotion regulation; IP, internalizing problems; EP, externalizing problems; QL, quality of life. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$, $^{\dagger} \leq .06$

Figure 3

Mediation model with parameter estimates



Notes. Bold arrows indicate significant effects. Dotted lines indicate insignificant effects. $^{*}p$ <.05, $^{**}p$ <.01, $^{***}p$ <.001, † ≤.06.

Discussion

Previous research indicates that young carers who perceive positive aspects of their challenging situation demonstrate better mental health (e.g., Gough & Gulliford, 2020; Landi, Pakenham, Benassi, et al., 2021; Pakenham & Cox, 2018), while the potential protective mechanisms between caregiving components and psychosocial adjustment are understudied. Hence, this study aims to address the gap and proposes that caregiving components are associated with psychosocial adjustment in young carers both directly and indirectly over the protective mechanisms.

The first aim of the study was to investigate the association between caregiving components and psychosocial adjustment (i.e., quality of life, internalizing and externalizing problems), as well as the relationship between protective factors (i.e., benefit finding and emotion regulation) and psychosocial adjustment. Partially in line with our hypothesis H1a, *direct effect hypothesis*, caregiving experiences have been positively associated with internalizing and externalizing problems. These results are consistent with previous studies indicating that caregiving experiences are related to poorer psychosocial adjustment (e.g., Cassidy et al., 2014; Chen & Panebianco, 2020; Landi, Andreozzi, et al., 2020; Landi, Duzen, et al., 2022; Pakenham & Cox, 2018; Pakenham & Cox, 2012b; Pakenham & Bursnall, 2006). Also, as anticipated, caregiving tasks have been significantly associated with quality of life, while directions of relations are positive, contrary to our expectations. The broader literature in this area has demonstrated that caregiving components are related to negative psychosocial adjustment outcomes in young carers, such as poorer quality of life (Landi, Andreozzi, et al., 2020; Landi, Pakenham, Crocetti, et al., 2021; Landi, Boccolini, et al., 2022; Pakenham & Cox, 2012a; 2012b; Pakenham & Cox; 2018). These unexpected findings might be explained by the previous study suggesting that social and emotional care participation may play a key role in fostering youth adjustment that causes better well-being (Landi, Pakenham, Crocetti, et al., 2021).

Nevertheless, we have not found any significant associations of caregiving responsibilities with either positive or negative psychosocial adjustment outcomes. Likewise, there is no significant associations between caregiving tasks and adverse psychosocial adjustment outcomes, as well as between caregiving experiences and positive psychosocial adjustment outcomes. Accounting the meta-analytic nature of the current study, such findings might be related to incongruent findings in extant studies indicating both detrimental and beneficial effects of caregiving components on psychosocial adjustment in young carers. For example, it has been found that caregiving tasks are positively linked to internalizing problems in one study (e.g., Cassidy et al., 2014), whereas caregiving tasks have appeared to be negatively associated with internalizing problems in another (e.g., Landi, Boccolini et al., 2022). However, most of these findings stem from cross-sectional data; therefore, one might be further suggested for future research to apply longitudinal designs in order to better capture the underlying mechanism in the relationship between caregiving components and psychosocial adjustment outcomes among young carers.

This study showed that the benefit finding is positively related to the positive psychosocial adjustment outcomes but not to adverse psychosocial adjustment outcomes. In other words, finding meaning in caregiving roles increase the quality of life in young carers, as has been shown in prior studies (Pakenham & Cox, 2018). Notably, one can propose that promoting interventions targeting the protective factor of benefit finding might lead to better well-being in young carers. Nonetheless, there is no significant association between benefit finding and psychosocial adjustment problems. A possible explanation of result differences in the association of positive and negative psychosocial adjustment with benefit finding might be that young carers find benefits in situations where the role demand is not overly excessive and where the role is socially recognized and valued (Cassidy & Giles, 2013; Cassidy et al., 2014). In other words, increased quality of life might buffer against developing psychosocial adjustment problems, which are related to excessive caregiving demands.

Nevertheless, in line with the expectations, the caregiving tasks is negatively associated with benefit finding, whereas caregiving responsibilities are positively associated with benefit finding, contrary to what was expected. Caregiving tasks might be seen as unfair or developmentally inappropriate regarding the age of young carers, they may feel overwhelmed and threatened by their tasks, causing to decrease in benefit finding (Cassidy et al., 2013; Cassidy et al., 2014). Furthermore, recent research has highlighted that more perceived caring responsibility is associated with a higher benefit finding in young carers (Pakenham & Cox, 2018; Wepf et al., 2021). However, we have not found significant association between benefit finding and caregiving experiences, even though recent studies have reported that caregiving experiences are negatively associated with benefit finding (Cassidy et al., 2013; Cassidy et al, 2014; Pakenham & Bursnall, 2006).

Furthermore, consistent with our expectations, benefit finding mediated the relationship between caregiving tasks and quality of life. That is, more caregiving tasks lead to less quality of life because caregiving tasks decrease benefit finding, and less benefit findings lead to less quality of life. This finding expands previous findings (Cassidy et al., 2013; Cassidy et al., 2014; Pakenham & Cox, 2018; Wepf et al., 2021; Wepf et al., 2022) by highlighting the mediating role of benefit finding in the relation between caregiving tasks and positive psychosocial adjustment outcomes. According to broader young carer literature, youth with parental illness are at risk of psychosocial adjustment outcomes (Chikhradze et al., 2017; Morley et al., 2016; Pakenham & Cox, 2014), and caregiving experiences are similarly positively associated with psychosocial adjustment outcomes in this study. Nevertheless, benefit finding does not mediate the relation between psychosocial adjustment outcomes and caregiving experiences or caregiving responsibilities. The possible explanation of such unforeseen findings might be due to mixed evidence produced in prior studies reporting that quite strong negative correlations (e.g., Cassidy et al., 2013), on the one hand, and somewhat strong positive correlations (e.g., Stoeckel, 2015; Pakenham & Cox, 2018), regarding the links between caregiving components (i.e., caregiving experiences, responsibilities) and benefit finding, on the other. To better understand the differences between the results, future research should look into potential interactions between protective factors, caregiving components, and psychosocial adjustment by using longitudinal data.

Nonetheless, unlike to the expectations, our results have showed that emotion regulation is associated with neither psychosocial adjustment outcomes nor any caregiving components, as well as does not mediate the association between any of the caregiving components and psychosocial outcomes. A potential explanation for this finding might be the lack of studies on emotion regulation in young carers literature. Hence, future research should further investigate the association between emotion regulation and psychosocial adjustment in youth living with parental chronic illness. Previous research has nonetheless highlighted that due to the unpredictable demands associated with caregiving roles that necessitate more reactive coping responses, caregiving might be negatively associated with emotion regulation (Pakenham & Bursnall, 2006). On the other side, it has also been reported that coping strategies positively relate to some caregiving components dimension, such as caregiving confidence and worry about parents (Pakenham, 2001). Taken together, one might conclude that the lack of relationships between caregiving components and emotion regulation in our study may be due to differential (and mostly incongruent) findings provided by a relatively limited number of studies in the relevant literature.

Overall, the findings of the current study suggest that caregiving components increase adverse psychosocial adjustment, while protective factors increase positive psychosocial adjustment in young carers. Furthermore, it should be remarked that benefit finding seems to mediate the relationship between caregiving tasks and quality of life, which leads to benefits from adversities and promotes well-being among young carers. While previous studies have shown that young carers who perceive the positive aspects of their challenging situations exhibit better mental health, findings regarding potential mechanisms between caregiving components and psychosocial adjustment are limited and understudied (e.g., Gough & Gulliford, 2020; Landi, Pakenham, Benassi, et al., 2021; Pakenham & Cox, 2018). In this regard, our study has provided a novel piece of evidence to address this gap by proposing that caregiving components can be associated with psychosocial adjustment in young carers not only directly but also indirectly through protective mechanisms (i.e., benefit finding).

As for the practical implications, it should be highlighted that young carers are at risk of psychosocial adjustment problems, while there is a need to raise awareness about young carers through policies and professionals. While social policies provide person-centered services to ill parents, it is also important to consider the needs of young carers who face significant challenges in balancing their livelihoods and caring responsibilities and are underutilizing professional support services. In this sense, failure to support young carers might further aggravate the negative consequences of providing care in the long term. Furthermore, given that protective factors decrease adverse psychosocial adjustment outcomes, as well as increase positive psychosocial adjustment outcomes, professionals within the health and child protection services, should provide tailored intervention programs, targeting the protective factors to mitigate the effect of adverse caregiving experiences in the young carers.

Inevitably, this study has several limitations that can be addressed in the future research. First, most quantitative studies included in this systematic review with meta-analysis are cross-sectional, which causes cannot assess changes in the relationship between caregiving components, benefit finding, and psychosocial adjustment over time. Thus, the absence of time presence in cross-sectional studies means it can only be assumed that caregiving components shaped protective factors. In addition, there is an absence, of rigorous longitudinal studies on how caregiving components are associated with protective factors over time and how protective factors, in turn, are associated with youth psychosocial adjustment. These longitudinal studies can shed more light on the bidirectionality of caregiving components and youth psychosocial adjustment. Second, although it has been emphasized that people from lower socioeconomic status might be less likely to find benefits from adverse experiences (Wepf & Leu, 2021), it was not possible for us to take into account such an additional factor that might influence the interplay between caregiving components and protective factors. Therefore, it should be noted that the pattern might be attributed to, or at least, confounded by the families' socioeconomic background more than the caregiving components themselves. Future research on young carers should more carefully assess the diverse types of caregiving components and their relationship with protective factors and youth psychosocial adjustment taking into account such additional factors that might influence the interplay between caregiving components and protective factors. In addition, future research should examine the potential moderating roles of the protective factors as well as mediating roles in the relation between caregiving components and youth psychosocial adjustment.

Nonetheless, this study also has some strengths. First, this is the first study examining the mediating role of protective factors in the association with caregiving components and psychosocial adjustment by using MASEM. Hence, our meta-analytic mediation model has allowed us to test whether protective factors partially mediate the effect of caregiving components of youth psychosocial adjustment. This is particularly relevant, especially when considering the primary mediation models are scarce.

Conclusion

Overall, this study ensured novel insights with the meta-analytic mediation model referring to the association between caregiving components (i.e., caregiving experiences, responsibilities, tasks) and psychosocial adjustment (i.e., quality of life, internalizing and externalizing problems) in young carers both directly, and more importantly, indirectly over protective mechanisms. In this regard, a deeper understanding of the circumstances and mechanisms through which protective factors can mediate the effect of adverse caregiving experiences might be gathered. Given the result of this study, it has addressed the mediating role of protective factors on the relationship between tripartite caregiving components and youth psychosocial adjustment in young carers. It is hoped that the present findings may be valuable to develop relevant policies and intervention programs to help young carers reflect on their way of finding benefits and coping with difficulties, thereby promoting their well-being.

CHAPTER 4

“Living with Parental Chronic Illness” Understanding Experiences and Benefit Finding in Young Carers: A Qualitative Study

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Duzen, A., Landi, G., Koc, Y., Agostini, F., Boccolini G., Grandi, S., & Tossani, E. (2023**).** “Living with parental chronic illness” understanding experiences and benefit finding in young carers: A qualitative study. [Manuscript under review]

Abstract

Objective: Young carers might experience both psychological distress and positive changes from living with their chronically ill parent. This study examined the experiences of young carers as well as the specific effects of the COVID-19 pandemic on young carers.

Methods: A total of 26 young carers (M_{age} = 19.73; 84% females) living with a parent with a chronic illness participated in semi-structured interviews via video conferencing. All interviews were analyzed using thematic analysis.

Results: Three themes were highlighted related to young carers' experiences: *Our life has changed/ Everything turned upside down, Psychological burden, Anything can happen at any moment*. Two additional themes were also derived from being young carers in the context of the COVID-19 pandemic: *Restricted life,* and *Benefit finding related to pandemic*.

Conclusion: These results expand previous findings by examining in detail the caregiving experiences of youth and the effects of the COVID-19 pandemic on young carers. Overall, the present study provided novel insights into young carers' caregiving experiences by emphasizing how they could benefit from such a challenging situation triggered by the COVID-19 pandemic.

Keywords: Young Carers; Parental Illness; Youth Adjustment; Benefit Finding; COVID-19; Qualitative Study

Introduction

Parental illness adversely affects youth and family functioning (Pedersen & Revenson, 2005), and this phenomenon might have been amplified during the COVID-19 pandemic. More than 25% of children and adolescents live with a parent who has a serious physical or mental illness (Jørgensen et al., 2021), and this prevalence is rising globally as a result of improved medical techniques extending ill parents' life expectancies, as well as people deciding to have children at an older age which, in turn, is associated with a higher vulnerability to develop a serious illness when parenting their young offspring (Morley et al., 2016).

Youth living with a parent with a chronic illness are referred to as young carers and tend to assume extra family caregiving responsibilities, providing regular and significant care to their ill parent (e.g., assistance with household tasks, self-care tasks, health and medical care, provision of emotional support) (Pakenham et al., 2006; Pakenham & Cox, 2014a). Youth caregiving is a "hidden" phenomenon, especially because many young carers do not self-identify as caregivers (Aldridge & Becker, 1993), and many are not willing to share their experiences with friends, at school or work because of fear of stigma attached to it (McDougall et al., 2018). For these reasons, they tend to be invisible or ignored in clinical practices and research, receiving inadequate attention and professional assistance (Pakenham et al., 2006; Smyth et al., 2011). Nevertheless, a large body of qualitative and quantitative research has highlighted that intensive youth caregiving hinders or disrupts normative development in youth and is associated with adverse outcomes in this vulnerable population (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Landi, Andreozzi, et al., 2020; Iacobucci et al., 2022; Waters et al., 2021). Young carers are at increased risk of internalizing (e.g., depressive symptoms, anxiety, and somatic symptoms) and externalizing problems (e.g., aggressive and delinquent behaviors) as well as lower life satisfaction and poorer quality of life (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Gallagher et al., 2022; Landi, Boccolini, et al., 2022; Landi, Duzen, et al., 2022; Landi, Pakenham, Crocetti, et al., 2021). These outcomes are supported by the FEF, which posits that parental illness influences youth indirectly through family role redistributions which often requires youth taking on more family caregiving activities and, in turn, increased stress experiences (Pedersen & Revenson, 2005).

The COVID-19 pandemic might have further intensified the adverse psychosocial outcomes in youth living in families impacted by a parental illness and have far-reaching adverse consequences for young carers (Blake-Holmes & McGowan, 2022; King, 2021; Nakanishi et al., 2022; Landi, Pakenham, Grandi & Tossani, 2022). The COVID-19 related stressors, such as the lockdown and associated social isolation, travel restrictions, school and university closures, as well as the uncertainties about the future, might have further impacted the everyday life of young carers (Blake-Holmes & McGowan, 2022; Landi, Pakenham, Grandi & Tossani, 2022). Carers have also reported intense fears of getting infected with COVID-19 and infecting their ill family members and having them experience serious COVID-19 complications or death by COVID-19 (Zucca et al., 2021), and these fears might apply to young carers as well.

To the best of our knowledge, only four studies have examined the possible risk factors of the COVID-19 pandemic on young carers, highlighting poorer mental health and increased stressors in young carers such as looking after siblings, difficulty home learning, as well as reduced access to social care services duriayng the lockdown (Blake-Holmes & McGowan, 2022; Landi, Pakenham, Grandi & Tossani, 2022; King, 2021; Nakanishi et al., 2022). Nevertheless, these studies only examined risk factors for young carers, while they did not analyze protective factors of the COVID-19 pandemic on young carers.

Furthermore, recent studies have underlined that many young carers report benefits or gains from their adversity, including the ability to find meaning, perceptions of personal growth, the strengthening of relationships (intimacy and interdependence between family members), and changes in priorities and goals (e.g., Jørgensen et al., 2021; McDougall et al., 2018; Pakenham & Cox, 2018; Wepf et al., 2021). These benefit findings processes, along with increased perceived maturity, the ability to set some 'time out' from the role of young carers participating in leisure activities, the willingness to seek social support from both friends and other young carers sharing similar experiences, have been highlighted as protective factors against the adverse effects related to the caregiving role (e.g., Landi, Pakenham, Benassi, et al., 2021; Pakenham & Cox, 2018). Based on the literature stating that people who encounter major personal crises generally also experience positive changes (August & Dapkewicz, 2021), the highly challenging circumstances of the caregiving experiences during the COVID-19 pandemic should also be evaluated through a positive psychological lens. In particular, benefit finding might be an adaptive strategy that people might use in times of crises (Burke & Arslan, 2020). Considering that the COVID-19 pandemic is a new crisis for young carers who are already facing demanding caregiving tasks and/or challenging caregiving experiences, benefit finding might be a protective coping strategy young carers use to mitigate the adverse impact of the COVID-19 pandemic on mental health.

Accordingly, the current study has aimed to qualitatively examine the experiences of young carers as well as the effects of the COVID-19 pandemic on this vulnerable population, also considering possible benefit finding young carers might experience. Therefore, this study aims to answer the following questions on the impact of the caregiving role on young carers and to improve knowledge about young carers' experiences: How does parental chronic illness affect young carers' experiences? How and in what ways does COVID-19 affect the lives of young carers? Since the study is exploratory in nature, no a priori hypotheses have been developed.

Method

Participants

Twenty-six young carers from Turkey aged 15–25 years participated in this study. Inclusion criteria were being aged 15–25 years, living with one's families, and providing ongoing support and/or care to parents with a mental illness, a chronic condition, or a terminal illness. The mean age of participants was 19.73 years (*SD* = 2.80), with 16% being male and 23% high-school students. Participants indicated an average family size of 4.84 members (*SD* = 1.28), with a mean number of siblings of 1.278 (*SD* = 1.33). All participants lived in a dual-parent family. Of the ill parents, 65.5% were female, while 19.2% of youth reported both parents had a chronic illness. Parental illnesses were classified according to the International Classification of Diseases 11th Revision (ICD-11) into: breast cancer (7.7%), chronic kidney disease (11.5%), type 1 and type 2 diabetes mellitus (26.9%), cardiovascular diseases (7.7%), mental illnesses (3.8%), rheumatic diseases (7.7%), chronic obstructive pulmonary disease (7.7%), chronic lymphocytic thyroiditis (3.8%), epilepsy (3.8%), ankylosing spondylitis (3.8%), inflammatory bowel disease (3.8%), multiple sclerosis (3.8%), systemic lupus erythematosus (3.8%) and essential hypertension (3.8%).

The first participant was reached through the research announcement made on different platforms in December 2020. A snowballing procedure was used to recruit the sample in which young carers were asked if they had any friends in similar circumstances who might like to participate.

Design

We developed a qualitative explorative research design using semi-structured in-depth interviews.

Interview Procedure

We received the appropriate ethical approval from the University of Bologna Ethics Committee. Participants' written informed consent forms were obtained before starting the interview. For minors, informed consent was obtained from the parents or authorized legal guardian of the subject.

Semi-structured interviews were conducted by one of the authors (A. D.) with twenty-six young carers, were held using the online video conferencing platform, and were digitally recorded. The interviews contained twenty-one open-ended questions based on previous literature on participants' caregiving experiences (e.g., Pakenham & Cox, 2018; Pedersen & Revenson, 2005); specific questions were included about how parental chronic illness affects their lives and responsibilities (e.g., "What changes have happened in your life after being diagnosed?"), how COVID-19 affects their lives and caregiving roles (e.g., "How has COVID-19 affected your responsibilities at home?"). Interview length ranged from 30 to 60 minutes ($M = 45$).

Participants had the opportunity to add any other comments or ask questions. Prompts and follow-up questions were used, such as "Could you expand on that?" to gain insight into the essence of participants' experiences and obtain examples. Participants were screened by telephone to see if they met inclusion criteria. Interviews were conducted in Turkey between December 14th, 2020, and January 26th, 2021, during the first phase of the COVID-19 pandemic when cases were spiraling, and lockdowns were in place.

Data Analysis

Descriptive statistics summarized demographic, socio economic and clinical data of parents. Qualitative analysis proceeded as follows. First, interviews were transcribed verbatim and analyzed by two authors (A. D. and Y. K.) using thematic analysis, which refers to a method for identifying and analyzing patterns in qualitative data (Braun & Clarke, 2006). The transcripts were read several times to become familiar with the data. Second, transcripts were coded into units of meaning, and the themes began to emerge. Third, similar meaning units were organized into sub-themes. Fourth, sub-themes were organized into larger themes. Fifth, the classified structure of the meaning units, sub-themes, and themes was reviewed by the research team, the themes were simplified, their number were reduced, and representative names for some themes were selected. Data saturation (Fusch & Ness, 2015) was initially noted at the sixth interview. Saturation was confirmed by the thirteenth interview and further verified across the remaining thirteen interviews, with the provision of additional examples that were representative of the themes and sub-themes. Final analysis was conducted only on the contents for which consensus was reached after discussion and revision.

Results

The following three main themes (*i.e., Our life has changed/ Everything turned upside down, Psychological burden, Anything can happen at any moment)* regarding the experiences of young carers and two further main themes (*i.e., Restricted life, and Benefit finding related to pandemic*) regarding the effect of the COVID-19 pandemic emerged from the thematic analysis, as displayed in Table 1.

Our Life Has Changed/Everything Turned Upside Down

The first main theme is *our life has changed/everything turned upside down* that contain the following three sub-themes: *negative effect on academic achievement, endless treatment,* and *altruistic healthy parent.* Many young carers reported parental chronic illness as a milestone that caused the change in many aspects of their life. For instance, one participant described her life has changed from babyhood due to parental illness; even her family moved away from their own society due to illness and began to live in a different place.

Table 1

Main themes and sub-themes emerging from thematic analysis of young carers' experiences of living with a chronically ill parent during the COVID-19 pandemic

Main Themes	Sub-themes
Our life has changed/Everything turned upside down	Negative effect on academic achievement Endless treatment Altruistic healthy parent
Psychological Burden	Increased household responsibility Psychological limits for future Anger/ Turning into a nervous person Reclaim of control
Anything can happen at any moment	Fear of loss Alarmism Helplessness
Restricted life	Fear of transmission Increased health anxiety Increased household responsibility Inefficient education
Benefit finding related to pandemic	Stronger family ties Personal growth

Negative Effect on Academic Achievement

Many participants described how parental illness negatively affects their education life which has an important place in their lives. One participant, whose academic life has been influenced by the depressive affectivity that she experienced when she learned about her mother's illness, expresses her experience:

"It was already a depression process when we found out about my first mother's condition. [....] My grades dropped, and I didn't want to do anything, [....] there was a thought about like stopping the time, just sleeping, or should letting me go."

Moreover, one participant described important life changes that started when her family had to move to another city to treat the ill parent and caused many difficulties in her entire life, mostly in her education life. In addition, the participants also reported that their parents could not take care of themselves due to their illness and that they missed their parents during the treatment process, which caused the difficulties they experienced in their education life.

Endless Treatment

Moreover, many participants stated that one of the reasons that lead parental illness to affect their entire lives negatively was the endless treatment process. One participant, whose mother’s disease had no specific treatment and compares his mother's treatment process with his friends' parents’ one, described his experience as follows:

“When I saw other parents, [....], it will upset me, but as I said, this is the situation, we do not have much to do, but we will go to hospitals again, we will go to hospitals again.”

Furthermore, some participants stated they were used to living with the illness, which could be seen as another result of the endless treatment process, while one participant described the illness like another family member whom they had to get used to living with.

Altruistic Healthy Parent

Moreover, participants stated that their healthy parents showed altruistic behavior towards the ill parent and family, which could be seen as a protective factor for young carers that might result in taking less caregiving responsibility. One of the participants, whose mother even had training on her husband's illness and care, provided the following quote:

“Always supportive, caring when sick, paying attention to his meals, reminding his medications, so really like a nurse, sometimes like a wife, sometimes like a friend. So really everything, [....] she had already attended the training about dialysis.”

In addition the above-mentioned healthy parent role in the treatment and care process, one participant defined the function of the healthy parent as a bridge between children and the ill as another form of altruism. Also, one participant stated that she and her sibling were not affected too much by parental illness because of her father's attitude, while one participant expressed how his father changed his life habits, taken many caregiving responsibilities, and even changed his workplace to be closer to home after her mother was diagnosed. However, some participants, particularly those whose mothers were ill, described economic support from a healthy parent as another type of altruism.

Psychological Burden

The second theme emerged is the *psychological burden,* and that contains four sub-themes: *increased household responsibility, psychological limits for the future anger/turning into nervous people and reclaim of control*. Almost all participants seemed to agree that being a young carers caused a psychological burden due to emerging or increased caregiving responsibilities. One participant, whose mother had a rare disease and had no specific treatment, talked about his experience as follows:

“It doesn't kill you completely like something that drains your energy, but it prevents you from moving faster. It’s like twisting the knife in the wound to have such a parent.”

Increased Household Responsibility

In our sample, all female participants described increased household responsibilities related to parental illness, except for one male participant. One participant described how she felt compelled to take on household responsibilities because her sick parent had to work, and she expressed her experience as follows:

“My mother was both a patient and a working person, and I had to provide some comfort to her. So, I felt it as an obligation in myself which is still valid. This will continue in this way.”

Moreover, female participants indicated how they turned into ‘little mothers’ for their siblings after parental chronic illness as another form of household responsibility.

Psychological Limits for the Future

Despite participants' increased household responsibility, many participants, predominantly female participants, stated how important it was for them to be close to home in relation to *psychological limits for the future*. We defined psychological limits for the future as young carers' sensitivity to being away from an ill parent and preventing themselves from planning a future in a different place than their parents. Some participants could not even imagine a future without being close to their family, whereas some participants expressed a sense of guilt while making plans for their future away from their parents. One participant, who was planning to go abroad for her education in the future, expressed her experience:

“Well, I experience its reasoning as more internally [....]. I have never said like “I will always stay with you. I will always live with you. I never said it, on the contrary, I guess this is a bit unconscionably, but slowly I'm trying to get her used to this idea.”

Anger/Turning into Nervous People

Furthermore, young carers described how they experienced anger or were turning into nervous people due to psychological burden. For instance, some participants stated that they had become nervous people because they had never been able to evade their caregiver responsibility. Besides, some participants specifically referred to adolescence for their anger related to parental illness, whereas one participant, whose father had a mental illness, expressed how she felt anger since there was no one to blame for her father's illness during adolescence, and talked about her experience as follows:

“Anger when I learned first. Because you're a teenager and have been given the responsibility, to whom will you direct the anger to the person responsible, but he's not guilty.”

Reclaim of Control

Some of the participants, particularly those whose both parents are ill, described how they were trying to reclaim control in this uncontrollable situation. In addition, participants described different young carer tasks that caused the willing reclaim of control. For example, one participant indicated that she was taking almost all sibling responsibilities, whereas one participant indicated that she was taking almost all domestic duties after her parent was diagnosed. One participant, whose both parents were ill, in other words, who took on many responsibilities that might cause increased psychological burden, described her experiences as follows:

"You always have to think up to plan Z, not just plan A or B [....]. Usually, you have a conversation like 'you have to live a moment, you should think like this' ... I can't live that way (laughs)."

In conclusion, young carers clearly reported psychological burden and female carers tended to the more impacted than male carers. All in all, increased caregiving responsibility has been associated with the risk of psychological burden.

Anything Can Happen at Any Moment

The third theme emerged from the analysis is *anything can happen at any moment,* which contains three sub-themes: *alarmism, fear of loss,* and *helplessness.* Many participants described they feared that their parents' health condition could worsen suddenly. For instance, some participants expressed how they worried about the parental health condition due to the fact that anything could happen at any moment.

Fear of Loss

Many young carers reported experiencing fear of loss related to feeling that anything could happen at any moment to their parent. For instance, one participant, whose depressive affectivity accompanied fear of loss, talked about his experience as follows:

"Sometimes, as I said, she tells me that she feels very bad, I say that maybe when she wakes up tomorrow morning she will not even say I feel bad, maybe she will die. I get really upset when I think of these things, negative things often come to my mind."

Similarly, to this experience, some participants stated that they could not stop themselves from thinking about the possible loss of their parents. Also, unlike other participants, one participant talked about how her fear of losing an ill parent turned to fear of losing everybody in her life.

Alarmism

In addition to fear of loss, some participants reported feeling of alarmism about their parents' illness. For example, one participant, whose both parents were ill, indicated she could not sleep because of worries about parental illnesses, whereas one participant, whose father had diabetes, stated that she checked her father's meal by phone even when she was at school. Also, some young carers indicated experiencing social life problems due to feeling alarmism; for example, one participant, who had some difficulties in social life due to not wanting to leave her parent at any moment, expressed her experience as follows:

"I have the feeling that I should be there all the time [....]. So, this impacts my social life. It always gave me the feeling of being attached to her, the feeling of being unable to leave her."

Helplessness

Moreover, some participants described feeling helplessness related to not being able to do anything about parental illness. For example, one participant expressed that this feeling affected her personality negatively and caused problems in her social life, while one participant, whose father had been in several surgeries, talked about her sense of helplessness:

"So, every time he went to surgery when I felt that pain, I was experiencing a real emotional breakdown because I could not do anything. His writhing was deeply affecting me."

In sum, the unpredictable nature of aggravations of chronic illnesses has caused young carers many struggles. Worrying about their ill parent's health has been increased young carers' need for finding functional coping strategies to handle the perception of illness unpredictability. Moreover, as some participants have stated, the feeling that anything can happen at any moment appears to increase their attachment to the family as well as the reluctancy to leave the family.

Restricted Life

The fourth theme that we have identified is *restricted life and* this theme is specifically tied to the COVID-19 pandemic that contains four sub-themes: *increased health anxiety, fear of transmission, increased household responsibility,* and *inefficient education*. Many participants stated that they felt restricted in all life aspects because of the COVID-19 pandemic.

Fear of Transmission

Many young carers reported fear of transmission, particularly for their ill parent. One participant, who could choose face-to-face education but decided to opt for online education to protect her mother from the risk of COVID-19 transmission, expressed her fear as follows:

"I preferred distance education because I couldn't trust it again [....]. Although I am in Antep, my university is also in Antep, but I couldn't, I couldn't go, we were afraid."

Moreover, one participant stated that she and her family members had to pay more attention to COVID-19 than other people because her mother had a chronic illness. In addition to that, a few participants also mentioned that they believed there was no turning back if their parents got infected by COVID-19 due to parental chronic disease.

Increased Health Anxiety

In addition to fear of transmission, many young carers reported more health anxiety than before the COVID-19 pandemic. For instance, one participant reported that during the COVID-19 pandemic, her health anxiety for both herself and her parents increased, whereas another participant, whose sick parent had already been infected but worried he might contract the disease again, felt she could not handle it and described her anxiety as follows:

"Just anxiety, health anxiety. Let nothing happen, let nothing happen to anyone. My father had it once, he may not get over it if he has it again."

Increased Household Responsibility

Also, many participants, predominantly female young carers, noted that they had been taking more household responsibility during the COVID-19 pandemic due to restricted life. One participant described increasing household responsibility, including care for a sibling during the COVID-19 pandemic, as follows:

"In this process, since I was always at home, my responsibility increased, I started to run everywhere. I rushed to my brother, chores, many other things of course."

Similar to the experience described above, one participant indicated she had been cleaning the house and controlled her parents' medication more because of her increased health anxiety during the COVID-19 pandemic. Moreover, one participant expressed that she was caring for her sibling, cleaning the house, and cooking more frequently during the lockdown whereas she was used to only cooking in the household before the lockdown.

Inefficient Education

Many young carers described how online education had negatively affected their life. One participant was supposed to conduct an internship in the social services field for her future profession but had to do everything online due to the COVID-19, talked about her situation as follows:

"So, I can't get any efficiency [...]. I know that no matter how hard I try, I can't get efficiency. Our teachers say that too [...]."

Furthermore, one participant stated that she showed somatic symptoms because of the uncertainties of the COVID-19 pandemic:

"Because I was under too much stress, because I didn't know what to expect, because not being able to meet with my friends [...]. Well… Because it is a stress-related illness. It had a very bad effect on me."

In summary, the lockdown had diverse effects on young caretakers and had a negative impact on many aspects of their lives. Given these results, young carers might be at risk of experiencing health anxiety and other difficulties related to the restrictions imposed by the COVID-19 pandemic.

Benefit Finding Related to COVID-19 Pandemic

The fifth theme is *benefit finding related to the COVID-19* pandemic that contains two sub-themes*: stronger family ties,* and *personal growth.* Many young carers described indeed how they found benefit from the COVID-19 pandemic.

Stronger Family Ties

Many participants stated how their family ties became stronger thanks to sharing more time together during the COVID-19 pandemic. One participant, who realized that she had not spared enough time for her family before the COVID-19 pandemic, talked about her experience as follows:

"I can say that our relations have become stronger [...]. I understand that we have time for our family, but we don't use it much."

Similar to this experience, some participants stated they had gotten to know family members better and understand the importance of family during this period, while another participant expressed that she felt that her family became a 'real family' thanks to lockdown during the COVID-19 pandemic.

Personal Growth

In addition to family ties, many young carers described that spending more time with themselves created personal growth during the COVID-19 pandemic. One participant expressed that her experience during the COVID-19 pandemic was associated with personal growth.

"I started to appreciate the things that I did not know the value of before [....]. Therefore, it has contributed a lot to me in spiritual terms, [....] I will live by knowing the value of the moment [....] I try to experience such things, as many things as I can, even at home".

Moreover, some participants stated that they questioned life, plans, and human relations and made new decisions during these processes, while another participant indicated that she realized what she had postponed her life until the pandemic but started to take actions to improve her life during the COVID-19 pandemic.

In sum, the majority of the participants in our study reported at least one benefit finding associated with the COVID-19 regardless of the perceived psychological impact of the pandemic. Even though young carers are at higher risk of developing psychological distress associated with the pandemic, they also seem to be able to adapt to stress and find meaning in adverse life events.

Discussion

This study aimed to understand the experiences of young carers whose parents had a chronic illness as well as the effects of the COVID-19 global pandemic on this vulnerable population. After conducting twenty-six in-depth interviews, three main themes related to the experiences of young carers were highlighted, while two themes associated with the context of the COVID-19 pandemic were identified.

The first theme referring to the fact that young carers' life had changed, and everything felt upside down after their parent was diagnosed align with a previous study using the FEF (Pedersen & Revenson, 2005), which states that parental chronic illness could disrupt the entire family system and affect young people's adjustment. Also, consistent with previous literature, our participants specifically reported educational and social difficulties (e.g., Chen & Panebianco, 2020; Chikhradze et al., 2017; Szafran et al., 2016). Moreover, in line with the broader literature addressing the endless process of chronic illness and its treatment, this study has presented initial evidence regarding young carers' endless treatment perception, which might be associated with psychosocial distress (e.g., Plank et al., 2012; Sakakibara et al., 2015). Furthermore, in addition to previous findings indicating young carers who had a single parent to be at risk of experiencing psychosocial difficulties (e.g., Chikhradze et al., 2021), this study highlighted the altruistic healthy parents' protective role on young carers' psychosocial adjustment. On the other hand, it was remarkable how young carers perceived their healthy parents as altruistic while tending to see their own caregiving tasks as an obligation instead of another type of altruism.

The second highlighted theme was the psychological burden expressed by many participants, which might be used/taken into account to improve interventions. As we expected, all of our female participants expressed increased household responsibilities that refer to basic household chores often undertaken by young carers and that could negatively affect their school and social development and personal relationships in adulthood (Landi, Boccolini, et al., 2022; Landi, Pakenham, Crocetti, et al., 2021; Landi, Pakenham, Benassi, et al., 2021; Pakenham & Cox, 2012a; 2014a; Szafran et al., 2016). Consistent with the literature, our participants expressed restrictions about their future due to caring responsibilities that might affect their higher education and job life (Aldridge & Becker, 1993; Robison et al., 2020), participants in this study reported psychological limits for their future. In particular, they highlighted worrying about being away from their ill parent and that these preoccupations were preventing them from planning a future and a life away from their parents. Given that participants in this study were high school and university students, it was inevitable that these worries would negatively affect their educational and career plans. Moreover, many participants expressed their anger which could be seen as the consequence of the young carer's lack of choice and trying to make sense of their caregiving experiences (Landi, Boccolini, et al., 2022; Smyth et al., 2011). Furthermore, the sub-theme of reclaim of control provided initial evidence regarding young carers’ effort to control everything in this unpredictable situation (Landi, Boccolini, et al., 2022; Landi, Duzen, et al., 2022; Pakenham et al., 2006; Pakenham et al., 2007; Pakenham, 2011) and could be interpreted as a counterbalancing behavior. Consistent with the literature stating that young carers' duties were excessive compared to their age (Warren, 2007), potentially all these excessive demands caused psychological burden and reclaim of control might be seen as a coping strategy in this uncontrollable situation.

The third theme was related to the negative psychosocial consequences of the unpredictable conditions of parental illness. In line with the literature (Landi, Boccolini, et al., 2022; Pakenham, 2011; Pakenham et al., 2006), our participants reported fear of parental loss that was sometimes accompanied by depressive affectivity, associated with unpredictability and loss of control toward the illness, which in turn would cause negative emotional reactions. In addition, similar to the findings of previous studies (e.g., Sieh et al., 2010), participants expressed their state of alertness, which could embody the response to the imposed stressor, while some participants expressed a sense of helplessness in relation to the unpredictable conditions of the illness and not being able to do anything. On the other hand, one study highlighted that worrying about the ill parent might cause more engagement in the caregiving role and lead to adaptive coping processes (Landi, Boccolini, et al., 2022). Given these adverse caregiving experiences, young carers might need coping strategies to be supported by interventions in order to handle this uncertain situation.

The COVID-19 pandemic was also associated with adverse mental health consequences for young carers (Landi, Pakenham et al., 2020; Landi, Pakenham, Crocetti, et al., 2022). Blake-Holmes & McGowan, 2022). In line with previous studies stating that individual and systemic factors might make children and young people particularly vulnerable to health-related worries in the context of COVID-19 (Blake-Holmes & McGowan, 2022; Dhiman et al., 2020; Haig-Ferguson et al., 2021), participants in this study expressed their fear of transmission and experienced more health anxiety than before the COVID-19 pandemic. However, predominantly female young caregivers reported more household responsibilities, consistent with previous literature indicating increased domestic duties as another consequence of restricted life during the COVID-19 pandemic (Blake-Holmes & McGowan, 2022). Moreover, consistent with the previous literature (Reilly et al., 2021), some participants indicated that they could not really benefit from their online education. Considering that restricted life has caused more caregiving responsibilities, it is possible to draw the conclusion that young carers might be more at risk during the COVID-19 pandemic.

Given the results of this study, young carers seem to show an increased risk of experiencing some difficulties during the COVID-19 pandemic. To date, the picture painted has referred to caregiving experiences related to parental illness in general; however, the COVID-19 pandemic has caused other challenging situations for young carers who have already been struggling with parental illness. Furthermore, preventive interventions regarding the psychosocial adjustments of young carers whose access to necessary services has been restricted during the COVID-19 pandemic should be taken into consideration.

Nevertheless, in line with the literature stating that young carers might also be able to cope with stress and find meaning in adversity (Blake-Holmes & McGowan, 2022; Poli et al., 2021), participants in this study stated benefits from the COVID-19 pandemic as well as negative sides. Consistent with the previous study conducted on people with multiple sclerosis (Poli et al., 2021), many participants expressed that they had stronger family ties than before the COVID-19 pandemic, as well as personal growth during the COVID-19 pandemic due to an increased in spending time with parents. These benefit findings provided initial evidence that young carers could use coping strategies and obtain positive results in the face of challenges such as the COVID-19 pandemic.

Apart from the aforementioned continuous difficulties that young carers might experience, this study provided findings on how young carers dealed with difficulties during extraordinary situations such as COVID-19. On the other hand, it seemed that young carers had negative caregiving experiences as well as finding benefits from these experiences before and during the COVID-19 pandemic. Nonetheless, their way of finding meaning in negative experiences of being young carers during the COVID-19 pandemic is remarkable. Furthermore, it was clear that young carers potentially focused more on the consequences of the parent's illness rather than on their caregiving experience, while they became more grateful for what life had given them during the COVID-19 pandemic. Given that, to the best of our knowledge, there is no study examining the benefit findings of young carers' experience during the COVID-19 pandemic, these novel findings might pave the way to future research and clinical interventions on the psychosocial adjustment of young carers during the COVID-19 pandemic.

This study also has some methodological limitations. First, our study does not comprehensively represent the diverse and wide-ranging experiences of all young carers but instead considers a number of examples of young carers’ experiences. Another limitation is that all the semi-structured interviews were conducted in Turkey; thus, it is necessary to conduct future research on how different cultural contexts might shape the experiences of young carers. Also, as the majority of participants were female, it might supposedly be that females are more likely to become the carers for their ill parents, therefore further studies will be required to test this assumption. Furthermore, the generalizability of the findings may be further limited by the lack of control over the representativeness of the sociodemographic characteristics of the sample for the wider population of young carers.

Conclusion

These results expand previous findings by examining in detail the caregiving experiences of youth and documenting important dimensions of living with parents with chronic illness, as well as the effects of the COVID-19 pandemic on young carers. Moreover, as benefit findings in the caregiving process appears largely understudied, the present study could represent a first step towards further qualitative investigations on the risk and protective factors of being young carers. Overall, this study will pave the way for the development of tailored intervention programs, targeting the protective factor of benefit finding in the young carers field.

CHAPTER 5

General Discussion

General Discussion

The aim of this dissertation is threefold: (1) to investigate the mediating role of unmet needs on the relationship between illness unpredictability and psychosocial adjustment; (2) to examine the mediating effect of protective factors on the relationship between caregiving components and psychosocial adjustment; (3) to understand the lived experiences of young carers in detail as well as the effects of the COVID-19 global pandemic. To address these aims, three separate studies, adopted distinct methodological approaches (i.e., quantitative, systematic review with meta-analysis, qualitative), were conducted. As such, it could be possible to reliably capture both risk and protective factors in driving the links between caregiving components and psychosocial adjustment among young carers.

The findings of the initial study presented in Chapter 2 detected an indirect association between illness unpredictability and psychosocial adjustment through the mediating role of unmet needs in young carers. In other words, higher levels of illness unpredictability of the parent are related to higher levels of unmet needs among youth, which, in turn, are associated with lower levels of health-related quality of life among young carers. Considering the main tenant of the FEF (Pedersen & Revenson, 2005), proposing that characteristics of parental illness may indirectly affect youth psychosocial adjustment through the proximal mediators (e.g., increasing stress and daily hassles among youth), the findings of this study suggest unmet needs as an additional individual-level mediator in the mechanism mentioned above. Along this line, one might further explore the conceptual model of the FEF by incorporating the youth's unmet needs as an additional mediator linking the characteristics of parental illness and the psychosocial adjustment of youth with an ill parent.

Even though the findings of the initial study illustrating the disruptive effects of the crucial risk factor of youth's unmet needs, it is of utmost importance to unravel which factors may protect these youth from the adverse of caring for an ill parent. Drawing upon the seminal contribution of Pakenham & Cox (2018) suggesting the need for accounting protective factors (e.g., benefit finding) among youth whose need of operating caregiving tasks, experiences, and responsibilities (Landi, Pakenham, Crocetti, et al., 2021), our meta-analytic study in Chapter 3 aimed to portray a comprehensive picture of how the links between caregiving components and youth psychosocial adjustment may be mediated by benefit finding and emotional regulation. In general, the systematic review with meta-analysis presented in Chapter 3, has ensured the mediating role of benefit finding in the relationship between caregiving components (i.e., responsibilities ad tasks) and quality of life. This study has initially ascertained the caregiving responsibilities, experiences, and tasks as being the distinct but closely related dimensions reflecting the youth's caregiving processes, as proposed within the tripartite model of youth caregiving in the context of parental illness (Landi, Pakenham, Crocetti, et al., 2022). Afterward, Chapter 3 also provided novel insights into the protective effects of benefit finding (but not emotion regulation) to understand better the circumstances and ways that enable positive outcomes that might mitigate the impact of caregiving responsibilities and tasks. The current findings thereby suggest benefit finding as being an alternative individual-level mediator influencing, to some extent, youth psychosocial adjustment in the parental illness context. Nonetheless, future empirical investigation with longitudinal designs is needed.

In addition to the substantial knowledge produced by means of robust statistical approaches findings in these empirical Chapters 2–3, in this last empirical study of this dissertation (i.e., Chapter 4), it is aimed to address the lived experiences of young carers before and during COVID-19. The findings of this qualitative study highlighted how young carers deal with their challenging caregiving process as well as how to find benefits even from extra challenging situations like COVID-19.

This research contributed to understanding how young carer deal with their challenging caregiving process as well as how to find benefits even from extra challenging situations like

COVID-19. Examining individual differences regarding the caregiving experiences (i.e., psychological burden, benefit finding related to the pandemic) further allowed us to consider the possible different difficulties and coping strategies among young carers. In particular, this study expands previous findings by going beyond examining in detail the caregiving experiences of youth and documenting important dimensions of living with the parental chronic illness, as well as the provided novel insights by emphasizing how young carers could benefit from extraordinarily challenging situations triggered. Consistent with the FEF (Pedersen & Revenson, 2005), the findings of the study in Chapter 4 also portrayed a more nuanced picture of how the distribution of new roles within the family after parental illness have affected the social, educational, and personal lives of young carers

Overall, the findings of this dissertation suggest that young carers can find benefits from adversities through protective factors that might lessen the unfavorable effects of caregiving processes can play in increasing positive psychosocial adjustment and decreasing adverse psychosocial adjustment. Although previous studies have demonstrated that young carers who perceive the positive aspects of their challenging situations exhibit better mental health, findings regarding potential mechanisms between caregiving components and psychosocial adjustment (e.g., Gough & Gulliford, 2020; Landi, Pakenham, Crocetti et al., 2021; Pakenham & Cox, 2018). However, these studies have not drawn broader picture of youth psychosocial adjustment to better understand their psychosocial adjustment process in the context of parental illness. Altogether, it is hoped that studies in this dissertation can enhance the development of further insights into the dynamic and relatively sensitive nature of psychosocial adjustment among young carers.

Theoretical and Practical Implications

The significant number of children exposed to parental illness, the observed social inequality due to parental illness, and the increased risk of poor health due to parental illness should make these children a high-priority group for policymakers and health promotion. In light of the results, indicating that young carers are at risk of psychosocial difficulties, the first empirical study of this dissertation suggests that interventions should target unmet needs and perception of illness unpredictability to ameliorate the adverse psychosocial adjustment outcomes. Moreover, considering the findings of the remaining studies (i.e., Chapters 3 and 4) that highlight young carers' ability to derive benefits and meaning from their caregiving experiences, it is further suggested that professionals within health and child protection services should offer tailored intervention programs, targeting the protective factor of benefit finding while simultaneously reducing the impact of risk factors on young carers. More specifically, given that Chapter 4 emphasizes the fact that young caregivers can cope with stress and find meaning in challenges, such as COVID-19, professionals might particularly consider possible coping strategies that yield positive results in the face of difficulties, specifically these youth who has already experiencing challenging life conditions. Besides, considering the likelihood of future world events like a global pandemic, there is an urgent need for all countries to consider how to identify and support those children who are or will be forced into caring roles and in potentially greater numbers as a result of strained health and social care systems and new extraordinary conditions. In this regard, future interventions and resource allocation for this target group should consider focusing on the impairment and potential difficulties in their lives caused by the parent's illness, with all illnesses under the umbrella of chronic illness, rather than focusing on the parent's specific diagnoses.

Even though there have been various studies on young carers because of the wide variety of their needs, young carers should be looked at in the context of their own region in order to understand the actual needs of this group so that policy can be tailored accordingly (Joseph et al., 2009). From this point of view, there is a need to raise awareness of young caregivers in terms of policies and professionals, highlighting that young carers are at risk for psychosocial adjustment problems. While social policies provide person-centered services to ill parents, it is also important to consider the needs of young carers who face significant challenges in balancing their livelihoods and caring responsibilities and are underutilizing professional support services in both cultural streams. In this sense, failure to support young carers might further aggravate the negative consequences of providing care in the long term. Thus, another implication of this dissertation is that further studies need to investigate not only the magnitude and consequences of taking on caring responsibilities but also caregiving experiences and possible protective factors on the psychosocial adjustment of young carers to develop a social policy that recognizes and provides adequate support for young carers. Recognizing the possible risk and protective factors among young carers, social workers and other professionals need to avoid a deficit approach in viewing young carers as consistently vulnerable and in need of help and rather seek to strengthen young carers' coping strategies.

Limitations and Future Directions

The findings of the studies in this dissertation should be regarded in light of some limitations that might be addressed in future research. Considering the key role of parents in the family context, we have assessed the effects of parental chronic illness through young carers' perceptions of their caregiving components. Given that this dissertation relies solely on youth self-report data from the perspective of the youth themselves rather than including parental assessment, it might be suggested to take parental assessments into account in addition to youth-self reports. In this way, possible discrepancies that might arise between parents' and young carers' perceptions of how parental chronic illness affect youth psychosocial adjustment may be diminished. In addition, accounting for both perspectives in dyadic designs may further enable the identification of whether parents' perception affects young carers' psychosocial adjustment and vice versa.

Because Chapters 2 and 3 have been conducted with cross-sectional design and with a meta-analytic structural equation model (MASEM), it is not possible to capture the directionality of the links under examination. Thus, future studies with longitudinal designs enable to unravel of in-depth information regarding the interplay of illness unpredictability, unmet needs, and psychosocial adjustment outcomes and address how parental illness affects youth psychosocial adjustment in the longer time frame. Considering the prior argument (Fairchild & McDaniel, 2017) stressing the limits of having cross-sectional data in testing the mediation process, it is of utmost importance to test the mediating role of unmet need in the association between illness unpredictability and psychosocial adjustment. Future research with longitudinal designs could address such a crucial limitation. However, to somewhat overcome this shortcoming, future studies with cross-sectional designs could also test alternative models simply reversing the dependent (i.e., unmet needs) and independent (i.e., illness unpredictability) variables in addition to the model tested in Chapter 2 (see, e.g., Safa et al., 2022).

In addition, Chapter 4 also has focused on the effect of COVID-19 on young carers; however, due to the lack of support for many young carers, as well as the increased isolation and level of responsibility, there may be long-term consequences of the pandemic that set young carers back in their development and opportunities (Stamatopoulos, 2018). Hence, future longitudinal studies that follow young carers during and after the pandemic might be helpful for gaining a deeper understanding and fully comprehending the devastations that it is causing for young carers. Moreover, since this dissertation has investigated the effects of caregiving processes on youth adjustment in proximal contexts, future studies should also consider the impact of variables from the macrosystem (e.g., laws, social policies) and exosystem (most importantly, the availability of health services) to enhance the awareness of young carers regarding policies and professionals (Wepf & Leu, 2022). Hence, it is expected that the scientific knowledge produce in this dissertation would enable policy makers to take the necessary actions to make each country to achieve at least emerging degree based on the classification of awareness and support for young carers (Leu & Becker, 2017).

Besides these limitations, the present dissertation has several strengths. First, this dissertation involves three studies conducted with different designs that might ensure increased reliability of the findings. Second, Chapter 2 enhances our understanding by providing novel insight into the relationship between unmet needs and positive (quality of life) and negative psychosocial adjustment outcomes (internalizing problems) in young carers. Third, Chapter 3 provides novel knowledge on the role of protective factors by investigating the mediating effect of protective factors (i.e., benefit finding and emotion regulation) in the relationship between each caregiving components (i.e., caregiving experiences, caregiving tasks, caregiving responsibilities) and psychosocial adjustment (i.e., quality of life and internalizing, and externalizing problems). Finally, Chapter 4 expands on previous findings by examining in detail the caregiving experiences of youth, documenting important dimensions of living with parents with chronic illness, and the effects of the COVID-19 pandemic on young carers while providing illuminating perspective into caregiving experiences. Overall, this dissertation sheds some light on the impact of risk and protective factors on the psychosocial adjustment of young carers.

General Conclusion

Overall, this dissertation has highlighted the vital role of protective factors mitigating the adverse effects of caregiving activities can play in increasing positive and decreasing detrimental outcomes in young carers. To better understand the circumstances and ways that enable positive outcomes that might improve the effect of adverse caregiving processes, it has addressed the mediating role of risk and protective factors in the associations between psychosocial adjustment and caregiving components (i.e., responsibilities and tasks). Most importantly, all these results regarding psychosocial adjustment in young carers suggest that interventions and social policies should consider possible protective factors and risk factors to improve youth’ positive psychosocial adjusment. The present findings of the dissertation suggest that it may be valuable to help young carers reflect on their way of finding benefits thereby promoting their well-being. To conclude, this dissertation provides essential insight into the potential risk factors causing adverse psychosocial adjustment and protective factors as crucial factors that can promote young carers’ positive psychosocial adjustment in improving interventions and social policies by investigating potential mechanisms in the association between caregiving components and psychosocial adjustment in young carers. By highlighting possible protective factors as the key factor of young carers to derive benefits from adverse caregiving processes, this dissertation opens new possibilities in research and practice that are relevant for young carers.

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