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INVESTIGATION OF THE IMPACTS OF PARENTAL CHRONIC ILLNESS ON YOUTH CAREGIVING EXPERIENCES AND PSYCHOSOCIAL ADJUSTMENT

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Abstract

Objective: Parental chronic illness has an impact on several aspects of offspring's life. Three major impediments to research progress in this field are undeveloped and untested theoretical frameworks, no clear conceptualization of *youth caregiving*, and no available instrument to assess such construct in Italian. To address these weaknesses, the aims of this PhD dissertation were: (1) to investigate the psychometric properties of the Italian version of the Young Caregiver of Parents Inventory-Revised (YCOPI-R); (2) to empirically examine a model of the effects of parental illness on youth and family functioning innovatively analyzing the role of *psychological flexibility*; (3) to test a refined conceptualization of youth caregiving. ***Methods:*** A total of 501 adolescents aged 11 to 24 (295 young caregivers and 206 young noncaregivers) completed a questionnaire regarding youth caregiving, parental illness, and youth adjustment. In the first study, young caregivers were compared to noncaregivers, while the other studies used only the young carers subgroup. ***Results:*** The first study indicated that the Italian version of the YCOPI-R demonstrated sound psychometric and was able to discriminate between young caregivers and noncaregivers. The second study underlined the key protective role of *psychological flexibility* in shaping youth adjustment and family functioning in the context of parental illness. The third study innovatively clarified the nature of youth caregiving, indicating that it is a tripartite construct related to both positive and negative youth adjustment outcomes. ***Conclusions.*** This PhD project drew attention towards youth of chronically ill parents, a segment of the young population which is presently almost completely neglected in Italy by health policies and healthcare providers. This PhD project ultimately shed light into the processes through which parental illness results in detrimental youth outcomes and highlighted avenues for interventions that target empirically supported mechanisms which ameliorate the detrimental effects of parental illness on youth.

Chapter 1

General Introduction

1.1 General Introduction

Children and adolescents who assume responsibilities associated with caring for a parent with a chronic illness or disability are referred to as young caregivers (Pakenham, Bursnall, Chiu, Cannon & Okochi, 2006; Pakenham & Cox, 2014). Estimates in the literature suggest that approximately 5% to 15% of children and adolescents (aged 4-18) grow up with a parent who is affected by a chronic illness (Barkmann, Romer, Watson, & Schulte-Markwort, 2007; Worsham, Compas, & Sydney, 1997). In Italy 6.6% of youth aged 15-24 help an ill family member at least once a week (ISAT, 2017). However, these numbers are likely to be an underestimation because of the 'hidden' nature of young caregiving and the tendency for young people not to self-identify as 'caregivers' (Aldridge & Becker, 1993; Stamatopoulos, 2015). Furthermore, given the improvement in medical technologies and increases in parental age at conception, more young people are living with a parent with serious chronic health problems (Aldridge & Becker, 1993; Shifren & Kachorek, 2003).

Academics have applied a wide range of operational definition of young carers, researchers and support organizations. Several relied on the amount and type of duties they take on in relation to their parents' condition, as well as the subsequent restrictions. For example, young caregivers have been defined as "people between the ages of 8 and 18 who provides unpaid physical, emotional, or supportive help or care, often on a regular basis to disabled or chronically ill family members or relatives of any age" (NAC & UHF, 2005). Others have proposed that this term should include all those "children and young people under 18 who provide or intend to provide care, assistance or support to another family member by carrying out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult" (Becker, 2007). However, given the ambiguity of terms such as 'regular', 'significant' and 'substantial' as indicators of caring, researchers moved their focus on examining the impact of caring on offspring's psychosocial adjustment (Aldridge, 2018; Pakenham, 2009). In addition, such a definition does not mention the level of responsibilities young carers face

(Pakenham, 2009), and it is also considered excessively restrictive (Newman, 2002). In fact, a broader definition allows more young people with ill family members to be taken into consideration when speaking of public health benefits and related services available. In line with this approach, some research does not include self-identification as criteria to select young carer samples because many offspring might not describe themselves as caregivers (Pakenham et al., 2006; Siskowski, 2006). Furthermore, in those families impacted by parental chronic illness where adult family members primarily perform the caregiving, children and adolescents tend, nonetheless, to provide care and are part of the familiar caregiving system (Cox & Pakenham, 2014). More recently, the study of youth caregiving has extended from children and adolescents to young adults and they were defined as ‘young adult carers’ indicating young adults aged between 18 and 24 who provide care (Becker & Becker, 2008).

Intensive youth caregiving may interfere or disrupt normative development in youth and, thereby, pose a potential threat to their physical, mental and social functioning (Pakenham & Cox, 2015). In fact, while some youth cope well with their parents' illness, a significant percentage becomes highly distressed or develops psychological problems (Krattenmacher, Kühne, Ernst, Bergelt, Romer, & Möller, 2012; Sieh, Meijer, Oort, Visser-Meily, & van der Leij, 2010). Therefore, young caregivers are a high-risk group that should receive particular attention – especially because their role is still mainly unrecognized or ignored by the public, healthcare providers, researchers, academics and policymakers (Earley, Cushway, Cassidy, 2007; Siskwoski, 2006).

1.1.1 The Impact of Parental Chronic Illness on Children and Adolescents’ Caregiving Experiences and Psychosocial Adjustment

The literature on youth carving in the context of parental chronic illness has focused both on disease-specific studies and studies with mixed diseases samples: many of the disease-specific studies investigated cancer, the remaining disease-specific studies have mainly examined Multiple

Sclerosis, HIV, stroke, Parkinson disease, rheumatoid conditions, chronic pain, brain injury, and hemophilia (Bogosian, Moss-Morris, & Hadwin, 2010; Higgins et al., 2015; Morris, Turnbull, Preen, Zajac, & Martini, 2018; Pessar, Coad, Linn, & Willer, 1993; Razaz, Nourian, Marrie, Boyce, & Tremlett, 2014; Sieh et al., 2010; Walczak, McDonald, Patterson, Dobinson, & Allison, 2018). There also are many studies on parental mental illness (van Santvoort, Hosman, Janssens, van Doesum, Reupert, & van Loon, 2015). These researches indicate that children and adolescents are particularly affected by parental chronic illness due to their dependence on parental care and support and run an increased risk of developing internalizing and externalizing problems, such as distress, anxiety, depression, and somatic complaints (Barkmann et al., 2007; Bultmann, Beierlein, Romer, Möller, Koch, & Bergelt, 2014; Chen, 2016; Krattenmacher et al., 2012; Morris et al., 2018; Sieh et al., 2010; Walczak et al., 2018). Furthermore, these studies suggest that among children of all ages whose parents have an illness, older children and adolescents tend to report the highest level of psychosocial symptoms and are at the most risk of experiencing anxiety and depression – even though the literature investigating on younger children is still scarce (Davey, Kissil, & Lynch, 2016; Martini, Morris, Jackson, & Ohan, 2019; Pakehnam & Cox, 2015; Walczak et al., 2018). In addition, female gender has been highlighted as a significant predictor of problem behavior in the context of parental illness even if evidence is still mixed (Joseph, Becker, Becker, & Regel, 2009; Krattenmacher et al., 2012; Pakehnam & Cox, 2012b, 2015; Sieh, Oort, Visser-Meily, & Meijer, 2014). Moreover, more problem behaviours in youth were associated with longer parental illness duration and higher unpredictability of parental illness (Ireland & Pakenham, 2010b; Krattenmacher et al., 2014; Pakenham et al., 2006; Pakenham & Cox, 2014, 2015; Sieh, Oort, Visser-Meily, & Meijer, 2012b, 2013) as well as to lower socioeconomic status, single-parent families, poorer quality of parent attachment, worse communication about parental illness, and lower family functioning (Evans, Keenan, & Shipton, 2007; Krattenmacher et al., 2012; Morris et al., 2016; Sieh, Dikkers, Visser-Meily, & Meijer, 2012a; Sieh et al., 2012b).

Offspring of parents affected by a chronic illness also experience poorer quality of life and often face emotions of shame and guilt, feelings of loneliness and perceptions of lacking social support (Gazendam-Donofrio et al., 2010; Pakenham, & Bursnall, 2006; Pakenham, Chiu, Bursnall, & Cannon, 2007; Pakenham et al., 2006; Sieh et al., 2012b; Thastum et al., 2009). Compared to peers, children of parents with chronic illness are also at risk of weakened immune responses, poorer social outcomes and reduced overall psychosocial functioning (Armistead, Klein, & Forehand, 1995; Sieh et al., 2013, 2014). Research also indicated that children and adolescents' needs when caring for a parent with a chronic illness tend to be neglected. A recent study underlined that 10% of young carers frequently thought their life did not seem worth living, or they felt so sad that they could not handle it (Kallander, Weimand, Ruud, Becker, Van Roy, & Hanssen-Bauer, 2018). Furthermore, young carers report high level of unmet psychosocial needs such as help with family issues and information about parental physical diagnosis – e.g. to feel that parents are open about their illness and to receive information about their parents' treatment and chances of recovery, opportunities for time out and recreation – e.g. need to feel like a "normal" young person again without having to care for their parents, support from friends and peers who are in the same situation, help in dealing with feelings about parental physical illness and practical assistance (Kallander et al., 2017, 2018; McDonald, Patterson, White, Butow, Costa & Kerridge, 2016; Nagl-Cupal & Hauprich, 2018; Nicholls, Patterson, McDonald & Hulbert-Williams, 2017; Patterson, McDonald, Butow, White, Costa, Pearce, & Bell, 2013; Patterson, McDonald, White, Walczak, & Butow, 2017).

Not only parental chronic illness itself, but also the level of caregiving responsibilities and the amount of help youth provide, have been associated with poorer mental health outcomes in offspring (Chikhradze, Knecht, & Metzing, 2017; Pakenham & Cox, 2012a, 2012b, 2015; Sieh et al. 2012b; Stamatopoulos, 2018). Young carers often face multiple difficulties including isolation and stigma, they may feel overwhelmed with the emerging caregiving tasks, worry about the health condition of their parents and about becoming ill themselves (Ireland & Pakenham, 2010b;

Korneluk & Lee, 1998; Lackey & Gates, 2001; Pakenham et al., 2006, 2007). On the other hand, youth caregiving is also associated with positive psychosocial outcomes such as benefit finding related to the caregiving role, increased perceived maturity and greater willingness to seek social support (Cassidy & Giles, 2013; Pakenham & Bursnall, 2006; Pakenham & Cox 2012a, 2018; Pakenham et al., 2007). Moreover, some studies highlighted that young carers might also gain a sense of fulfilment by caring for their parents and build up a cohesive support system (Jeppesen, Bjelland, Fosså, Loge, & Dahl, 2016; Morris, Martini, & Preen, 2016; Pakenham & Cox, 2018; Wong, Cavanaugh, MacLeamy, Sojourner-Nelson, & Koopman, 2009). However, despite the potential positive aspects of living with a chronically ill parent, the association between parental chronic illness and youth higher risk of mental and physical health problems is a public health concern. In fact, many young carers report disadvantage through childhood, adolescence and young adulthood that persist into adulthood (Krattenmacher et al. 2012; Morris et al., 2016; Pakenham, 2009; Sieh et al., 2010; Walczak et al., 2018). For all of these reasons, it is imperative that research targets young career welfare. The most promising theoretical framework that has been used to understand how parental illness impacts on youth and families' psychosocial adjustment is presented next.

1.1.2 The Family Ecology Framework – Revised

A theoretical framework is needed to guide research in order to fully comprehend and empirically test how parental illness impacts on youth and families' psychosocial adjustment. The Family Ecology Framework (FEF; Pedersen & Revenson, 2005) is the most promising in this context. It proposes that parental illness affects youth and family functioning indirectly through four responses the child has to parental illness: (1) an increase in caregiving duties undertaken by children as a result of redistribution of family roles due to parental illness; (2) perceptions of stigma related to the parental illness; (3) an increase in daily hassles as routines are disrupted; and (4) most centrally, an increase in perceived stress. In particular, it posits that parental illness severity does not directly disrupt youth adjustment and family functioning but instead, its effect is mediated by the abovementioned four responses offspring has to parental illness. The only published empirical test of a model derived from the FEF (Pakenham & Cox, 2012a) provided support for these mediational processes. A revised version of the Family Ecology Framework-Revised (FEF-R; Landi, Benassi, Pakenham, Grandi, & Tossani, 2019a; Pakenham & Cox, 2015) has been used in this PhD dissertation and is depicted in Figure 1.1. Compared to the original FEF, the Family Ecology Framework-Revised (FEF-R) adds a refined conceptualization and measurement of youth caregiving and underlines the role of psychological flexibility within this model. Given the promising role of psychological flexibility in children and adolescents' psychosocial adjustment and the advancement in the conceptualization of the key construct of youth caregiving, this PhD thesis has included psychological flexibility and the new hypothesized tripartite structure of youth caregiving in the FEF-R. The final aim is to test both the role of psychological flexibility and the individual and joint effects of each youth caregiving components on youth outcomes and family functioning in the context of parental illness. The new component and the modifications in the youth caregiving construct included in FEF-R will be described next.

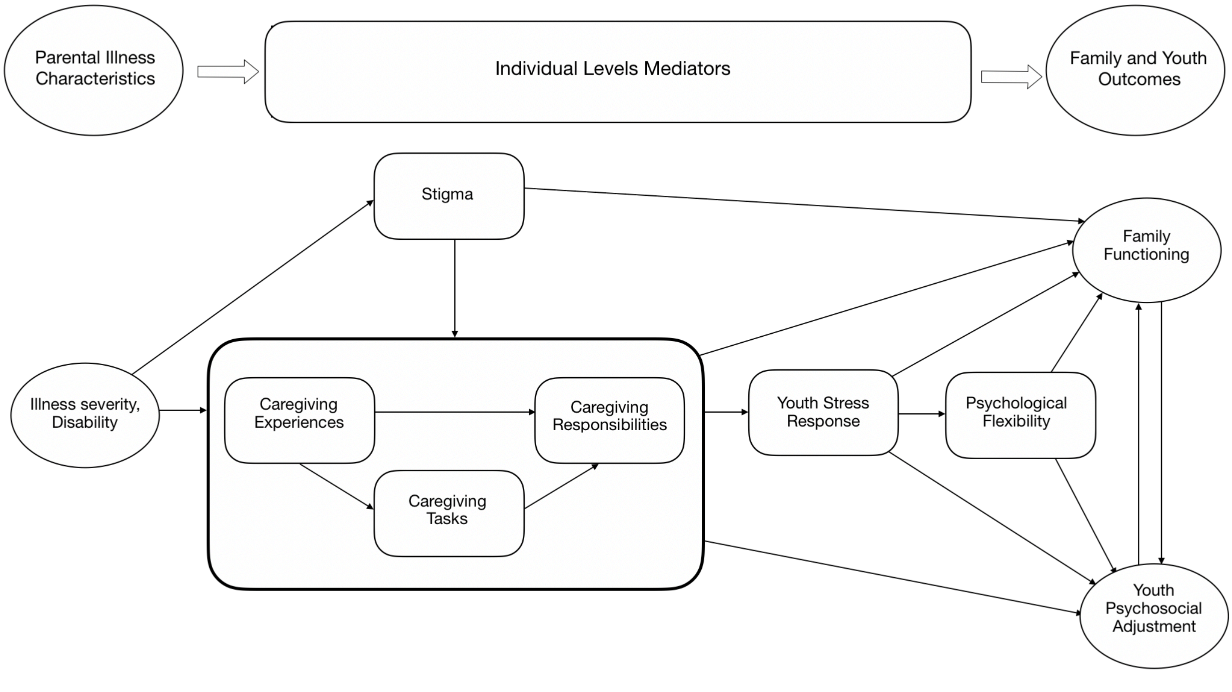

Figure 1.1 – Family Ecology Framework-Revised (FEF-R). Adapted and modified by Pakenham & Cox (2012b, 2015) and Pedersen & Revenson (2005).

1.1.3 Psychological Flexibility

Psychological flexibility is the ability to effectively manage unhelpful thoughts and emotional discomfort in the present moment without expending effort to change them, while at the same time engaging in behaviour to pursue life values, thereby enabling optimal adaptation to changing circumstances. For example, psychological flexibility in a young carer may involve being focused on the present and noticing with acceptance stigma thoughts related to their parent's illness, without investing energy in changing them, and instead diverting attention to engagement in a valued activity (e.g. playing a cherished sport), leading to greater fulfilment. Psychological flexibility is a cornerstone of psychological health (Kashdan & Rottenberg, 2010) and is a potent predictor of a range of psychosocial outcomes concurrently and over a one-year interval (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). It is a contemporary construct that underpins the most recent and widely researched 'third wave' Cognitive and Behaviour Therapy (CBT) called Acceptance & Commitment Therapy (ACT; Hayes, Pistorello, & Levin, 2012). Increasing psychological flexibility is the core goal of ACT, which specifies six therapeutic processes that produce psychological flexibility. Many studies indicated that ACT interventions improve well-being in adults living with a chronic illness (Graham, Gouick, Krahe, & Gillanders, 2016; Hulbert-Williams, Storey, & Wilson, 2015). Some studies have also shown that increases in psychological flexibility mediate these improvements (Åkerblom, Perrin, Fischer, & McCracken, 2015; Wicksell, Olsson, & Hayes, 2010). ACT further revealed to be effective in the improvement of psychological flexibility in youth (Livheim et al., 2015). This PhD project is the first in the young carer field to harness a core construct from the burgeoning ACT literature that spans the last 15 years and demonstrate its relevance to shaping youth and family functioning in the context of parental illness. Examining the role of psychological flexibility within the FEF-R represents an important innovation of this PhD dissertation that might lead to significant theoretical developments and pave the way for interventions.

1.1.4 The Tripartite Nature of Youth Caregiving

Pakenham and Cox (2015) proposed that youth caregiving – a key component of the FEF – is composed of three parts: (1) behavioural caregiving tasks, (2) a psychological sense of caregiving responsibilities and (3) broader psychological experiences associated with caregiving. *Behavioural caregiving tasks* refer to specific caregiving activities that youth undertake, many of which are performed by youth who have healthy parents (e.g. shopping and cleaning) and are typically measured by checklists. Ireland & Pakenham (2010a) operationalized these care tasks with the Youth Activities of Caregiving Scale (YACS) and grouped them into four categories through factor analysis: instrumental, personal-intimate, social-emotional and domestic-household. While this component of youth caregiving is a behavioural one, the other two components represent psychological constructs: *caregiving responsibilities* is the psychological sense of duty or responsibility related to roles involved in contributing to family functioning while *caregiving experiences* are defined by a range of positive and negative psychosocial experiences produced by youth caregiving responsibilities (Pakenham & Cox, 2015). Caregiving responsibilities and caregiving experiences have been operationalized by the Young Carer of Parents Inventory-Revised (YCOPI-R; Cox & Pakenham, 2014; Pakenham et al., 2006). There are five empirically distinguishable caregiving experiences that all children potentially may experience: perceived maturity, worry about parents, global activity restrictions, study/work activity restrictions and isolation (Cox & Pakenham, 2014; Pakenham et al., 2006). A subset of caregiving experiences more specific to caregiving that is intensified by parental illness may also emerge, including caregiving discomfort, isolation, guilt, and support and information needs (Cox & Pakenham, 2014). Conceptually, caregiving responsibilities thus refer to the psychological sense of responsibilities associated with the caregiving role as described by caregiving tasks, whereas the other caregiving experiences tap the factors that influence and maintain this young caregiver role (Pakenham & Cox, 2015).

Considerable research shows that youth with an ill parent report higher levels of caregiving tasks than youth of healthy parents and that higher youth caregiving tasks are related to poorer youth well-being in the context of parental illness (Pakenham et al., 2006). Fewer studies have examined the roles of caregiving responsibilities and caregiving experiences. Pakenham & Cox (2014) underlined that youth caregiving responsibilities and experiences are intensified with the presence of an ill parent relative to healthy parents and that both constructs are related to poorer youth adjustment (Ireland, & Pakenham, 2010b; Pakenham & Cox, 2014). Furthermore, the association between higher caregiving responsibilities and poorer youth adjustment is independent of the effects of parental illness, and youth caregiving responsibilities mediate the effects of parental illness on youth well-being, as hypothesized by the FEF (Pakenham & Cox, 2012a). However, while there is support for the role of each of the proposed components of youth caregiving, no study has tested the simultaneous effects of all three components on youth and family functioning, and this PhD thesis addresses this research gap.

1.2 PhD Dissertation Outline

There is the need for additional research to obtain more insight into protective and risk factors for the high-risk group of children and adolescents with chronically ill parents (Pakenham & Cox, 2015; Patterson et al., 2017) in order to inform the development of young carer interventions that target empirically supported mechanisms which ameliorate the detrimental effects of parental illness on youth. Three major impediments to research progress in this field are: (1) frameworks that explain how parental illness affects youth are mainly undeveloped and untested; (2) although previous research indicates that *youth caregiving* is a central component of such frameworks, a clear conceptualization and well-developed measures that tap this construct in a range of parental illness contexts is lacking; (3) there is currently no instrument available in Italian to measure youth caregiving. To address these weaknesses, the aims of this PhD dissertation are threefold: (1) to investigate the psychometric properties of the Italian version of the YCOPI-

R; (2) to test an expanded model of the effects of parental illness on youth and family functioning derived from the Family Ecology Framework-Revised (Landi et al. 2019a; Pakenham & Cox, 2015; Pedersen & Revenson, 2005) further examining the role of *psychological flexibility* within this model; (3) building on Pakenham and Cox (2015) pioneering research on youth caregiving, to test a refined conceptualization and measurement of youth caregiving. This thesis includes three studies which will be presented in separate chapters. Each study is focused on one of the previously described aims. The first study is based on a sample of 501 adolescents (295 young caregivers and 206 noncaregivers), while the second and third studies focus only on the young caregivers sub-sample.

The first study (Chapter 2) focuses on developing a suitable questionnaire to assess youth caregiving responsibilities and experiences to use in the Italian population of children and adolescents aged 11-24. To this aim, an examination of the psychometric properties of the Italian version of the Young Caregiver of Parents Inventory-Revised (YCOPI-R; Cox, & Pakenham, 2014) was conducted by examining the factor structure, reliability, and validity of the instrument in two different children and adolescent samples: youth of chronically ill and ‘healthy’ parents. The YCOPI-R is a self-report instrument that measures caregiving responsibilities and experiences that all youth potentially may experience and those more specific to youth living with a chronically ill parent.

The second study, Chapter 3, innovatively investigates the role of *psychological flexibility* within the Family Ecology Framework-Revised (FEF-R), a model examining the effects of parental illness on youth psychosocial adjustment. Including psychological flexibility as a key mediator in this context might lead to new theoretical and intervention development. In fact, while many of the potential mediating mechanisms in the FEF-R are not amenable to intervention, this study points to one that, if empirically-supported, provide a pathway for developing tailored individual and family interventions. There is currently no such research in the young carer field.

The third study (Chapter 4) further refines the conceptualization of *youth caregiving* by proposing that it is a tri-partite construct – comprising caregiving responsibilities, experiences, and tasks. Given the dearth of research on the tripartite nature of youth caregiving, this study aimed to examine the individual and joint effects of each component within the FEF-R. While the literature provided support for the role of each of the proposed dimensions of youth caregiving, no study has tested the simultaneous effects of all three components on youth adjustment. For this reason, the third study included in this PhD dissertation is conceptually innovative as it transforms the key but amorphous construct youth caregiving into a theoretically tight and measurable concept embedded within a broader conceptual framework of the effects of parental illness on youth.

Chapter 2

Psychometric Evaluation of the Italian Version of the Young Carer of Parents Inventory-Revised (YCOPI-R)

Abstract

Objective**:** Parental chronic illness has an impact on several aspects of offspring's life. Due to the lack of a contextually sensitive measure of caregiving responsibilities and experiences in Italian, the purpose of this study is the establishment of the factor structure, reliability and construct validity of the Italian version of the Young Caregiver of Parents Inventory-Revised (YCOPI-R) (Cox, & Pakenham, 2014; Pakenham et al., 2006). ***Methods:*** A multistep approach was selected with forward-backward translation in order to translate the YCOPI-R from English to Italian. 501 adolescents aged 11 to 24 (295 young caregivers and 206 young noncaregivers) completed a questionnaire regarding youth caregiving, parental illness and caregiving context variables, and youth adjustment. ***Results:*** The Italian version of the YCOPI-R also demonstrated good psychometric properties, maintaining the same factors structure of the original instrument. Furthermore, the instrument exhibited high internal reliability and discriminant validity, as it significantly differentiated between young caregivers and noncaregivers. Convergent and predictive validity of the Italian YCOPI-R have been supported through evidence of associations between its subscales and measures of caregiving activities, caregiving context and youth psychosocial adjustment. In addition, Caregiving Confidence was associated with higher levels of health-related quality of life, corroborating the positive and negative nature of youth caregiving. Ultimately, the YCOPI-R was found to be a solid measure of youth caregiving. ***Conclusions:*** This study confirmed that the YCOPI-R is a valid measure of caregiving responsibilities and experiences in Italian youth and points to clinical and research implications for the evaluation of young career services and preventive interventions in the Italian context.

2.1 Introduction

Children and adolescents who assume responsibilities associated with caring for a parent with an illness or disability are referred to as young caregivers (Pakenham & Cox, 2014; Pakenham et al., 2006). Estimates in the literature suggest that approximately 5% to 15% of children and adolescents (aged 4-18) grow up with a parent who is affected by a chronic illness (Barkmann et al., 2007; Worsham et al., 1997). In Italy 6.6% of youth aged 15-24 help an ill family member at least once a week (ISAT, 2017). However, these numbers are likely to be an underestimation because of the "hidden" nature of young caregiving and the tendency for young people not to self-identify as "caregivers" (Aldridge & Becker, 1993; Stamatopoulos, 2015). Furthermore, given the improvement in medical technologies and increases in parental age at conception, more young people are living with a parent with serious chronic health problems (Aldridge & Becker, 1993; Shifren & Kachorek, 2003).

Intensive youth caregiving may increase the risk of negative psychosocial outcomes, including poorer mental and physical health (Chikhradze et al., 2017; Nagl-Cupal, Daniel, Koller, & Mayer, 2014; Pakenham & Cox, 2012a, 2012b, 2015; Sieh et al., 2010), lower well-being and restrictions on school and leisure activities (Bolas, Wersch, & Flynn, 2007; Chen, 2016; De Roos, De Boer & Bot, 2017; Lloyd, 2013). On the other hand, youth caregiving is also associated with positive psychosocial outcomes such as benefit finding related to the caregiving role, increased perceived maturity and greater willingness to seek social support (Cassidy & Giles, 2013; Pakenham & Bursnall, 2006; Pakenham & Cox 2012a, 2018; Pakenham et al., 2007).

Despite the potential positive aspects of youth caregiving, the association between youth caregiving and greater risk of mental and physical health problems is a public health concern – many young carers report disadvantage through childhood, adolescence and young adulthood (Chikhradze et al., 2017; Nagl-Cupal et al., 2014; Pakenham & Cox, 2015; Sieh et al., 2010). Therefore, the plight of young carers is recognized as a growing social crisis that has forced their inclusion on national and international political agendas; it is imperative that research targets young carer welfare. Hence, a sound measure of youth caregiving is needed in Italy in order to develop and evaluate young carer services and interventions.

The most widely used instrument assessing young caregiving responsibilities and experiences related to living with an ill parent is the Young Carer of Parents Inventory-Revised (YCOPI-R) (Cox & Pakenham, 2014; Pakenham et al., 2006). The measure was first developed in a two-phase study in which young caregiving themes were identified from qualitative research, and then an inventory assessing those themes was created, and its construct and internal validity were examined (Pakenham et al., 2006). Its psychometric properties were further analyzed across three independent samples of youth (i.e., youth who do not have a family member with a serious health condition, youth of a parent with a significant medical condition, and youth of a parent with MS). Based on this investigation the original instrument was revised. Validity of the YCOPI-R has been supported through evidence of associations between its subscales and measures of caregiving activities and context variables (Ireland & Pakenham, 2010a; 2010b; Pakenham & Cox, 2012b, 2015; Pakenham et al., 2006), and youth adjustment outcomes (Pakenham & Cox, 2014; Pakenham et al., 2006).

The YCOPI-R is a psychometrically sound and contextually sensitive measure of the nature and breadth of youth caregiving experiences across a range of caregiving contexts (Cox & Pakenham, 2014; Pakenham et al., 2006). In fact, the YCOPI-R can be used to compare youth with chronically ill parents and youth with ‘healthy’ parents as well as to distinguish among different types of parental chronic illness (i.e., physical illness, mental illness or substance use) (Fraser & Pakenham, 2008, 2009; Ireland & Pakenham, 2010a, 2010b; Pakenham & Cox, 2015). The YCOPI-R has also been utilized in studies with self-identified young carer samples (Ireland & Pakenham, 2010b) and in research on children and adolescents who have an ill parent with no requirement self-identification as a young carer (Pakenham et al., 2006; Sieh et al., 2012b). The YCOPI-R has also been shown to be sensitive to the effects of young carer interventions (Coles, Pakenham & Leech, 2007; Fraser & Pakenham, 2008; Pakenham & Cox, 2015).

According to the Family Ecology Framework (FEF; Pedersen & Revenson, 2005), parental chronic illness disrupts family functioning and household routines often leading to the redistribution of roles among family members, which typically results in children taking on caregiving roles. Pakenham and Cox (2015) have operationalized caregiving responsibilities and experiences – the psychosocial components of family role redistribution – with the YCOPI-R. The *caregiving responsibilities* dimension of the instrument assesses the sense of duty or responsibility related to caregiving roles involved in contributing to family functioning. In contrast, the other dimensions of the YCOPI-R describe positive and negative psychosocial *caregiving experiences* associated with caregiving responsibilities.

The YCOPI-R is composed by two sections: Part A investigates generic caregiving experiences and responsibilities of youth irrespective of levels of family caregiving demands and the presence or absence of an ill family member, while Part B specifically examines caregiving experiences in the context of living with an ill parent. Part A includes six domains: caregiving responsibilities and five empirically distinguishable caregiving experiences (i.e., perceived maturity, worry about parents, global activity restrictions, study/work activity restrictions and isolation). Part B is composed by five domains and specifically assesses a subset of caregiving experiences specific to caregiving for an ill parent (i.e., caregiving guilt, isolation, confidence, discomfort, information/support needs). The YCOPI-R dimensions include both the costs (i.e., caregiving responsibilities, guilt and discomfort) and rewards (i.e., perceived maturity and caregiving confidence) of caregiving and highlight the complex nature of youth caregiving (Cox & Pakenham, 2014; Pakenham et al., 2006). The dimensions of the YCOPI-R are described in Table 2.1.

Table 2.1 – *Young Carer of Parents Inventory-Revised (YCOPI-R) Dimensions and Themes*

YCOPI-R Dimension	Theme
YCOPI-R, Part A	
• **Caregiving Responsibilities**	Refers to the psychological sense of duty or responsibility related to roles involved in contributing to family functioning
• **General Caregiving Experiences**	
- Perceived maturity	Refers to the "adult child" theme and how taking on adult roles within the family can foster a sense of independence and personal growth
- Worry about parents	Refers to worry and hypervigilance about the parent's safety and health and monitoring of their parent for signs of health changes
- Activity restrictions global	Refers to the interference of the caregiving role in many areas such as leisure time and socializing
- Activity restrictions study/work	Refers to the interference of the caregiving role with school and/or work
- Isolation	Refers to feelings of aloneness and difficulties in sharing caregiving experiences with others
YCOPI-R, Part B	
• **Caregiving Experiences of Living with an Ill Parent**	
- Caregiving guilt	Refers to relentless and inescapable caregiving, how young caregivers feel compelled to care for their parent and the associated guilt when they engage in noncaregiving activities
- Caregiving isolation	Refers to the "hidden" nature of young caregiving and difficulties talking about the parent's illness or asking people for help
- Caregiving confidence	Refers to the positive outcomes of young caregiving; the enhanced self-efficacy through the development of new skills and knowledge
- Caregiving discomfort	Refers to the distress and stigma associated with caregiving
- Caregiving information/support	Refers to young caregivers' needs for support and information about their parent's medical condition and treatment

Notes. YCOPI-R = Young Carer of Parents Inventory.

Given its establishment as a reliable and valid measure of youth caregiving responsibilities and experiences (Cox & Pakenham, 2014; Pakenham et al., 2006) and the fact that there is currently no such instrument available in Italian, the purpose of this study was to investigate the psychometric properties of the Italian version of the YCOPI-R by examining the factor structure, reliability, and construct validity of the instrument in two different children and adolescent samples: youth of chronically ill and 'healthy' parents.

2.2 Method

2.2.1 Scale Translation

A multistep approach was selected (Acquadro, Conway, Hareendran, & Aaronson, 2008). The original version of the YCOPI-R was first 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 submitted to the original author for approval. After applying a few suggested changes, the Italian version of the YCOPI-R was administered to a pilot group of 30 youth to evaluate the extent to which the instrument was clear and understandable. Final modifications were carried out according to this pilot study.

2.2.2 Participants and Recruitment Procedure

A total of 501 participants between 11 and 24 years of age participated in the study: 295 young caregivers – i.e. youth who indicated that they had a parent with an illness or disability – and 206 young noncaregivers – i.e. participants with 'healthy' parents. Exclusion criteria were insufficient command of Italian, severe somatic diseases, and cognitive disabilities. Participants were recruited through different procedures across Italy: information brochures and posters in primary and secondary schools, universities and groups of youth (e.g., library, music and sport groups), illness-related local community organizations (e.g., cancer, epilepsy, diabetes, cardiovascular disease and MS self-help and family support groups), and waiting rooms of health facilities (i.e., general practitioner, hospital and specialist clinics). Participation was also advertised through social networks. Potential participants who showed interest in taking part in the study contacted the researchers by telephone or email. Subsequently, a researcher administered the questionnaires after the required informed consents were signed – i.e., by both parents if youth were underage or by youth themselves if they were 18 years old or above. Administration procedure was pencil and paper-based. The variation in recruitment methods precluded calculation of an overall response rate. The study was approved by the University of Bologna ethics committee.

2.2.3 Measures

Demographics and family structure variables. Youth indicated their age (via date of birth), gender, education, employment ("Do you have a paid part-time job") and ethnicity. Information was also acquired regarding dual or single-parent family, number of family members, number and gender of siblings and – for young caregivers only – amount of daily contact with their ill parent.

Caregiving responsibilities and experiences. The Young Caregiver of Parents Inventory-Revised (YCOPI-R) (Cox & Pakenham, 2014; Pakenham et al., 2006) is a self-report instrument that assesses caregiving responsibilities and experiences and is divided in two parts. Part A is composed of 26 items measuring generic youth caregiving responsibilities and experiences and can be completed by all youth irrespective of family caregiving demands. It contains 6 factors: caregiving responsibilities (8 items; e.g. "My parent(s) relies on me to help them with household chores"), perceived maturity (4 items; e.g. "I am more grown up and mature than others my age"), worry about parents (3 items; e.g. "I always wonder if my parent (s) is/are safe"), activity restrictions global (4 items; e.g. "Helping my parent stops me from doing a lot of the things I want to do"), activity restrictions study/work (4 items; e.g. "I sometimes miss school/work because I have to help my parents") and isolation (3 items; e.g. "Other people do not understand me and my situation"). Part B includes 18 items assessing family caregiving experiences more specific to youth who care for a parent with a significant medical condition and is therefore only completed by children who have a parent with such a condition. It is composed of five factors: caregiving guilt (3 items; e.g. "I feel guilty when I don't help out at home"), caregiving isolation (2 items; e.g. "I find it difficult to ask other people for help in my caring role when I need it"), caregiving confidence (4 items; e.g. "I know exactly what to do to help my parent"), caregiving discomfort (5 items; e.g. "I find it hard explaining to my friends that my parent has an illness/disability"), and caregiving information/support (4 items; e.g. "I wish I had more information about my parent's illness/disability"). All items are rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). YCOPI-R psychometric properties have been described above.

Parental illness variables. Youth caregivers indicated which parent had a health condition (mother, father, both). If "both" was selected, participants were requested to complete all questions with respect to the parent with the most severe health condition. Illness seriousness: youth evaluated the seriousness of their parent's health condition on a 5-point scale (1 *not at all serious* to 5 *very serious*). Illness duration: participants indicated the duration of their parent's illness in years and months. Parental functional difficulty: participants rated the extent to which their parent had difficulty performing daily activities (e.g., eating and dressing) as a result of their illness on a 5-point scale (1 *no difficulty*, 3 *some difficulty*, 5 *extreme difficulty*) (Pakenham et al. 2006). Illness unpredictability: youth indicated the extent to which they agreed with 5 items examining parental illness unpredictability (e.g., "My parent's condition could change at any time with little warning"). Items were rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*) (Pakenham et al. 2006).

Caregiving context variables. The following caregiving context variables were measured and have been used in prior young carer research (Pakenham et al., 2006). Amount of caregiving: youth reported how much help they gave their parent on a 5-point scale (1 *no help at all* to 5 *lots of help*). Choice in helping parents: participants rated the extent to which they perceived they had a choice in helping their parent on a 5-point scale (1 *no choice* to 5 *free to make any choice*). Helping duration: participants indicated how long they had been helping their ill parents in years and months.

Caregiving activities. The Youth Activities of Caregiving Scale (YACS) (Ireland & Pakenham, 2010a) is a self-report measure that consists of 28 items assessing specific caregiving tasks. All items are rated on a 5-point scale, ranging from 0 for *No help at all*, to 4 for *Lots of help*. It consists of four subscales: instrumental care (i.e. paying bills and managing money, shopping, remembering things, etc.), social/emotional care (i.e. helping them when they feel bad, keeping them company, helping them when they are tired, etc.), personal/intimate care (i.e. dressing, going to the toilet, getting in and out of bed, etc.) and domestic/household care (i.e. preparing meals, chores outside the house, looking after other children or family, etc.). The YACS reported to be a psychometrically sound measure, with good internal reliability (from .74 to .92) and both convergent and criterion validity. It was validated for Australian young caregivers of age 10 to 25, with parents suffering from various chronic illnesses such as cancer, MS, depression, bipolar disorder and others (Ireland & Pakenham, 2010a).

Youth adjustment outcomes. The following positive and negative youth adjustment outcomes were assessed: health-related quality of life (HRQoL) and internalizing and externalizing problems.

Health-related quality of life (HRQoL). The Kidscreen-27 is a shorter version of the Kidscreen-52 (The Kidscreen Group Europe, 2006; Ravens-Sieberer et al., 2007) and consists of 27 items measuring child and adolescent HRQoL across five domains: physical well-being (5 items; e.g., “Have you felt fit and well?”), psychological well-being (7 items; e.g., “Have you been happy with the way you are?”), autonomy and parent relations (7 items; e.g., “Have you been able to do the things that you want to do in your free time?” and “Have your parent(s) treated you fairly?”), peers and social support (4 items; e.g., “Have you been able to rely on your friends?”), and school environment (4 items; e.g., “Have you been happy at school?”). Items are rated on a 5-point Likert-scale (0 *not at all* to 4 *extremely* or 0 *never* to 4 *always*). Raw scores were used in the analysis to allow for maximum variance (The Kidscreen Group Europe, 2006). Higher scores indicate greater HRQoL. The KIDSCREEN-27 was validated in a large population-based sample of children and adolescents from several European countries, and it demonstrated adequate internal consistency, test-retest reliability and convergent and divergent validity (Ravens-Sieberer et al., 2007). Its construct validity was recently replicated in a sample of children and adolescents whose parents had a physical, mental, or substance abuse illness (Hagen, Hilsen, Kallander, & Ruud, 2019).

Internalizing and externalizing problems. The internalizing and externalizing problem scales of the Youth Self-Report (YSR) were used to assess emotional and behavioral functioning of children and adolescents (Achenbach, 1991; Achenbach & Rescorla, 2001). The YSR internalizing problems scale reflects three dimensions: anxious/depressed (i.e., fears, nervousness and feeling of being worthless), withdrawn/depressed scale (i.e., loneliness, shyness and sadness) and somatic complaints (i.e., dizziness, vomiting and headaches). The YSR externalizing scale is composed by two factors: rule-breaking behaviours (i.e., antisocial behaviours, substance use, and lying), and aggressive behaviours (i.e., destructive behaviours, disobedience and acting out). Items are rated on a 3-point scale (0 *not true*, 1 *somewhat or sometimes true* and 2 *very true or often true*) and are summed to obtain a total score for internalizing symptoms and externalizing symptoms, with higher scores indicating more problems. The YSR has demonstrated sound psychometric proprieties including test-retest reliability (.79 to .88), internal consistency (.67 to .83) and good content, criterion-related and construct validity (Achenbach & Rescorla, 2001; Frigerio, Cattaneo, Cataldo, Schiatti, Molteni, & Battaglia, 2004). Raw scores were used in the analysis as recommended by Achenbach and Rescorla (2001).

2.2.4 Data Analysis

Confirmatory factor analyses were performed with the IBM SPSS AMOS 24 software. All other analyses were conducted with the IBM SPSS version 24. Cronbach’s alpha was used to estimate the internal reliability of all measures, with values greater than .70 considered to be satisfactory and above .80 considered to be high (Kline, 2016).

Factor analysis. In order to examine the facture structure of the YCOPI-R (Cox & Pakenham, 2014; Pakenham et al., 2006) in the Italian context two Confirmatory Factor Analyses (CFAs) were carried out using maximum likelihood on a covariance matrix: the first was used to confirm the factor structure of the YCOPI-R Part A and was conducted on the total youth sample (i.e., young caregivers and non-caregivers), while the second was used to confirm the factor structure of the YCOPI-R Part B and was carried out on the young caregiver subsample. Model fit was assessed using the following test indices: Chi-square, ratio of Chi-square divided by degrees of freedom ($\chi2/df < 2$), comparative fit index (CFI > .90), and root mean square error of approximation (RMSEA < .10). Because the fits of the models were unsatisfactory, two exploratory factor analyses (EFAs) were also conducted in order to identify the factorial structure of the Italian version of the YCOPI-R. Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy test and Bartlett's test of sphericity were used to check whether the data were adequate to apply factor analysis. Following the original validation's methodology (Pakenham et al., 2006), an oblique rotation was used. The maximum likelihood method with Promax rotation was selected given the fact that YCOPI-R Part A and B components are interrelated and cannot be partitioned into separate units that function independently of one another. Factors were extracted based on Kaiser's criterion (1960) of eigenvalue higher than 1. Items with loadings greater than .40 and cross-loadings less than .10 were considered for inclusion in a factor.

Construct validity. In order to examine the *convergent validity* of the Italian version of the YCOPI-R, correlations were conducted between the YCOPI-R Part A and Part B factors, caregiving tasks and caregiving context variables. *Discriminant validity* of the Italian version of the YCOPI-R was investigated by comparing caregivers and non-caregivers on YCOPI-R Part A factors. To analyze the *predictive validity* of the Italian version of the YCOPI-R, correlations between its subscales and measures of youth adjustment (i.e. HRQoL and internalizing and externalizing problems) were carried out.

2.3 Results

2.3.1. Sample Characteristics

The sample consisted of 501 youth (47% male with a mean age of 17.31): 295 young caregivers – i.e. youth who indicated that they had a parent with an illness or disability – and 206 young noncaregivers – i.e. participants with 'healthy' parents. For young caregivers parental chronic illnesses or disabilities were classified according to the International Classification of Diseases 11th Revision (ICD-11) (World Health Organization, 2018) into: cancer (37.6%), neurological diseases (18.3%), Type I and II diabetes (13.9%), mental illnesses (12.2%), cardiovascular diseases (3.4%), autoimmune diseases (3.4%), gastrointestinal diseases (2.4%), rheumatic diseases (2.4%), respiratory diseases (1.7%), infectious diseases (1.4%), physical disabilities and musculoskeletal diseases (1.3%), liver diseases (1%) and others (.3 %). Almost all youth (98 %) were native Italian. Four participants were of Lithuanian, Ukrainian, or Romanian nationality. Other demographic information as well as family, parental illness and caregiving context variables are represented in Table 2.2

Table 2.2 – Participants' Characteristics: Demographic, Family Structure, Parental Illness and Caregiving Context Variables (N = 501)

	Young caregivers (*n* = 295)			Non caregivers (*n* = 206)		
Variable	%	*M* (*SD*)	Range	%	*M* (*SD*)	Range
Demographics						
Age years		17.61 (3.26)	11.04-24.94		16.74 (3.32)	11-24.64
Gender: male	42.70			46.11		
Currently studying	88.52			90.78		
Currently working	27.87			14.08		
Family structure						
Family size		4.27 (1.19)	2-9		4.13 (.82)	2-7
Number of older brothers		1.16 (.37)	1-2		1.11 (.40)	1-3
Number of older sisters		1.16 (.44)	1-3		1.08 (.27)	1-2
Single parent family	6.04			3.40		
Daily contact with ill parent	91.80					
Parental illness						
Ill mother	69.95					
Ill father	22.40					
Both parents	7.65					
Illness duration (years)		12.66 (13.43)	1-51			
Seriousness of illness		2.95 (.98)	1-5			
Parental functional difficulty		1.87 (1.05)	1-5			
Illness unpredictability		1.57 (.83)	0-4			
Caregiving context						
Amount of help		2.93 (.78)	1-5			
Choice in helping		3.54 (1.24)	1-5			
Helping duration (years)		5.55 (3.56)	.30-16			

2.3.2 Factor Analysis of the Italian Version of YCOPI-R Part A

The results of the confirmatory factor analysis (CFA) of the Italian version of the YCOPI-R Part A suggested a moderate to poor fit between the six-factor model of YCOPI-R Part A and the observed data: $\chi 2$ (396) = 1,223.64, $p < .001$; $\chi 2/\mathrm{df} = 3.09$; CFI = .86; RMSEA = .07. Refinement of the model, based on the examination of the modification indices, did not allow a significant improvement of the fit of the model. Therefore, an exploratory factor analysis (EFA) was conducted in which the Kaiser-Meyer-Olkin measure of sampling adequacy proved to be extremely good (KMO = .85; Hutcheson & Sofroniou, 1999) and Bartlett's test of sphericity was highly significant ($p < .001$). According to Kaiser's criterion (1960), seven factors had an eigenvalue > 1 and explained 55.6% of the variance. However, two items did not comply with the criteria set for allocating an item into a specific factor and were eliminated – item 4 and 11, respectively belonging to Perceived Maturity and Activity Restriction Global. A new EFA was conducted on the remaining 24 items leading to a final six-factor solution explaining 54.1% of the variance. Factors loadings are presented in Table 2.3. The first factor accounted for 17.03% of the variance and comprised seven items that reflected Caregiving Responsibilities. The second factor accounted for 16.06% of the variance and consisted of five items that tapped into the Activity Restriction Study/Work factor. In the original version of the YCOPI-R Part A, item 19 – i.e., “If I do not take on extra responsibilities the house will fall apart” – was included in the Caregiving Responsibilities subscale, while in the Italian version loaded higher (.41 compared to .30) in the Activity Restriction Study/Work factor. The third factor accounted for 7.47% of the variance and comprised three items that reflected Perceived Maturity. The fourth factor accounted for 5.34% of the variance and was composed of three items that tapped Isolation. The fifth factor accounted for 4.82% of the variance and comprised three items that reflected Worry About Parents. The final factor accounted for 3.33% of the variance and comprised three items that tapped Activity Restrictions Global.

Table 2.3 – Factor Loadings of the Italian Version of the YCOPY-R Part A's Items After Promax Rotation (N = 501)

Factors and Items	Factors					
	1	2	3	4	5	6
Caregiving Responsibilities						
23 My parent(s) relies on me to do the shopping and budgeting	.773					
26 My parent(s) relies on me to make sure our family is organized	.714					
22 My parent(s) relies on me to help them with household chores	.706					
25 My parent(s) relies on me for emotional support …	.637					
21 My parent(s) expect me to help care for them	.527					
24 I have to look after my other family members	.460					
20 Others expect me to help my parent(s)	.449					
Activity Restrictions Study/Work						
17 I sometimes feel tired at school/work because I have been helping …		.849				
16 Because of helping my parent(s) I sometimes feel too tired…		.810				
15 I sometimes miss school/work because I have to help my parent(s)		.748				
18 Helping my parent(s) stops me from doing paid work		.723				
19 If I do not take on extra responsibilities the house will fall apart		.413				
Perceived Maturity						
6 I feel more like an adult than other people my age			.974			
7 I am more grown-up and mature than other people my age			.841			
5 I know more about looking after a household than other people my age			.593			
Isolation						
13 I sometimes feel alone				.850		
14. Other people do not understand me and my situation				.651		
12 I wish that I had other people to talk to about my feelings and worries				.424		
Worry About Parents						
3 I worry about what will happen to my parent(s)					.874	
2 I always wonder if my parent(s) is/are safe					.785	
1 I worry about my parent(s)					.677	
Activity Restrictions Global						
9 I miss out on a lot of activities because of my home responsibilities						.861
10 I feel as though I am missing out on things that other people my age are doing						.709
8 Helping my parent(s) stops me from doing a lot of things that I want to do						.560
Eigenvalue	2.72	6.47	1.92	1.46	1.70	1.19
Eigenvalue after Promax rotation	4.57	4.46	2.99	2.20	2.42	3.67
Percent of explained variance	17.03	16.06	7.47	5.34	4.82	3.33

2.3.3 Factor Analysis of the Italian Version of the YCOPI-R Part B

Model fit of the Italian version of the YCOPI-R Part B was also moderate to poor: $\chi2$ (237) = 540.36, *p* < .001; $\chi2$/df = 2.28; CFI = .78; RMSEA = .08 and model fit did not improve with refinement of the model. Consequently, an EFA was conducted in which the Kaiser-Meyer-Olkin measure of sampling is adequate (KMO = .65) and Bartlett's test of sphericity proved to be significant (*p* < .001). According to Kaiser's criterion (1960), six factors had an eigenvalue > 1 and explained 49.5% of the variance. However, three items did not comply with the criteria set for allocating an item to a specific factor and were eliminated – item 4, 9 and 12, respectively belonging to the Caregiving Discomfort, Caregiving Guilt, Caregiving Information/Support factors. A new EFA was finally conducted on the remaining 15 items leading to a five-factor solution explaining 49.7% of the variance. Factors loadings are presented in Table 2.4. The first factor accounted for 12.75% of the variance and comprised four items that reflected Caregiving Isolation. The Italian version of this factor includes items 5 and 6 – i.e., “I find it hard explaining to my friends that my parent has an illness /disability” and “I feel embarrassed about my parent's illness/disability” – that in the original version were allocated in the Caregiving Discomfort subscale. The second factor accounted for 12.22% of the variance and consisted of two items that tapped into Caregiving Guilt. The third factor accounted for 10.34% of the variance and comprised four items that reflected Caregiving Confidence. The fourth factor accounted for 9.23% of the variance and was composed of two items that tapped Caregiving Information. Compared to the original Caregiving Information/Support factor, the Italian version contains two items related only to caregiving information instead of including items also referring to caregiving support. In fact, item 16 – i.e., “I wish there was someone who was able to look out for me – was removed from the Caregiving Information factor and included in Caregiving Discomfort. The final factor accounted for 5.13% of the variance and comprised three items that reflected Caregiving Discomfort. This last factor is the one that undergone the most changes since items 5 and 6 of the original scale highly loaded to the Caregiving Isolation subscale while item 16 was moved to Caregiving Information. All the discarded items and changes from the original to the Italian version of the YCOPI-R are depicted in Table 2.5.

Table 2.4 – Factor Loadings of the Italian Version of the YCOPY-R Part B's Items After Promax Rotation (n = 295)

Factors and Items	Factors				
	1	2	3	4	5
Caregiving Isolation					
5 I find it hard explaining to my friends that my parent has an illness/disability	.778				
11 I find it difficult to ask other people for help in my caring role when I need it	.533				
6 I feel embarrassed about my parent's illness/disability	.447				
10 I do not talk to my family about my concerns..., I do not want to upset them	.412				
Caregiving Guilt					
8 When I am out with friends I feel that I should be at home instead		.909			
7 I feel guilty when I go out and have fun		.754			
Caregiving Confidence					
14 I know exactly what to do to help my parent			.783		
17 I am confident that I can care for my parent			.77		
3 I am good at helping my parent and I always know what to do…			.672		
15 I am included in making decisions about my parent's illness/disability			.441		
Caregiving Information					
13 I wish I had more information about my parent's illness/disability				.023	
18 I wish the doctors would talk to me and explain things…				.568	
Caregiving Discomfort					
16 I wish there was someone who was able to look out for me					.653
1 I wish that someone else could care for my parent					.612
2 I wish that I did not have to help my parent as much as I do					.506
Eigenvalue	1.91	1.83	1.55	1.38	.77
Eigenvalue after Promax rotation	1.79	1.78	1.89	1.67	1.55
Percent of explained variance	12.75	12.22	10.34	9.23	5.13

Table 2.5 – List of Discarded Items and Changes from the Original to the Italian Version of the YCOPI-R

Excluded items of Italian Version of YCOPI-R Part A

4 I take on more responsibility around the house than other people my age (Perceived Maturity)
11 I have a lot of time to do the things that I want to (Activity Restriction Global)

Factor changes in the Italian Version of the YCOPI-R Part A

19 If I do not take on extra responsibilities the house will fall apart (Caregiving Responsibilities → Activity Restriction Study/Work)

Excluded items of Italian Version of YCOPI-R Part B

4 I like bringing friends home (Caregiving Discomfort)
9 I feel guilty when I don't help out at home (Caregiving Guilt)
12 I wish I could talk to other people my age who also have a parent with an illness/disability (Caregiving Information/Support)

Factor changes in the Italian Version of the YCOPI-R Part B

5 I find it hard explaining to my friends that my parent has an illness /disability (Caregiving Discomfort → Caregiving Isolation)
6 I feel embarrassed about my parent's illness/disability (Caregiving Discomfort → Caregiving Isolation)
16 I wish there was someone who was able to look out for me (Caregiving Information/Support → Caregiving Discomfort)

***Notes**:* 2 Items of the original YCOPI-R Part A and 3 items of the original YCOPI-R Part B did not comply with the criteria set for allocating an item to a specific factor and were excluded.

2.3.4 Psychometric Properties of the Italian Version of the YCOPI-R Factors

The descriptive and psychometric properties of the Italian version of the YCOPI-R Factors are presented in Table 2.6. All of the subscale scores had internal reliabilities above .70 except for Caregiving Isolation (α = .62) and Caregiving Discomfort (α = .59). Most of the intercorrelations within the YCOPI-R Part A factors as well as the intercorrelations within Part B factors were positive and of a small to moderate magnitude, while associations among Part A and Part B factors were not significant with only a few exhibiting low magnitude correlations. Details of correlations with all the subscales are displayed in Table 2.7.

Table 2.6 – Cronbach's Alphas and Descriptive of YCOPI-R Factors and other Scales (N = 501)

		Young caregivers (*n* = 295)		Noncaregivers (*n* = 206)			
Scale	N. of items	*M* (*SD*)	Range	*M* (*SD*)	Range	Total *M* (*SD*)	α
YOCPI-R, Part A							
Caregiving responsibilities	8	1.49 (.78)	0-3.50	1.17 (.70)	0-2.88	1.27 (.75)	.84
Perceived maturity	4	2.39 (.89)	.50-4	1.89 (.96)	0-4	2.13 (.96)	.83
Worry about parents	3	2.88 (.78)	0-4	2.84 (.92)	0-4	2.86 (.86)	.82
Activity restrictions global	4	1.16 (.81)	0-5	.93 (.66)	0-3.75	1.04 (.74)	.71
Activity restrictions study/work	4	.51 (.70)	0-3.50	.36 (.56)	0-3.25	.43 (.64)	.85
Isolation	3	1.67 (.97)	0-4	1.52 (.95)	0-4	1.59 (.96)	.70
YCOPI-R, Part B							
Caregiving guilt	3	1.50 (.88)	0-4			1.50 (.88)	.69
Caregiving isolation	2	1.45 (1.01)	0-4			1.45 (1.01)	.51
Caregiving confidence	4	1.91 (.78)	0-4			1.91 (.78)	.74
Caregiving discomfort	5	.86 (.56)	0-2.60			.86 (.56)	.52
Caregiving information/support	4	1.71 (.84)	0-3.75			1.71 (.84)	.62
Illness unpredictability	5	1.57 (.83)	0-4			1.57 (.83)	.72
Total YACS	28	1.22 (.52)	.07-2.96	.99 (.52)	0-2.36	1.11 (.55)	.91
Instrumental care	7	1.09 (.73)	0-3.71	.84 (.60)	0-3.57	.96 (.68)	.77
Social-emotional care	7	2.08 (.80)	.29-4	1.76 (.95)	0-3.86	1.92 (.89)	.86
Personal care	8	.44 (.62)	0-3.25	.24 (.41)	0-2.13	.34 (.54)	.85
Domestic care	6	1.47 (.73)	0-3.17	1.26 (.72)	0-4	1.37 (.73)	.69
Total Kidscreen-27	27	97.43 (14.12)	46-126	100.76 (12.98)	55-129	99.20 (13.61)	.90
Physical well-being	5	15.28 (3.56)	6-23	16.31 (3.03)	7-23	15.82 (3.32)	.75
Psychological well-being	7	26.68 (4.38)	10-35	27.63 (4.43)	11-35	27.18 (4.43)	.86
Autonomy & parent relations	7	26.39 (4.65)	12-35	26.74 (4.50)	11-35	26.58 (4.57)	.76
Peers & social support	4	15.19 (3.44)	4-20	16.09 (3.17)	4-20	15.67 (3.33)	.83
School environment	4	13.91 (2.66)	5-20	14.00 (2.83)	5-20	13.95 (2.75)	.74
Internalizing problems	31	14.03 (9.00)	0-53	11.50 (8.08)	0-36	12.80 (8.81)	.90
Externalizing problems	32	9.48 (6.24)	0-36	8.23 (5.57)	0-30	8.93 (6.09)	.90

Table 2.7 – Correlations among Italian version of Young Caregivers of Parents Inventory-Revised Factors, Caregiving Context Variables, Caregiving Tasks and Youth Adjustment Variables (N = 501)

	YCOPI-R Part A						YCOPI-R Part B				
	1	2	3	4	5	6	7	8	9	10	11
YCOPI-R, Part A											
1. Caregiving responsibilities											
2. Perceived maturity	.34**										
3. Worry about parents	.26**	.28**									
4. Activity restrictions global	.39**	.23**	.13*								
5. Activity restrictions study/work	.47**	.16**	.09	.53**							
6. Isolation	.27**	.26**	.07	.30**	.27**						
YCOPI-R, Part B											
7. Caregiving guilt	.04	.05	.19**	.03	-.03	.08					
8. Caregiving isolation	.08	.06	.10	.13	.22**	.20**	.25**				
9. Caregiving confidence	.16*	.14	.21**	-.02	.06	-.15*	-.05	.01			
10. Caregiving discomfort	.09	-.04	.04	.10	.04	.28**	.19*	.25**	-.04		
11. Caregiving information	.12	-.00	.15*	-.05	-.05	-.03	.22**	.21**	.00	.24**	
Caregiving context variables											
Amount of help	.14	.09	.10	.06	.02	-.10	.08	.15*	.42**	.01	.10
Choice in helping	-.10	-.04	.05	-.11	-.05	-.11	-.05	-.10	.05	-.09	-.05
Helping duration (years)	.00	.01	-.10	-.12	.06	.12	-.05	.00	.15	-.14	.04
Daily contact with ill parent	-.13	-.10	.04	-.11	-.10	.03	-.18*	-.23**	.03	-.03	-.09
Total caregiving tasks	.45**	.38**	.37**	.21**	.19**	-.00	-.01	.10	.28**	-.12	.13
Instrumental care	.36**	.38**	.29**	.21**	.23**	.08	-.15	.01	.26**	-.17	.10
Social-emotional care	.39**	.29**	.45**	.07	.06	-.00	.05	.08	.26**	-.13	.25**
Personal care	.20**	.24**	.16*	.24**	.14	-.02	.09	.08	.15	-.01	-.03
Domestic care	.43**	.27**	.20**	.19**	.19**	-.08	-.02	.15	.20*	-.07	.07
Young Caregivers Adjustment Variables (n = 295)											
Total HRQoL	-.13	-.07	.13	-.29**	-.23**	-.56**	-.10	-.16*	.24**	-.19*	.09
Physical well-being	-.09	.05	.06	-.11	-.15*	-.36**	-.03	-.07	.22**	-.04	.07
Psychological well-being	-.17**	-.09	.07	-.23**	-.18*	-.56**	-.09	-.14	.12	-.14	.06
Autonomy & parent relations	-.20**	-.10	.05	-.39**	-.33**	-.40**	-.09	-.17*	.18*	-.18**	-.00
Peers & social support	-.08	-.18*	.11	-.25**	-.14	-.43**	-.11	-.14	.12	-.08	.12
School environment	.03	.09	.21**	-.09	-.05	-.33**	-.04	-.08	.25**	-.24**	.06
Internalizing problems	.33**	.19*	.05	.20**	.19**	.61**	.23**	.15*	-.12	.13	.04
Externalizing problems	.22**	.13	-.03	.09	.15*	.31**	.11	-.07	-.04	-.02	-.06

Notes. * p < .05, ** p < .01. Correlations for adjustment variables are presented only for the young caregivers' subgroup.

2.3.5 Convergent Validity of the Italian Version of the YCOPI-R

Correlations were used to examine relations between the Italian version of the YCOPI-R Part A and B factors and the continuous and dichotomous caregiving context variables as well as caregiving tasks. Results indicated that there were no correlations between the Italian YCOPI-R Part A factors and the caregiving context variables. Caregiving Responsibilities, Perceived Maturity and Worry About Parents were all positively related to youth caregiving tasks with moderate to high magnitude correlations. Activity Restriction Global and Activity Restriction Study/Work exhibited a small positive correlation with almost all caregiving tasks subscales.

Compared to Part A factors, many Part B factors correlated with caregiving context variables and related caregiving demands. Caregiving Confidence and Isolation exhibited a low to moderate positive correlation with amount of help. Caregiving Guilt and Isolation were negatively correlated with daily contact with ill parent. Most of Part B factors did not correlate with caregiving tasks apart from Caregiving Confidence which was positively associated with all of the caregiving tasks subscales – except for personal care tasks. Finally, Caregiving Information exhibited a small positive correlation with social-emotional care.

2.3.6 Discriminant Validity of the Italian Version of the YCOPI-R

A Multivariate analysis of variance was conducted to determine whether young caregivers differed from noncaregivers on the Italian version of the YCOPI-R Part A factors. A significant difference was found, Wilks' $\lambda = .93$, $F(6,494) = 5.01$, $p < .001$, $\eta^2 = .07$, meaning that the Italian YCOPI-R Part A was able to discriminate between young caregivers and noncaregivers. Univariate analyses revealed that the scores of Caregiving Responsibilities – F (1, 499) = 7.19, $p < .01$, Perceived Maturity – F (1, 499) = 24.66, $p < .001$, Activity Restrictions Global – F (1, 499) = 7.15, $p < .01$, and Activity Restriction Study/Work – F (1, 499) = 6.08, $p < .05$, were all significantly higher for the young caregiver subgroup. However, Worry About Parents – F (1, 499)

= .21, *p* = .65, and Isolation – F (1, 499) = 2.39, *p* = .12, did not significantly differ between groups.

2.3.7 Predictive Validity of the Italian Version of the YCOPI-R

To determine the relationships between the Italian version of the YCOPI-R factors and youth adjustment variables, Pearson's correlations were conducted on the young caregiver subgroup (see Table 2.7). In general, most of Part A and B factors were related to poorer youth adjustment. Activity Restrictions Global, Activity Restrictions Study/Work and Isolation in Part A were negatively associated with youth health-related quality of life with small to moderate magnitude correlations. The only high magnitude negative correlations were evinced for Isolation and total HRQoL and for Isolation and psychological well-being. In addition, weak negative correlations were exhibited by Caregiving Responsibilities and both psychological well-being and autonomy and parent relations, and by Perceived Maturity and peers and social support. Worry About Parents was, unexpectedly, positively related to school environment (*r* = .21**). Most of Part A subscales were positively related to internalizing problems with small magnitude correlations – apart from Isolation which was highly correlated with it. Isolation, Caregiving Responsibilities and Activity Restriction Global were weakly associated with externalizing problems.

A few of Part B factors exhibited small negative correlations with youth health-related quality of life. Caregiving Confidence was the only factor positively related to total HRQoL, physical well-being, autonomy and parent relations and school environment with low magnitude correlations. Caregiving Guilt and Caregiving Isolation were the only YCOPI-R Part B factors which were positively associated with internalizing problems. None of Part B factors correlated with externalizing problems.

2.4 Discussion

This study aimed to investigate the psychometric properties of the Italian version of the YCOPI-R assessing caregiving responsibilities and experiences in youth. We examined factor structure, reliability, and construct validity of the instrument in two different children and adolescent samples: youth of chronically ill and ‘healthy’ parents. Results from factorial analyses indicated that the Italian version of the YCOPI-R has the same factors structure of the original instrument (Cox & Pakenham, 2014). However, some items were discarded and a few were transferred into a different factor. In particular, one item from the YCOPI-R Part A Caregiving Responsibilities subscale – “If I do not take on extra responsibilities the house will fall apart” – loaded higher into the Activity Restriction Study/Work factor. Its original meaning pertaining to a sense of duty might have been interpreted as caregiving demands ultimately interfering with school/work activities because the Italian translation stressed less the focus on ‘extra responsibilities.’ This item should be reformulated to resolve its ambiguities. In addition, two items from the original YCOPI-R Part B Caregiving Discomfort subscale were allocated to the Italian Caregiving Isolation factor – i.e., “I find it hard explaining to my friends that my parent has an illness/disability” and “I feel embarrassed about my parent's illness/disability.” In the Italian culture, both of these items seem to fit better the difficulties associated with talking about parental illness with others more than the distress related to caregiving. Finally, one item from the original YCOPI-R Part B Caregiving Information/Support subscale was transferred to the Caregiving Discomfort factor – i.e., “I wish there was someone who was able to look out for me”. A reason for this change might be due to the fact that in the Italian context the feeling of not having somebody who looks after oneself is more related to the distress associated with caregiving rather than the need for information/support. In addition, the other items comprehended in the Italian Caregiving Information subscale refer more to the need for information regarding parental illness offered by professional figures rather than the need for support form a close one. Nevertheless, the original structure of the YCOPI-R was replicated in the Italian context.

The Italian version of the YCOPI-R also demonstrated good psychometric properties: almost all its subscales exhibited high internal reliability with the only exception of the two subscales of YCOPI-R Part B requiring additional refinement: Caregiving Isolation and Caregiving Discomfort. In line with the original YCOPI-R (Cox & Pakenham, 2014), further work for Part B is required in order to establish a stable structure in the Italian context as well. Despite this, the low and not significant correlations between Part A and B factors indicate that the Italian version of the instrument is able to discriminate between generic caregiving experiences and those specific to young carers.

The validity of the Italian version of the YCOPI-R has been supported through evidence of associations between its subscales and measures of caregiving activities and context variables and youth adjustment outcomes. Specifically, convergent validity was supported by positive association with caregiving tasks and caregiving context variables confirming the ability of the Italian version of the instrument to sensitively detect variations in the youth caregiving context. The Italian version of the YCOPI-R Part A also indicated good discriminant validity and was able to differentiate between young caregivers and noncaregivers (Cox & Pakenham, 2014), even though the Worry About Parents and Isolation subscales were not significantly higher for young caregivers in this sample. Correlations of Part A and B Factors and psychosocial adjustment indicated good predictive validity for the Italian version of the instrument. In fact, higher scores in Part A and B factors were associated with poorer health-related quality of life and more internalizing and externalizing problems. In line with Pakenham and colleagues (Pakenah et al., 2006, Cox & Pakenham, 2014), higher scores in the Caregiving Confidence factor were associated with higher levels of total HRQoL, physical well-being, autonomy and parent relation and school environment. This reflects the positive and negative nature of youth caregiving and points to the fact that young caregivers could also benefit from their role as carers (Pakenham & Cox, 2018). Finally, the Worry About Parents factor was positively related to school environment indicating that some young carers could feel happy and do well at school as they might perceive their time there as a momentary ‘break’ from the caregiving context.

This study has some limitations that should be discussed. First of all, the use of nonrandom sampling that might limit the generalizability of findings. Moreover, given that the original YCOPI-R Part B already required further work, its Italian structure is tentative as well. In fact, factor analysis for its Italian validation ended up leaving some of its subscales with only two items – even if for purpose of reliability, no factor should have fewer than four. Despite these limitations, this study has several strengths such as the fact that it is the first to validate the YCOPI-R in the Italian population, opening up the possibility to develop and evaluate young carer services and interventions with a solid instrument for the assessment of young caregivers in Italy. In addition, this study underlined good psychometric properties of the Italian version of the instrument confirming the original factor structure of the YCOPI-R in the Italian context as well. Lastly, the sample of youth utilized in this study consisted of young caregivers of parents with mixed diagnosis, proving further support for the generalizability of the Italian version of the YCOPI-R regardless of parental illness type.

Future research should further refine the factor structure of the Italian version of the YCOPI-R Part B in order to strengthen its factors, especially for Caregiving Discomfort and Caregiving Isolation. Additional studies based on randomly selected Italian youth samples are needed in order to further establish the generalizability of the instrument.

In conclusion, this study underlined good factor structure, reliability, and construct validity in the Italian version of the YCOPI-R, which confirmed to be a sound measure of youth caregiving responsibilities and experiences in Italy. This study has clinical and research implications for the evaluation of young career services and preventive interventions in the Italian context.

Chapter 3

A Model of the Effects of Parental Illness on Youth and Family Functioning: The Mediating Role of Psychological Flexibility

Abstract

Objective: Parental chronic illness may adversely impact youth and family functioning. Research in this area lacks empirically supported comprehensive framework. This study examined a model derived from Pedersen & Revenson (2005) of the effects of parental illness on youth psychosocial adjustment, the Family Ecology Framework-Revised (FEF-R), innovatively investigating the role of *psychological flexibility* within the model. There is currently no such research in the young carer field. ***Method.*** 295 youth aged 11 to 24 with chronically ill parents completed questionnaires regarding their parent's illness, caregiving responsibilities, chronic stress, psychological flexibility, their psychosocial adjustment and family functioning. ***Results.*** Serial multiple mediation analyses provided support for the proposed mediating mechanism of psychological flexibility within the FEF-R. In fact, the adverse effects of parental illness on youth adjustment and family functioning were serially mediated by youth caregiving responsibilities, chronic stress and, most importantly, psychological flexibility. Results indicated that psychological flexibility represents a major protective factor in the link between parental illness severity and youth psychosocial adjustment – i.e. youth internalizing and externalizing problems and psychological well-being – and family functioning. ***Conclusions.*** While the other components of the FEF-R are intrinsically related to parental illness and not amenable to intervention, this study underlined the key protective role of psychological flexibility in shaping youth adjustment and family functioning in the context of parental illness. Tailored prevention and interventions programs for youth and families with parental chronic illness should target this mechanism.

3.1 Introduction

Approximately 5% to 15% of children and adolescents (aged 4-18) live with a chronically ill parent (Barkmann et al., 2007; Worsham et al, 1997). They are referred to as “young carers” and such number is most likely an underestimation, given the “hidden” nature of young caregiving and the tendency for young people not to self-identify as “caregivers” (Aldridge & Becker, 1993). Moreover, adults living with chronic illness are increasing in number every year due to advancement in medicine, hence the extent of young caregivers (Aldridge & Becker, 1993; Shifren & Kachorek, 2003). Growing with a chronically ill parent is associated with a significantly higher risk for adverse psychosocial outcomes (Chikhradze et al., 2017; Nagl-Cupal et al., 2014; Pakenham & Cox, 2015; Sieh et al., 2010). Therefore, young carers welfare represents a public health concern and it is imperative that research increases knowledge about the psychosocial adjustment of youth living with a chronically ill parent.

A major impediment to research progress in this field is that frameworks that explain how parental illness affects youth are largely undeveloped and untested. Creating and empirically examining such model is essential to inform young carer interventions that target empirically supported mechanisms which ameliorate the detrimental effects of parental illness on youth.

In addressing this research impediment, this study tested an expanded model of the effects of parental illness on youth and family functioning derived from the Family Ecology Framework (FEF; Pedersen & Revenson, 2005). The FEF is the most promising integrative framework in this field and relies on general systems, human ecology and stress/coping theories (Pedersen & Revenson, 2005). It proposes a set of *mediating processes* connecting parental illness to offspring psychosocial adjustment and family functioning. In particular, it posits that parental illness severity does not directly disrupt youth adjustment and family functioning, but instead its effect is mediated through various responses the offspring has to parental illness: (1) an increase in caregiving duties and daily hassles undertaken by children and adolescents as a result of redistribution of family roles due to parental illness; (2) perceptions of stigma related to parental illness; (3) an increase in daily hassles as routines are disrupted; and (4) most centrally, an increase in perceived stress.

There is only one study empirically testing a model derived from the FEF which provided support for these mediational processes on a sample of youth of parents with Multiple Sclerosis (Pakenham & Cox, 2012a). However, the FEF has not been tested in young caregivers of parents with various chronic illness. Therefore, the aim of this manuscript is to test in a mixed parental disease sample an expanded version of the FEF that includes the role of *psychological flexibility* as an additional serial mediator within the model: this newly adapted version of the FEF is from now on called the Family Ecology Framework-Revised (FEF-R) and is depicted in Figure 3.1.

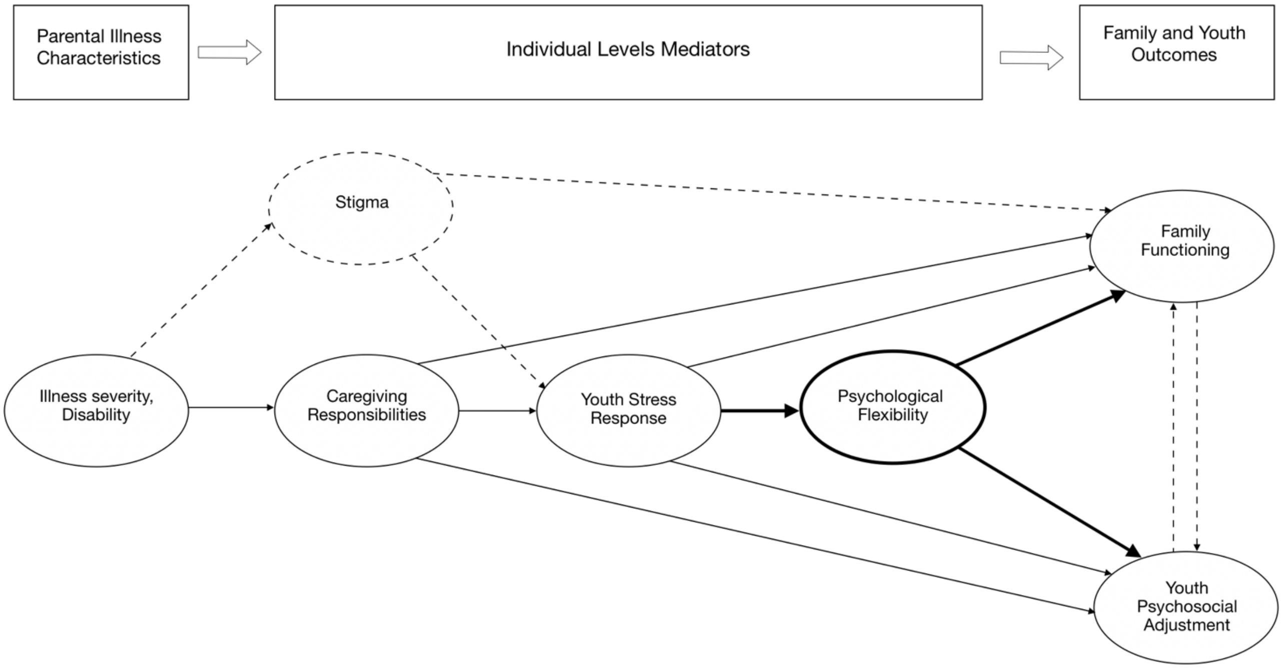

Figure 3.1 – Family Ecology Framework-Revised (FEF-R): the effects of family illness and youth caregiving on youth and family functioning. Notes: dotted lines and ellipse represent variable and paths in the original model not tested. Bolded lines and ellipse represent variable and paths added to the model. Adapted and modified by Pakenham & Cox (2012b, 2015) and Pedersen & Revenson (2005).

According to the FEF-R, parental illness severity has an indirect effect on youth adjustment and family functioning via three individual-level serial mediators: youth caregiving responsibilities (M1), youth chronic stress (M2) and, most importantly, youth psychological flexibility (M3). There is currently no such research in the young carer field. Therefore, including psychological flexibility as a key mediator in shaping youth and family functioning in the context of parental illness might lead to new theoretical and intervention development. In fact, while many of the potential mediating mechanisms in the FEF are not amenable to intervention, this study points to one that, if empirically supported, provide a pathway for developing tailored individual and family interventions.

3.1.1 Psychological Flexibility and its Association with Parental Illness

Psychological flexibility is the ability to effectively manage unhelpful thoughts and emotional discomfort in the present moment without expending effort to change them, while at the same time engaging in behavior to pursue life values, thereby enabling optimal adaptation to changing circumstances (Hayes, Strosahl, Bunting, Twohig, & Wilson, 2004). In the context of youth caregiving, psychological flexibility could represent the ability to focus on the present moment, accepting the possibility of thoughts regarding stigma related to parental illness without the intention of changing them, but instead diverting one's energy towards valued activities (e.g., playing a cherished sport), leading to greater fulfillment.

Psychological flexibility is a keystone of psychological health (Kashdan & Rottenberg, 2010) and research has shown its capability of predicting a variety of psychological outcomes, both concurrently and over a one-year interval (Hayes et al., 2006). It is a modern construct that reinforces the validity of Acceptance & Commitment Therapy (ACT; Hayes et al., 2012), one of the most recent psychological intervention belonging to the so-called 'third wave' Cognitive and Behavior Therapy (CBT) (Hayes et al., 2006). ACT aims to enhance psychological flexibility through six therapeutic mechanisms that are able to generate psychological flexibility (Arch & Craske, 2008). Research indicated that ACT interventions are related to improvement in adults' well-being (Bai, Luo, Zhang, Wu & Chi, 2019; Bohlmeijer, Fledderus, Rokx, & Pieterse, 2011; Kelson, Rollin, Ridout & Campbell, 2019) and their effects are mediated by an increase in psychological flexibility in many studies (Ciarrochi, Bilich, & Godsel, 2010; Lin, Klatt, McCracken, & Baumeister, 2018). ACT has also been shown to improve psychological flexibility in youth (Halliburton & Cooper, 2015; Livheim et al., 2014). Given the promising role of psychological flexibility in children and adolescents' psychosocial adjustment, we have included it as a final serial mediator in the FEF-R in order to test its link with youth outcomes and family functioning in the context of parental illness. Each of the other components of FEF-R will be described next.

3.1.2 Parental Illness Severity

The original FEF included both illness severity and type of diagnosis of parental illness. However, the recent literature underlined that different parental diagnoses have only a marginal effect on youth psychosocial adjustment (Pakenham & Cox, 2015; Sieh et al., 2014). In addition, within the same diagnostic label, there might be extremely different degrees of illness severity and, irrespective of diagnosis, more severe illnesses have a greater impact on the ill parents' ability to fulfill familial roles and responsibilities, placing higher demands on family members (Pedersen & Revenson, 2005). Therefore, in this study we used a mixed parental disease sample and not focus on a particular type of parental diagnosis.

3.1.3 Youth Psychosocial Adjustment and Family Functioning and their Association with Parental Illness

Research regarding youth psychosocial adjustment indicates that children with chronically ill parents display higher levels of withdrawn behaviors, somatic complaints, anxiety, depression and lower well-being when compared to children with healthy parents (Chikhradze et al., 2017; Grosse Schlarmann, Metzing-Blau, & Schnepp, 2008; Pakenham & Bursnall, 2006; Pakenham & Cox, 2012a, 2012b, 2015; Sieh et al., 2010). Due to parental illness, many young carers experience restrictions on school and leisure activities and consistently miss out on a wide range of opportunities (Kallander et al., 2018; Nicholls et al., 2017), consequently they deal with more isolation from their peers (Chalmers et al., 2000; Chen, 2016; De Roos et al., 2017; Lloyd, 2013; Pakenham, 2009; Pakenham & Burnsall, 2006).

Parental illness is related to dysfunctional family functioning (Pedersen & Revenson, 2005). Family with a chronically ill parent are more likely to display low cohesion or excessive parental involvement and higher levels of conflict between family members (Dura & Beck, 1988; Lewis, Woods, Hough, & Bensley, 1989; Sui, Wang, Liu, & Wang, 2015; Watson et al., 2006). Poor cohesion and inadequate communication in families with a chronically ill parent is, in turn, significantly associated with negative psychological outcomes in youth (Edwards et al., 2008; Harris & Zakowski, 2003; Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005).

3.1.4 Mediators of the FEF-R Model

In addition to the newly introduced role of psychological flexibility, the other mediating processes in the FEF-R are youth stigma, youth caregiving responsibilities, and youth chronic stress.

Youth stigma. Although stigma was not assessed in this study, parental illness has an influence on children relationships with their peer. In this context, youth could experience the so-called "courtesy stigma", which represents the occurrence of stigma in someone, only by virtue of proximity to the person who is ill or disable (Goffman, 1963). Therefore, children of a parent with chronic illness may engage in stigma concealment that can lead to secrecy and withdrawal which, in turn, may result in isolation and interfere with the typical development through adolescence (e.g., autonomy and individuation) (Bolas et al., 2007; Pakenham, 2009; Pakenham & Cox 2012a; Moffat & Redmond, 2017).

Caregiving responsibilities. When a parent has a chronic illness, the whole family has to readjust to the new situation: household routines often change and require redistribution of roles among family members. Children may take an unusual load of responsibilities and caregiving activities, being forced by the circumstances to substitute themselves to their parents and to care for them (Pakenham, & Bursnall, 2006; Pakenham et al., 2006, 2007). Regardless of the type of diagnosis, the burden of responsibility that young caregivers take strongly impact on their adjustment (Chikhradze et al., 2017; Pakenham & Cox, 2012a, 2012b, 2014 2015). Overload of duties and worries create a climate of tension between family members, easily leading to higher conflict and distress (Pakenham & Burnsall 2006; Power & Dell'Orto, 2004). The FEF component role redistribution among family members due to parental chronic illness has been operationalized at the individual level by Pakenham & Cox (2012a, 2015) with *youth caregiving*. According to these authors, the most important dimension of youth caregiving is *caregiving responsibilities* which refers to the psychological sense of duty or responsibility related to caregiving roles involved in contributing to family functioning (Pakenham & Cox, 2014, 2015; Pakenham et al., 2006). The FEF included daily hassles – defined as "the adoption of new roles" (Pedersen & Revenson, 2005) as a separate mediator. However, following Pakenham and Cox (2012b, 2015) advanced conceptualization of youth caregiving, role redistribution has been incorporated within the youth caregiving construct in the FEF-R.

Youth chronic stress. Youth caregiving impact on offspring chronic stress levels (de Bruin et al., 2017). In turn, higher level of chronic stress arising from caring for a chronically ill parent, are related to higher caregiving tasks and responsibilities and lower psychosocial adjustment, regardless of the type of parental diagnosis (Pakenham & Cox 2012a, 2015; Pakenham et al., 2007; Sieh et al., 2012a).

In summary, this manuscript aims to test the FEF-R with a mixed parental disease sample and to investigate the key role of *psychological flexibility* as a serial mediator in this revised framework. Specifically, we partially tested the FEF-R examining the following components: parental illness severity, three individual-level serial mediators (youth caregiving responsibilities, chronic stress, and psychological flexibility), and two outcomes (youth psychosocial adjustment – operationalized with youth internalizing and externalizing problems and youth psychological well-being – and family functioning).

3.2 Method

3.2.1 Participants and Recruitment Procedure

A total of 295 youth – aged between 11 and 24 years – living with a chronically ill parent participated in the study. Exclusion criteria were insufficient command of Italian, severe medical conditions, and cognitive impairments. Participants were recruited through several procedures across Italy: information brochures and posters in primary and secondary schools, universities and groups of youth (e.g., library, music and sport groups), illness-related local community organizations (e.g., cancer, epilepsy, diabetes, cardiovascular disease and MS self-help and family support groups), and waiting rooms of health facilities (i.e., general practitioner, hospital and specialist clinics). Participation was also advertised through social networks. Potential participants who showed interest in taking part in the study contacted the researchers by telephone or email. Subsequently, a researcher administered the questionnaires after the required informed consents were signed – i.e., by both parents if youth were underage or by youth themselves if they were 18 years old or above. Administration procedure was pencil and paper-based. The variation in recruitment methods precluded calculation of an overall response rate. The study was approved by the University of Bologna ethics committee.

Table 3.1 – Means, Standard Deviations, Correlations and Internal Consistency Among All Variables

Variable	Mean (*SD*)	α	1	2	3	4	5	6	7	8	9
1. Illness severity	2.95 (.98)										
2. Caregiving responsibilities	1.49 (.78)	.82	.12*								
3. Chronic stress	41.48 (8.01)	.85	.09	.28**							
4. Psychological flexibility	23.19 (5.51)	.77	-.02	-.21**	-.55**						
5. Internalizing problems	14.03 (9.00)	.90	.02	.33**	.63**	-.66**					
6. Externalizing problems	9.48 (6.24)	.90	.08	.22**	.46**	-.44**	.55**				
7. Psychological well-being	26.68 (4.38)	.86	-.06	-.17**	-.55**	-.43**	-.55**	-.34**			
8. Family functioning	3.11 (.49)	.88	-.06	-.17*	-.35**	.30**	-.42**	-.32**	.44**		
9. Youth gender (0 = f, 1 = m)	.43 (.50)		-.01	-.02	-.22**	.12	-.25**	.04	.17**	.12	
10. Youth age	17.61 (3.32)		.04	.04	.16**	-.05	-.01	.04	-.20**	.07	.08

Notes. * p < .05, ** p < .01.

3.2.2 Measures

Demographic information and illness characteristics. Youth indicated their age (via date of birth) and gender as well as their perception regarding severity of parental illness (i.e., "How serious is your parent health problem?") on a five-point Likert scale (1 *not at all serious,* 3 *a little bit serious*, 5 *very serious*).

Caregiving responsibilities. Caregiving responsibilities were assessed with a subscale of The Young Caregiver of Parents Inventory-Revised (YCOPI-R) an instrument measuring caregiving experiences and responsibilities in youth (Cox & Pakenham, 2014; Landi, Boccolini, Giovagnoli, Pakenham, Grandi, & Tossani, 2019b; Pakenham et al., 2006). The Italian version of the caregiving responsibilities subscale is composed by 7 items referring to the psychological sense of duty or responsibility related to roles involved in contributing to family functioning (e.g., "My parent(s) relies on me to help them with household chores"). All items are rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). The scale demonstrated good internal reliability and content and predictive validity (Landi et al., 2019b; Pakenham & Cox, 2014; Pakenham et al. 2006).

Youth chronic stress. The Chronic Stress Questionnaire for Children and Adolescents (CSQ-CA) (de Bruin, Sieh, Zijlstra, & Meijer, 2017; Hartong, Krol, Maaskant, Te Plate & Schuszler, 2003) was administered to examine chronic stress levels in youth. It is composed by 19 items with higher scores indicating more chronic stress in the past three months (e.g., "I feel that I have to do too many things at the same time", "I easily over react to situations", and "I often feel relaxed"). All items are rated on a 4-point scale (1 *not true for me at all* to 4 *completely true for me*). The CSQ-CA showed good reliability ($\alpha = .87$) and convergent and divergent validity (de Bruin, Sieh, Zijlstra & Meijer, 2017).

Psychological flexibility. The short form Avoidance and Fusion Questionnaire for Youth (AFQ-Y8) (Greco, Lambert, & Baer, 2008; Schweiger, Ristallo, Oppo, Pergolizzi, Presti, & Moderato, 2017) was used to assess youth psychological flexibility. It is a child and adolescents self-report measure that examines the ability to contact the present moment consciously and to change or persist in behavior when doing so serves valued ends. Psychological flexibility supports and maintains well-being, while psychologically inflexible behaviors facilitate the development and maintenance of mental health problems. It is composed of 8 items (e.g., “My life won’t be good until I feel happy” and “My thoughts and feelings mess up my life”). All items are rated on a 5-point scale (0 *not at all true* to 4 *very true*). For this study, a total score was obtained by summing the reverse ratings on all items, with higher scores indicating higher psychological flexibility. The scale showed good reliability (α = .90), and incremental, divergent and construct validity (Livheim, Tengström, Bond, Andersson, Dahl & Rosendahl, 2016).

Youth psychosocial adjustment outcomes. The following positive and negative youth psychosocial adjustment outcomes were assessed: internalizing and externalizing problems and psychological well-being.

Internalizing and externalizing problems. The internalizing and externalizing problem scales of the Youth Self-Report (YSR) were used to assess emotional and behavioral functioning of children and adolescents (Achenbach, 1991; Achenbach & Rescorla, 2001). The YSR internalizing problems scale reflects three dimensions: anxious/depressed (i.e., fears, nervousness and feeling of being worthless), withdrawn/depressed scale (i.e., loneliness, shyness and sadness) and somatic complaints (i.e., dizziness, vomiting and headaches). The YSR externalizing scale is composed by two factors: rule-breaking behaviours (i.e., antisocial behaviours, substance use, and lying), and aggressive behaviours (i.e., destructive behaviours, disobedience and acting out). Items are rated on a 3-point scale (0 *not true*, 1 *somewhat or sometimes true* and 2 *very true or often true*) and are summed to obtain a total score for internalizing symptoms and externalizing symptoms, with higher scores indicating more problems. The YSR has demonstrated sound psychometric proprieties including test-retest reliability (.79 to .88), internal consistency (.67 to .83) and good content, criterion-related and construct validity (Achenbach & Rescorla, 2001;

Frigerio et al., 2004). Raw scores were used in the analysis as recommended by Achenbach and Rescorla (2001).

Psychological well-being. In order to assess psychological well-being in youth we used the psychological well-being scale of the Kidscreen-27 (The Kidscreen Group Europe, 2006; Ravens-Sieberer et al., 2007). It is an instrument measuring youth health-related quality of life in five dimensions: physical well-being, psychological well-being, autonomy and parents, peers and social support and school environment. The psychological well-being subscale is composed by 7 items (e.g., "Have you felt fit and well?", "Have you been happy with the way you are?" and "Have you been able to rely on your friends?"). Items are rated on a 5-point Likert-scale (0 *not at all* to 4 *extremely* or 0 *never* to 4 *always*) with higher scores indicating greater psychological well-being. Raw scores were used in the analysis to allow for maximum variance (The Kidscreen Group Europe, 2006). The KIDSCREEN-27 was validated in a large population-based sample of youth from several European countries as well as in a sample of children and adolescents whose parents had a physical, mental, or substance abuse illness demonstrating adequate internal consistency, test-retest reliability and convergent and divergent validity (Hagen et al., 2019; Ravens-Sieberer et al., 2007).

Family functioning. Family functioning was evaluated with one dimension of the Family Assessment Device (FAD) (Epstein, Baldwin & Bishop, 1983; Grandi, Fabbri, Scortichini, & Bolzani, 2007), an instrument evaluating satisfaction or distress with how a family works. The general family functioning subscale is composed by 12 items and measures the overall health and pathology of the family system (e.g. "Planning family activities is difficult because we misunderstand each other" and "We don't get along well together"). All items are rated on a 5 point Likert scale (0 *strongly agree* to 4 *strongly disagree*), with higher scores indicating greater distress. The FAD is one of the most primarily utilized questionnaires in family functioning research and has solid test-retest reliability and concurrent reliability (Akister & Stevenson-Hinde, 1991). Moreover, studies have found that it is capable of discriminating between clinical samples and non-clinical samples as well as in families with parental cancer (Beierlein et al. 2017; Staccini, Tomba, Grandi, & Keitner 2015). In order to create an index of healthy family functioning, all items were reversed and the overall mean score was calculated, with higher scores indicating better family functioning.

3.2.3 Data Analysis

All analyses were performed in IBM SPSS 24 by using the Process macro v.3.4. First, the linear relationships between the key study variables were evaluated using Pearson's correlations. Following the FEF-R, we supposed that illness severity (X) would indirectly influence youth psychosocial adjustment and family functioning (Ys) through causally linked serial multiple mediators: youth caregiving responsibilities (M1), youth chronic stress (M2) and, most importantly, youth psychological flexibility (M3). Four models were tested, one for each dependent variable (i.e., youth internalizing and externalizing problems, youth psychological well-being and family functioning). Specifically, four serial multiple mediation analyses were performed using the Process macro (Hayes, 2017). Process model 6 was customized to make it coherent with the hypothesized FEF-R – compared to the original model, the links between illness severity and chronic stress, illness severity and psychological flexibility, caregiving responsibilities and psychological flexibility were removed (see Figure 3.2).

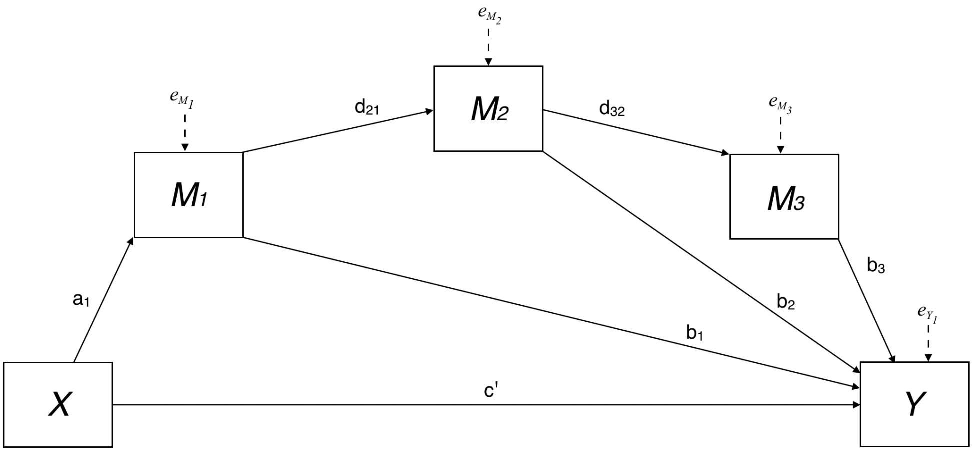

Figure 3.2 – Statistical Diagram of Customized Process Model 6. Notes: Indirect effect of X on Y through $M_1 = a_1\ b_1$; Indirect effect of X on Y through M_1 and M_2 in serial = $a_1\ d_{21}\ b_2$; Indirect effect of X on Y through M_1, M_2 and M in serial = $a_1\ d_{21}\ d_{32}\ b_3$.

Model 6 in Process macro allows to test direct and indirect effects in a serial multiple mediation model by generating path coefficients and computing bias-corrected 95% confidence intervals (CIs) and five thousand random bootstrap samples (Hayes, 2017; Preacher & Hayes, 2008). Statistical significance is established when zero is not included in the 95% CI. Path coefficients provide an index of the magnitude of the indirect effect size. Following the FEF-R, we examined the indirect effects of illness severity on youth adjustment and family functioning via caregiving responsibilities only (M1), via both caregiving responsibilities (M1) and youth chronic stress (M2) in serial and via caregiving responsibilities (M1), youth chronic stress (M2) and *psychological flexibility* (M3) in serial. Innovatively adding this last indirect effect enables to examine the contribution of psychological flexibility within the previously tested indirect paths.

3.3 Results

3.3.1 Sample Characteristics

The sample consisted of 295 youth of chronically ill parents (42.7% male with a mean age of 17.61). Parental chronic illnesses or disabilities were classified according to the International Classification of Diseases 11th Revision (ICD-11) (World Health Organization, 2018) into: cancer (37.6%), neurological diseases (18.3%), Type I and II diabetes (13.9%), mental illnesses (12.2%), cardiovascular diseases (3.4%), autoimmune diseases (3.4%), gastrointestinal diseases (2.4%), rheumatic diseases (2.4%), respiratory diseases (1.7%), infectious diseases (1.4%), physical disabilities and musculoskeletal diseases (1.3%), liver diseases (1%) and others (.3 %). Almost all youth (98 %) were native Italian. Four participants were of Lithuanian, Ukrainian, or Romanian nationality.

Means, standard deviations and Pearson correlations among all variables included in the tested models with the addition of youth age and gender are presented in Table 3.1. Small correlations were detected between psychological flexibility and externalizing problems (*r* = -

.44**), family functioning (*r* = -.39**) and caregiving responsibilities (*r* = -.21**). Psychological flexibility correlated moderately with psychological well-being (*r* =-.43**) and chronic stress (*r* = -.55**) and highly with internalizing problems (*r* = -.66**). Youth age exhibited a weak significant correlation with chronic stress (*r* = .16**). There were small significant correlations between youth gender and chronic stress (*r* = -.22**), internalizing problems (*r* = -.25**) and psychological well-being (*r* = .17**) – with girls exhibiting worse psychosocial adjustment.

3.3.2 Internalizing Problems

The first model evaluated whether caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and youth internalizing problems.

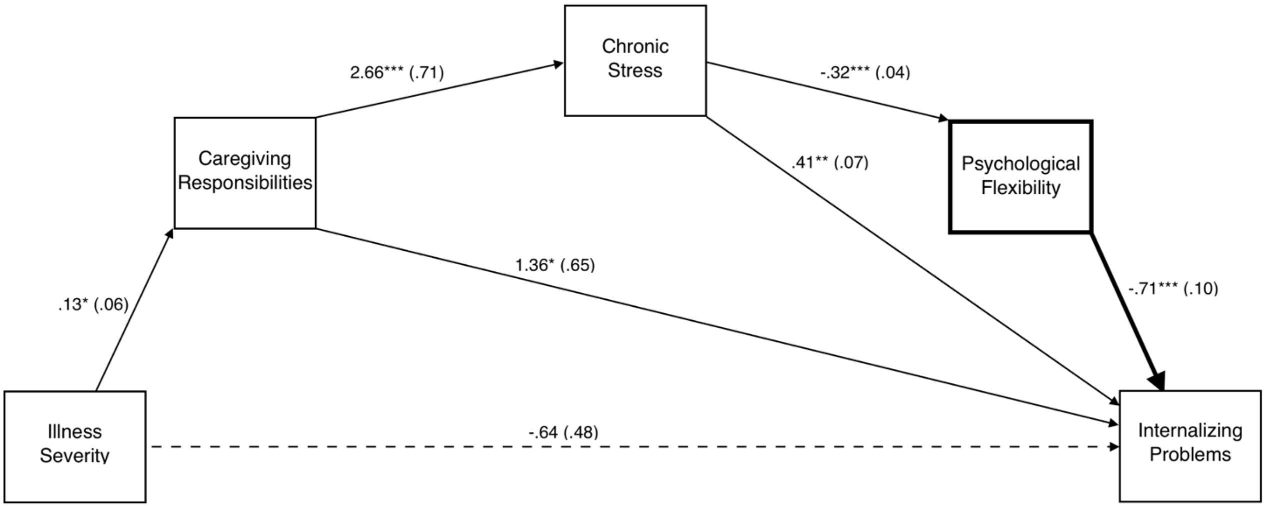

Figure 3.3 – Serial mediation linking illness severity to internalizing problems. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths.* p < .05, ** p < .01, *** p < .001.

As shown in Figure 3.3, the direct effect of illness severity on youth internalizing problems (*B* = -.64, *SE* = .48, *t* = -1.32, *p* = .19) was not significant. However, the total indirect effect of illness severity on youth internalizing problems via caregiving responsibilities, chronic stress and psychological flexibility in series was statistically different from zero, B = .41, SE = .20, 95% CI

[.056, .868] (see Table 3.2). In particular, the indirect effect of illness severity on youth internalizing problems via caregiving responsibilities alone – i.e. path indirect 1 – was significant, B = .18, SE = .12, 95% CI [.004, .471]. The indirect effect of illness severity on youth internalizing problems via caregiving responsibilities and chronic stress in serial – i.e. path indirect 2 – was significant as well, B = .15, SE = .07, 95% CI [.020, .315]. Most interestingly, the indirect effect of illness severity on youth internalizing problems via caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 3 – was significant, B = .08, SE = .04, 95% CI [.010, .184]. In other words, analyses of the indirect effects indicate that as parental illness severity increases, there is also an increase in youth caregiving responsibilities (B = .13, SE = .06, $p < .05$) which, in turn, increases youth chronic stress (B = 2.66, SE = .71, $p < .001$). Finally, increases in youth chronic stress tend to reduce youth psychological flexibility (B = -.32, SE = .04, $p < .001$). However, youth psychological flexibility ultimately decreases youth internalizing problems (B = -.71, SE = .10, $p < .001$). In sum, the inclusion of psychological flexibility in the model ultimately reduces the detrimental effect of parental illness on youth internalizing problems. In fact, the beta coefficient of the path including only caregiving responsibilities and stress is higher (B = .15) than the one including psychological flexibility as a third mediator (B = .08). Therefore, psychological flexibility represents a valuable protective factor in the link between parental illness severity and youth internalizing problems. Contrasts analyses establishing difference between the three specific indirect effects confirmed that the addition of psychological flexibility as a third serial mediator in the relationship between illness severity and youth internalizing problems created an indirect effect significantly different than the one including only the two serial mediators (B = .06, SE = .04, 95% CI [.001, .167]) (see second part of Table 3.2).

The overall model accounted for 53% of the variance in the internalizing problems score, $R^2 = .53$, $F(4, 290) = 49.97$, $p < .001$. In conclusion, the relationship between parental illness severity and youth internalizing problems was fully mediated by youth caregiving responsibilities, chronic stress and psychological flexibility in that order.

Table 3.2 – Mediation Model Linking Parental Illness Severity to Youth Internalizing Problems via Three Serial Mediators (Caregiving Responsibilities, Chronic Stress and Psychological Flexibility)

	Caregiving Responsibilities (M_1)		Chronic Stress (M_2)		Psychological Flexibility (M_3)		Internalizing Problems (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI
Illness Severity (X)	.134* (.063)	.100, .259					-.638 (.483)	-1.592, .316
Caregiving Responsibilities (M_1)			2.661*** (.707)	1.266, 4.057			1.357* (.592)	.188, 2.526
Chronic Stress (M_2)					-.316*** (.043)	-.400, -.233	.407*** (.066)	.277, .538
Psychological Flexibility (M_3)							-.713*** (.101)	-.913, -.514
Constant	1.125*** (.193)	.744, 1.506	37.282*** (1.221)	34.873, 39.691	36.361*** (1.788)	32.833, 39.890	13.590** (4.537)	4.636, 22.544
	$R^2 = .025$ $F\,(1,293) = 4.544$, $p < .05$		$R^2 = .073$ $F\,(1,293) = 14.158$, $p < .001$		$R^2 = .237$ $F\,(1,293) = 55.521$, $p < .001$		$R^2 = .532$ $F\,(4,290) = 49.973$, $p < .001$	

Indirect Effects	Coeff.	95 % CI
Total indirect Effects	.408 (.203)	.056, .868
Ind 1 X → Caregiving (M_1) →Y	.182 (.121)	.004, .471
Ind 2 X → Caregiving (M_1) → Stress (M_2) → Y	.145 (.075)	.020, .315
Ind 3 X→Caregiving (M_1) → Stress (M_2) → ***Flexibility* (*M_3*)** → Y	.081 (.044)	.010, .184
Contrasts		
Indirect 1 minus Indirect 2	.037 (.111)	-.167, .295
Indirect 1 minus Indirect 3	.102 (.107)	-.061, .355
Indirect 2 minus Indirect 3	.065 (.044)	.001, .167

Notes. *p < .05, **p < .01, ***p < .001. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

3.3.3 Externalizing Problems

The second model tested whether caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and youth externalizing problems.

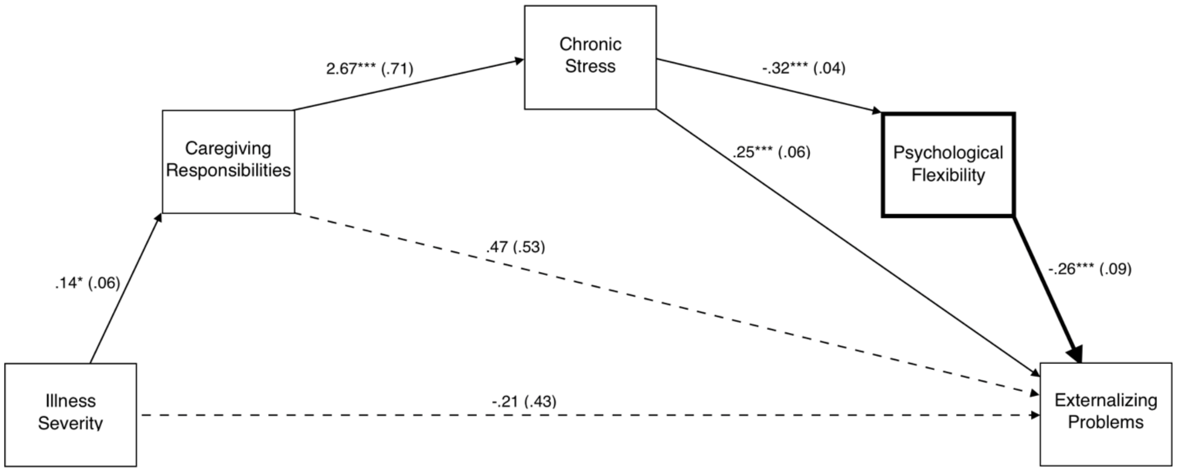

Figure 3.4 – Serial mediation linking illness severity to externalizing problems. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths.* $p < .05$, ** $p < .01$, *** $p < .001$.

As depicted in Figure 3.4, the direct effect of illness severity on youth externalizing problems (*B* = -.21, *SE* = .43, *t* = -.49, *p* = .62) was not significant. However, the total indirect effect was statistically significant, B = .19, SE = .11, 95% CI [.010, .446] (see Table 3.3). In particular, the indirect effect of illness severity on youth externalizing problems through caregiving responsibilities alone – i.e. path indirect 1 – was not significant, B = .07, SE = .08, 95% CI [-.078, .263] but the indirect effect of illness severity on youth externalizing problems via caregiving responsibilities and chronic stress – i.e. path indirect 2 – was significant, B = .09, SE = .05, 95% CI [.015, .204]. Most centrally, the indirect effect of illness severity on youth externalizing problems via caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 3 – was significant, B = .03, SE = .02, 95% CI [.003, .077]. In sum, psychological flexibility exerts its impact on youth externalizing problems with the same underlying indirect effect emerged for internalizing problems but with a lower magnitude – beta coefficient for the link between psychological flexibility and internalizing problems is -.71 while that for externalizing problems is -.26. Therefore, psychological flexibility can be considered a significant protective factor in the link between parental illness severity and youth externalizing problems as well. Contrasts analyses revealed that the addition of psychological flexibility as a third serial mediator in the relationship between illness severity and youth externalizing problems produced an indirect effect significantly different than the one including only two serial mediators (B = .06, SE = .04, 95% CI [.002, .161]; see second part of Table 3.3).

The overall model accounted for 24% of the variance in the externalizing problems score, $R^2 = .24$, $F(4, 290) = 14.09$, $p < .001$. In conclusion, the relationship between parental illness severity and youth externalizing problems was serially mediated by youth caregiving responsibilities, chronic stress and psychological flexibility in that order.

Table 3.3 – Mediation Model Linking Parental Illness Severity to Youth Externalizing Problems via Three Serial Mediators (Caregiving Responsibilities, Chronic Stress and Psychological Flexibility)

	Caregiving Responsibilities (M_1)		Chronic Stress (M_2)		Psychological Flexibility (M_3)		Externalizing Problems (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI
Illness Severity (X)	.143* (.063)	.019, .268					-.211 (.428)	-1.056, .635
Caregiving Responsibilities (M_1)			2.620*** (.713)	1.213, 4.028			.470 (.525)	-.566, 1.507
Chronic Stress (M_2)					-.316*** (.043)	-.340, -.231	.247*** (.058)	.132, .362
Psychological Flexibility (M_3)							-.260** (.089)	-.436, -.084
Constant	1.107*** (.063)	.727, 1.486	37.367*** (1.234)	34.931, 39.802	36.318*** (1.799)	32.768, 39.867	5.410 (3.999)	-2.484, 13.303
	$R^2 = .028$ F (1,293) = 5.191, $p < .05$		$R^2 = .071$ F (1,293) = 13.501, $p < .001$		$R^2 = .235$ F (1,293) = 54.689, $p < .001$		$R^2 = .244$ F (4,290) = 14.087, $p < .001$	

Indirect Effects	Coeff.	95 % CI
Total indirect Effects	.191 (.113)	.009, .446
Ind 1 X → Caregiving (M_1) →Y	.067 (.082)	-.078, .263
Ind 2 X → Caregiving (M_1) → Stress (M_2) → Y	.093 (.049)	.015, .204
Ind 3 X→Caregiving (M_1) → Stress (M_2) → ***Flexibility (M_3)*** → Y	.031 (.020)	.003, .077
Contrasts		
Indirect 1 minus Indirect 2	-.025 (.086)	-.212, .145
Indirect 1 minus Indirect 3	.037 (.083)	-.124, .226
Indirect 2 minus Indirect 3	.062 (.042)	.002, .161

Notes. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

3.3.4 Psychological Well-Being

The third model investigated whether caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and youth psychological well-being.

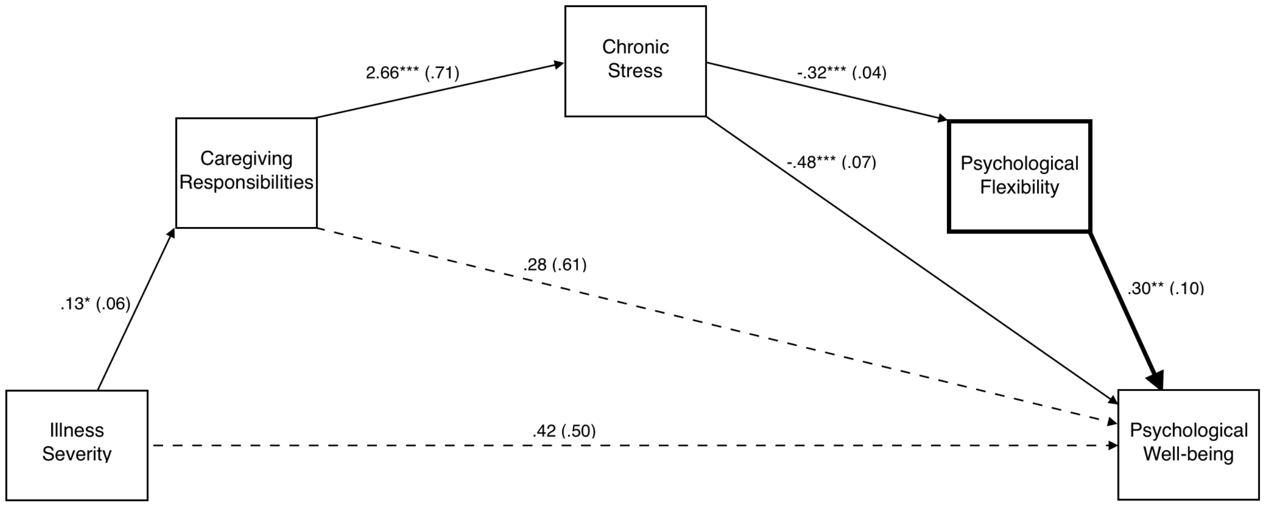

Figure 3.5 – Serial mediation linking illness severity to psychological well-being. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths.* $p < .05$, ** $p < .01$, *** $p < .001$.

As represented in Figure 3.5, the direct effect of illness severity on youth psychological well-being (*B* = .42, *SE* = .50, *t* = .85, *p* = .39) was not significant. The total indirect effect was not statistically significant, B = -.17, SE = .14, 95% CI [-.493, .033] as well as the indirect effect of illness severity on youth psychological well-being via caregiving responsibilities only – i.e. path indirect 1 – B = .04, SE = 0.9, 95% CI [-.164, .214]. However, the indirect effect of illness severity on youth psychological well-being through caregiving responsibilities and chronic stress – i.e. path indirect 2 – was significant, B = -.17, SE = .08, 95% CI [-.366, -.024]. Most interestingly, the indirect effect of illness severity on youth psychological well-being via caregiving responsibilities, chronic stress and psychological flexibility – i.e. path indirect 3 – was significant, B = -.03, SE = .02, 95% CI [-.084, -.003] (see Table 3.4).

Table 3.4 – Mediation Model Linking Parental Illness Severity to Youth Psychological Well-Being via Three Serial Mediators (Caregiving Responsibilities, Chronic Stress and Psychological Flexibility)

	Caregiving Responsibilities (M_1)		Chronic Stress (M_2)		Psychological Flexibility (M_3)		Psychological Well-Being (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI
Illness Severity (X)	.134* (.063)	.010, .259					.422 (.495)	-.555, 1.400
Caregiving Responsibilities (M_1)			2.661*** (.707)	1.266, 4.057			.280 (.607)	-.917, 1.478
Chronic Stress (M_2)					-.316*** (.043)	-.400, -.233	-.476*** (.068)	-.609, -.342
Psychological Flexibility (M_3)							.299** (.103)	.095, .503
Constant	1.125*** (.193)	.744, 1.506	37.282*** (1.221)	34.873, 39.691	36.361*** (1.788)	32.833, 39.890	56.759*** (4.647)	47.587, 65.930
	$R^2 = .025$ $F(1,293) = 4.544$, $p < .05$		$R^2 = .073$ $F(1,293) = 14.158$, $p < .001$		$R^2 = .237$ $F(1,293) = 55.521$, $p < .001$		$R^2 = .367$ $F(4,290) = 25.520$, $p < .001$	

Indirect Effects	Coeff.	95 % CI
Total indirect Effects	-.166 (.138)	-.493, .033
Ind 1 X → Caregiving (M_1) →Y	.038 (.091)	-.164, .215
Ind 2 X → Caregiving (M_1) → Stress (M_2) → Y	-.170 (.090)	-.366, -.024
Ind 3 X→Caregiving (M_1) → Stress (M_2) → ***Flexibility* (M_3)** → Y	-.034 (.022)	-.084, -.003
Contrasts		
Indirect 1 minus Indirect 2	.208 (.130)	-.013, .493
Indirect 1 minus Indirect 3	.072 (.095)	-.129, .259
Indirect 2 minus Indirect 3	-.136 (.077)	-.308, -.017

Notes. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

In sum, the inclusion of psychological flexibility in the model ultimately reduces the detrimental effect of parental illness on youth psychological well-being. In fact, the beta coefficient of the path including only caregiving responsibilities and stress is lower (B = -.17) than the one including psychological flexibility as a third mediator (B = -.03). Therefore, psychological flexibility represents a major protective factor in the link between parental illness severity and youth psychological well-being as well. The same pattern of contrasts analyses uncovered for the first and second model also emerged here: the inclusion of psychological flexibility as a third serial mediator in the relationship between illness severity and youth psychological well-being produced an indirect effect significantly different than the one including only two serial mediators (B = -.14, SE = .08, 95% CI [-.308, -.017] (see second part of Table 3.4).

The overall model accounted for 37% of the variance in the youth psychological well-being score, $R^2 = .37$, $F(4, 290) = 25.52$, $p < .001$. In sum, the relationship between parental illness severity and youth psychological well-being was fully mediated by youth caregiving responsibilities, chronic stress and psychological flexibility in serial.

3.3.5 Family Functioning

The fourth model investigated whether caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and family functioning.

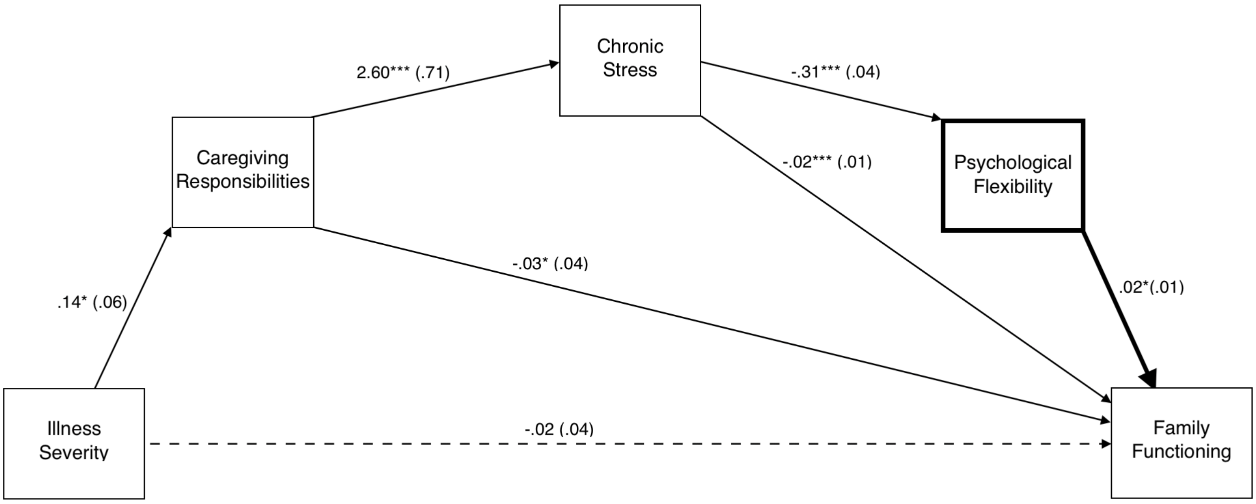

Figure 3.6 – Serial mediation linking illness severity to family functioning. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths.* p < .05, ** p < .01, *** p < .001.

As illustrated in Figure 3.6, the direct effect of illness severity on family functioning (*B* = -.02, *SE* = .04, *t* = -.50, *p* = .62) was not significant. However, the total indirect effect was statistically significant, B = -.01, SE = .01, 95% CI [-.032, .001]. In particular, the indirect effect of illness severity on family functioning via caregiving responsibilities alone – i.e. path indirect 1 – was significant, B = .00, SE = .01, 95% CI [-.02, .01]. The indirect effect of illness severity on family functioning through caregiving responsibilities and chronic stress – i.e. path indirect 2 – was also significant, B = .01, SE = .00, 95% CI [.013, -.001]. Most interestingly, the indirect effect of illness severity on family functioning via caregiving responsibilities, chronic stress and psychological flexibility – i.e. path indirect 3 – was significant, B = -.002, SE = .001, 95% CI [-.005, -.000] (see Table 3.5).

Table 3.5 – Mediation Model Linking Parental Illness Severity to Family Functioning via Three Mediators (Caregiving Responsibilities, Chronic Stress and Psychological Flexibility)

	Caregiving Responsibilities (M_1)		Chronic Stress (M_2)		Psychological Flexibility (M_3)		Family Functioning (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI
Illness Severity (X)	.145* (.063)	.020, .270					-.018 (.036)	-.090, .053
Caregiving Responsibilities (M_1)			2.600*** (.710)	1.199, 4.001			-.031* (.044)	-.118, .057
Chronic Stress (M_2)					-.314*** (.043)	-.399, -.229	-.015** (.005)	-.025, -.006
Psychological Flexibility (M_3)							.016* (.008)	.001, .031
Constant	1.099*** (.194)	.744, 1.506	37.282*** (1.221)	35.051, 39.897	36.244*** (1.817)	32.659, 39.830	3.474*** (.337)	2.809, 4.140
	$R^2 = .029$ $F(1,293) = 5.243$, $p < .05$		$R^2 = .070$ $F(1,293) = 13.413$, $p < .001$		$R^2 = .237$ $F(1,293) = 55.521$, $p < .001$		$R^2 = .150$ $F(4,290) = 7.658$, $p < .001$	
Indirect Effects					Coeff.		95 % CI	
Total indirect Effects					-.012 (.009)		-.032, .001	
Ind 1 X → Caregiving (M_1) → Y					-.005 (.007)		-.021, .007	
Ind 2 X → Caregiving (M_1) → Stress (M_2) → Y					-.006 (.003)		-.013, -.001	
Ind 3 X → Caregiving (M_1) → Stress (M_2) → ***Flexibility* (M_3)** → Y					-.002 (.001)		-.005, -.000	
Contrasts								
Indirect 1 minus Indirect 2					.001 (.007)		-.014, .016	
Indirect 1 minus Indirect 3					-.003 (.007)		-.019, .010	
Indirect 2 minus Indirect 3					-.004 (.003)		-.011, .001	

Notes. * p < .05, ** p < .01, *** p < .001. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

In sum, the inclusion of psychological flexibility in the model ultimately reduces the detrimental effect of parental illness on family functioning but with a lower magnitude compared to youth adjustment – the beta coefficient for the link between psychological flexibility and internalizing problems is only .02. Therefore, youth psychological flexibility seems to exert a protective role against the detrimental impact of parental illness severity on overall family functioning. However, contrasts analyses did not establish a significant difference in the indirect effects produced by the path including psychological flexibility as a third serial mediator and the one constituted by only two serial mediators (B = -.004, SE = .003, 95% CI [-.011, .001]; see second part of Table 3.5).

The overall model accounted for 15% of the variance in the total family functioning score, $R^2 = .15$, $F(4, 290) = 7.66$, $p < .001$. In conclusion, the relationship between parental illness severity and family functioning was fully mediated by youth caregiving responsibilities, chronic stress and psychological flexibility in serial.

3.4 Discussion

This study partially tested the FEF-R with a mixed parental disease sample innovatively examining the role of *psychological flexibility* as a serial mediator in the relationship between parental illness severity and youth psychosocial adjustment and family functioning. The results of path analyses provided support for the proposed serial mediating mechanisms of psychological flexibility within the FEF-R. As predicted, the adverse effects of parental illness on youth adjustment and family functioning were serially mediated by youth caregiving responsibilities, chronic stress, and most importantly, psychological flexibility. Therefore, psychological flexibility represents a major protective factor in the link between parental illness severity and youth psychosocial adjustment and family functioning. In fact, the inclusion of psychological flexibility in the models ultimately lowers the increase in internalizing and externalizing problems and the decrease in psychological well-being – in other words, psychological flexibility reduces the detrimental effect of parental illness on youth psychosocial adjustment. Noteworthy, the magnitude of this reduction is the highest for youth psychological well-being (as psychological flexibility raises by .14 the beta coefficient of the indirect effect), followed by youth internalizing problems (as psychological flexibility lowered the beta coefficient of the indirect effect by .07). Even though youth psychological flexibility slightly indirectly impact overall family functioning, it is nonetheless a promising result.

Overall, parental illness severity did not exert a direct effect towards any of the considered outcomes, meaning that for each model a full mediation of caregiving responsibilities, chronic stress and psychological flexibility in serial was established. Interestingly, an indirect effect of caregiving responsibilities alone, emerged only for youth internalizing problems and family functioning. The same pattern of results has been uncovered in another study pertaining to youth somatization but not family functioning (Pakenham & Cox, 2012a). Therefore, the link between caregiving responsibilities youth internalizing problems and general family functioning should be further investigated.

Future research should test other possible mediators and moderators within the FEF-R, such as youth coping strategies, social support and benefit finding, and examine whether these potential mediators or moderators have a direct or indirect effect on youth and family outcomes. While coping strategies and social support have been widely investigated in the caregiving literature, only one promising study indicated the association of benefit finding and youth caregiving with youth adjustment to parental illness (Pakenham & Cox, 2018). Finally, future studies should include longitudinal assessment in order to confirm causality of results over time.

This study has some limitations that should be discussed. First, our sample was nonrandomized as participants were recruited only if they lived with a chronically ill parent. Second, it only focused on youth self-report variables rather than including parental perspective. Third, using the Process macro for path analysis only permitted to test for observed variables and one dependent variable at a time while other structural equation modeling programs permit to examine latent variables and an overall model fit that included all dependent variables (Hayes, Montoya, & Rockwood, 2017). Another final limitation is the assessment of youth caregiving, including only one dimension of the Young Carer of Parents Inventory-Revised (YCOPI-R; Cox

& Pakenham, 2014; Pakenham et al., 2006). A more advanced conceptualization of youth caregiving in the context of parental illness suggests it is a multidimensional variable with different relationships between caregiving domains and youth outcomes (e.g., Ireland & Pakenham, 2010a; Pakenham & Cox, 2015).

Despite these limitations, this study has several strengths. It was the first in the young carers field to harness a core construct from the burgeoning ACT literature that spans over the last 15 years and demonstrate its relevance to shaping youth and family functioning in the context of parental illness. Secondly, it used a mixed parental diagnosis sample and assessed both positive and negative youth psychosocial adjustment outcomes as well as a family-level outcome. Third, including psychological flexibility as the last serial mediator allowed to identify its impact upon the other mediators in a chain of indirect effects and its ultimate unique contribution to youth adjustment and family functioning.

3.4.1 Conclusion

This study represents an important advancement in the creation of an empirically supported framework to understand the impact of parental illness on youth and family adjustment. This manuscript innovatively included *psychological flexibility* as a serial mediator in the FEF-R. Results indicated that psychological flexibility represents a major protective factor in the context of parental chronic illness. Its importance is further underlined due to the fact that, compared to the other components of the FEF-R, psychological flexibility is a mechanism concretely and promisingly amenable for intervention. Therefore, the results of this study have implications for potential tailored interventions programs targeting psychological flexibility in the young carers field – at youth, parent and family levels.

Chapter 4

An Examination of the Tripartite Nature of Youth Caregiving in the Context of Parental Illness

Abstract

Objective. Informed by the Family Ecology Framework-Revised (FEF-R), a model of the effects of parental illness on youth psychosocial adjustment, this study further refined the conceptualization of *youth caregiving* by proposing that it is a tri-partite construct – comprising caregiving responsibilities, experiences, and tasks. Given the dearth of research on the tripartite nature of youth caregiving, this study aimed to examine the individual and joint effects of each component within the FEF-R. ***Method.*** A total of 295 youth (mean age 17.61 years) who had a parent with a chronic illness completed questionnaires regarding their parent's illness, caregiving, chronic stress, psychological flexibility, and their psychosocial adjustment. ***Results.*** Serial multiple mediation analyses provided support for each of the proposed components of youth caregiving. In fact, the adverse effects of parental illness on youth adjustment were serially mediated by caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress and psychological flexibility in that order. Caregiving responsibility confirmed its key role as a bridge between the tripartite components of caregiving and the other mediators linking illness severity to youth outcomes. Caregiving experiences alone had in indirect effect on youth internalizing problems and psychological well-being, while the indirect path via both caregiving experiences and tasks was unexpectedly associated with a decrease in youth externalizing problems and an increase in psychological well-being. ***Conclusions.*** This manuscript clarified the nature of youth caregiving and examined its tripartite structure within the FEF-R, confirming the costs and benefits of youth caregiving previously reported in the young carer literature. These results have clinical implications with respect to the need for interventions that mitigate adverse and cultivate positive effect of youth caregiving.

4.1 Introduction

Approximately 5% to 15% of children and adolescents (aged 4-18) live with a parent who is affected by a chronic illness (Barkmann et al., 2007; Worsham et al., 1997). They are referred to as "young carers" and such number is most likely an underestimation, given the "hidden" nature of young caregiving and the tendency for young people not to self-identify as "caregivers" (Aldridge & Becker, 1993). Given the increase in numbers of adults living with chronic illness worldwide, estimates will rise steadily (Shifren & Kachorek, 2003; WHO, 2016). Most of these youth care for a parent with illness or disability and are at elevated risk for mental, social, educational and employment difficulties that persist well into adulthood (Chikhradze et al., 2017; Nagl-Cupal et al., 2014; Pakenham & Cox, 2015; Sieh et al., 2010). Hence, the plight of young carers is recognized as a growing social crisis that has forced their inclusion on national and international political agendas; it is imperative that research targets young carer welfare.

A major impediment to research progress in this field is that, although previous research indicates that *youth caregiving* is central in frameworks that explain how parental illness affects youth psychosocial outcomes, a clear conceptualization and well-developed measures that tap this construct in the context of parental chronic illness is lacking. To address this weakness, this study further refines the conceptualization and measurement of youth caregiving.

In the context of parental illness, families often meet illness demands by redistributing roles among family members; consequently, children may take on caregiving activities and become young caregiver (Pakenham et al., 2006). For this reason, role redistribution has been operationalized by Pakenham and colleagues as *youth caregiving* (Cox & Pakenham, 2014; Pakenham & Cox, 2012a) and is assessed at the individual level but taps family processes. Nonetheless, youth caregiving has emerged as a poorly conceptualized amorphous construct. Pakenham & Cox (2014, 2015) have advanced the conceptualization of youth caregiving by proposing that it is a tri-partite construct comprising: caregiving responsibilities, caregiving experiences, and caregiving tasks. However, to date, no study has tested the simultaneous effects of all three components on youth psychosocial adjustment nor included them in a formal model in this context. This study innovatively tested the tripartite nature of youth caregiving by examining the individual and joint effects of each component within a model analyzing the impact of parental illness on youth psychosocial adjustment.

The most promising integrative model in this field is the Family Ecology Framework (FEF; Pedersen & Revenson, 2005). It relies on general systems, human ecology and stress/coping theories and proposes a set of *mediating processes* connecting parental illness to offspring psychosocial adjustment and family functioning (Pedersen & Revenson, 2005). Pakenham and colleagues (Landi et al., 2019a) have proposed a revised version of this model, the Family Ecology Framework-Revised (FEF-R) which is depicted in Figure 4.1.

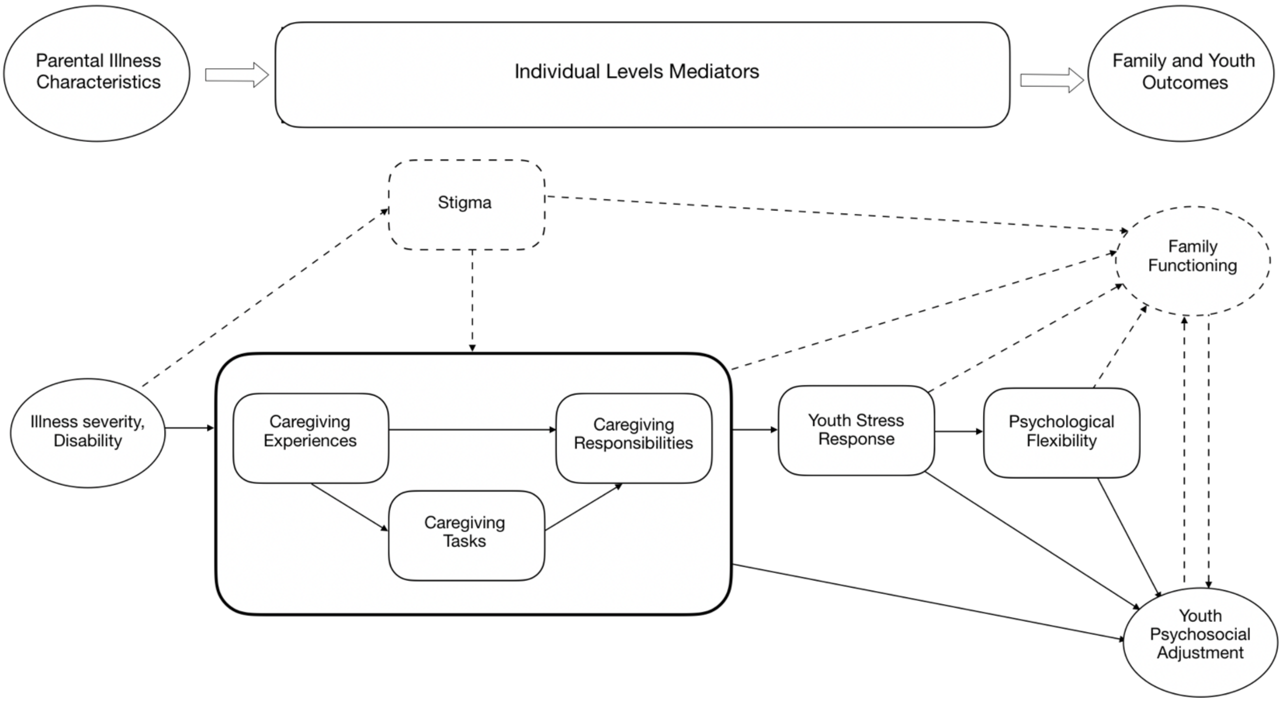

Figure 4.1 – Tripartite nature of youth caregiving within the Family Ecology Framework-Revised (FEF-R). Notes: dotted lines and ellipse represent variable and paths in the original model not tested. Adapted and modified by Pakenham & Cox (2012b, 2015) and Pedersen & Revenson (2005).

In particular, the FEF-R posits that parental illness severity does not directly disrupt youth adjustment and family functioning, but instead its effect is mediated through: (1) youth caregiving – newly tested in this study in its tripartite nature; (2) perceptions of stigma related to parental illness; (3) perceived chronic stress; and (4) youth psychological flexibility. Only two studies provided support for these mediational processes but they have considered only one component of youth caregiving (Landi et al., 2019a; Pakenham & Cox, 2012a). For this reason, this study aimed to test the role of all three dimensions of youth caregiving within the FEF-R.

A description of each component of youth caregiving is presented next and is also reported in Table 4.1. The first component of youth caregiving is *caregiving responsibilities* which is defined as the psychological sense of duty or responsibility related to roles involved in contributing to family functioning and is operationalized with a subscale of the Young Carer of Parents Inventory-Revised (YCOPI-R; Pakenham et al., 2006; Cox & Pakenham, 2014), an instrument assessing the psychosocial components of youth caregiving. The second component of youth caregiving is *caregiving experiences* which reflects a range of psychosocial experiences emerging from taking on caregiving responsibilities. Youth caregiving experiences are operationalized by all the subscale of the YCOPI-R except for the caregiving responsibilities subscale. Specifically, there are five caregiving experiences that all children may potentially experience – i.e., perceived maturity, worry about parents, global activity restrictions, study/work activity restrictions and isolation, while there is also a subset of caregiving experiences more specific to youth caregiving in the context of parental illness – i.e., caregiving guilt, isolation, confidence, discomfort, and information/support needs (Cox & Pakenham, 2014; Pakenham et al., 2006). Finally, *caregiving tasks* is the third component of youth caregiving and refers to the specific caregiving activities performed by young people in the context of parental illness/disability.

Table 4.1 – Tripartite Nature of Caregiving

Youth Caregiving Components	Description
• **Caregiving Responsibilities**	Refers to the psychological sense of duty or responsibility related to roles involved in contributing to family functioning – caregiving responsivity subscale of YCOPI-R, Part A
• **Caregiving Experiences**	Refers to a range of psychosocial experiences emerging from taking on caregiving responsibilities. It is composed by a set of general caregiving experiences and a subset of specific experiences of living with an ill parent **General Caregiving Experiences** – all other subscales of YCOPI-R, Part A: – *Perceived maturity*: Refers to the "adult child" theme and how taking on adult roles within the family can foster a sense of independence and personal growth – *Worry about parents*: Refers to worry and hypervigilance about the parent's safety and health and monitoring of their parent for signs of health changes – *Activity restrictions global*: Refers to the interference of the caregiving role in many areas such as leisure time and socializing – *Activity restrictions study/work*: Refers to the interference of the caregiving role with school and/or work – *Isolation*: Refers to feelings of aloneness and difficulties in sharing caregiving experiences with others **Caregiving Experiences of Living with an Ill Parent** – YCOPI-R, Part B: – *Caregiving guilt*: Refers to relentless and inescapable caregiving, how young caregivers feel compelled to care for their parent and the associated guilt when they engage in noncaregiving activities – *Caregiving isolation*: Refers to the "hidden" nature of young caregiving and difficulties talking about the parent's illness or asking people for help – *Caregiving confidence*: Refers to the positive outcomes of young caregiving; the enhanced self-efficacy through the development of new skills and knowledge – *Caregiving discomfort*: Refers to the distress and stigma associated with caregiving – *Caregiving information/support*: Refers to young caregivers' needs for support and information about their parent's medical condition and treatment
• **Caregiving Tasks**	Refers to specific caregiving activities performed by young people in the context of family illness/disability – YACS It is composed by the following subscales: – *Instrumental*: Refers to practical activities of daily living (e.g. transportation, managing finances and supervising medications) – *Social-emotional*: Refers to providing emotional support and companionship (e.g., ensuring the ill parent is happy, gainfully occupied and safe) – *Personal-intimate*: Refers to personal care tasks (e.g. toileting, changing dressings and assisting with mobility) – *Domestic-household*: Refers to basic domestic duties (e.g. laundry, cooking, cleaning) and family care tasks (e.g. supervising other siblings)

Notes. YCOPI-R = Young Carer of Parents Inventory-Revised (Cox & Pakenham, 2014); YACS = The Youth Activities of Caregiving Scale (Ireland & Pakenham, 2010a). Adapted and modified from Cox & Pakenham, 2014; Ireland & Pakenham, 2010a; Landi et al. 2019a.

Ireland & Pakenham (2010a) have operationalized these care tasks with the Youth Activities of Caregiving Scale (YACS) and grouped them into four categories: instrumental care tasks, such as practical activities of daily living (e.g. transportation, managing finances and supervising medications); social-emotional care tasks, such as providing emotional support and companionship (e.g., ensuring the ill parent is happy, gainfully occupied and safe); personal-intimate care tasks, such as parental self-care tasks (e.g. toileting, changing dressings and assisting with mobility); and domestic-household care tasks such as basic domestic duties (e.g. laundry, cooking, cleaning) as well as other family care tasks (e.g. supervising siblings).

Conceptually, caregiving responsibilities thus refers to the psychological sense of responsibilities associated with the caregiving role, whereas the other caregiving experiences tap the broader psychosocial factors that influence and maintain the caregiver role. Caregiving tasks is the behavioral component of youth caregiving and quantifies the level of involvement in specific caregiving activities youth may undertake. This last component has been the most studied in research (Joseph et al., 2009). In fact, considerable studies indicate that youth with an ill parent report higher levels of caregiving tasks than youth of healthy parents and that higher youth caregiving tasks is related to poorer youth well-being in the context of parental illness (e.g. Ireland & Pakenham, 2010b; Kallander et al., 2018; Pakenham et al., 2006).

Fewer studies have examined the roles of the caregiving responsibilities and experiences underlying that they are intensified with the presence of an ill parent relative to ‘healthy’ parents and that both constructs are related to poorer youth adjustment (Pakenham & Cox, 2014, 2015). Furthermore, the association between higher caregiving responsibilities and poorer youth adjustment was found to be independent of the effects of parental illness itself (Landi et al., 2019a; Pakenham & Cox, 2012a). Other research has shown youth caregiving can also be associated with positive outcomes (Cassidy & Giles, 2013; Pakenham & Bursnall, 2006; Pakenham and Cox, 2018; Pakenham et al., 2006, 2007). Specifically, while an increase in caregiving responsibilities in general have detrimental effects on adjustment, they might also trigger the possibility that young caregivers search for meaning in their caregiving activities and, thereby, find benefits in their role. In fact, a study underlined that benefit finding could in part ameliorate the negative impact of caregiving on youth adjustment outcomes (Pakenham & Cox, 2018). In addition, caregiving experiences such increased confidence or perceived maturity in caring have been associated with pro-social behavior, social support and strengthened relationships (Pakenham & Cox, 2014; Pakenham et al., 2006). Finally, more involvement in care tasks – especially social/emotional – has also been related to positive outcomes (Ireland & Pakenham, 2010b).

However, while the literature provided support for the role of each of the proposed dimensions of youth caregiving, no study has tested the simultaneous effects of all three components on youth adjustment. For this reason, this study is conceptually innovative as it transformed the key but amorphous construct youth caregiving into a theoretically tight and measurable concept embedded within a broader conceptual framework of the effects of parental illness on youth. Building on previous work on youth caregiving (Pakenham & Cox, 2012a, 2015), this study tested a refined conceptualization and measurement of youth caregiving using a tri-partite structure consisting of caregiving responsibilities, experiences, and tasks. There is currently no such research in the young carer field.

4.2 Method

4.2.1 Participants and Recruitment Procedure

A total of 295 youth living with a parent affected by a chronic illness or disability – aged between 11 and 24 participated in the study. Exclusion criteria were insufficient command of Italian, severe medical conditions, and cognitive impairments. Participants were recruited through several procedures across Italy: information brochures and posters in primary and secondary schools, universities and groups of youth (e.g., library, music and sport groups), illness-related local community organizations (e.g., cancer, epilepsy, diabetes, cardiovascular disease and MS self-help and family support groups), and waiting rooms of health facilities (i.e., general practitioner, hospital and specialist clinics). Participation was also advertised through social networks. Potential participants who showed interest in taking part in the study contacted the researchers by telephone or email. Subsequently, a researcher administered the questionnaires after the required informed consents were signed – i.e., by both parents if youth were underage or by youth themselves if they were 18 years old or above. Administration procedure was pencil and paper based. The variation in recruitment methods precluded calculation of an overall response rate. The study was approved by the University of Bologna ethics committee.

4.2.2 Measures

Demographic information and illness characteristics. Youth indicated their age (via date of birth) and gender as well as their perception regarding severity of parental illness (i.e., "How serious is your parent health problem?") on a five-point Likert scale (1 *not at all serious,* 3 *a little bit serious*, 5 *very serious*).

Caregiving responsibilities and experiences. The Italian version of Young Caregiver of Parents Inventory-Revised (YCOPI-R) (Cox & Pakenham, 2014; Landi et al., 2019a; Pakenham et al., 2006) is a self-report instrument that assesses caregiving responsibilities and experiences and is divided in two parts. Part A is composed of 24 items measuring generic youth caregiving responsibilities and experiences and can be completed by all youth irrespective of family caregiving demands. It contains 6 factors: caregiving responsibilities (7 items; e.g. "My parent(s) relies on me to help them with household chores*"*), perceived maturity (3 items; e.g. "I am more grown up and mature than others my age"), worry about parents (3 items; e.g. "I always wonder if my parent (s) is/are safe*"*), activity restrictions global (3 items; e.g. "Helping my parent stops me from doing a lot of the things I want to do"), activity restrictions study/work (5 items; e.g. "I sometimes miss school/work because I have to help my parents") and isolation (3 items; e.g. "Other people do not understand me and my situation*"*). Part B includes 15 items assessing family caregiving experiences more specific to youth who care for a parent with a significant medical condition and is therefore only completed by children who have a parent with such a condition. It is composed of five factors: caregiving guilt (2 items; e.g. "I feel guilty when I go out and have fun"), caregiving isolation (4 items; e.g. "I find it difficult to ask other people for help in my caring role when I need it"), caregiving confidence (4 items; e.g. "I know exactly what to do to help my parent"), caregiving discomfort (3 items; e.g. "I wish that I did not have to help my parent as much as I do"), and caregiving information (2 items; e.g. "I wish I had more information about my parent's illness/disability"). All items are rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). The scale demonstrated good internal reliability and content and predictive validity (Pakenham & Cox, 2014; Pakenham et al. 2006). For this study, we used the mean score of the caregiving responsibilities subscale, and we created an index of caregiving experiences with the mean total score of Part A – with the exception of the caregiving responsibilities subscale – and Part B combined, with higher scores indicating higher caregiving responsibilities and experiences.

Caregiving activities. The Youth Activities of Caregiving Scale (YACS) (Ireland & Pakenham, 2010a) is a self-report measure that consists of 28 items assessing specific caregiving tasks. All items are rated on a 5-point scale, ranging from 0 for *No help at all*, to 4 for *Lots of help*. It consists of four subscales: instrumental care (i.e. paying bills and managing money, shopping, remembering things, etc.), social/emotional care (i.e. helping them when they feel bad, keeping them company, helping them when they are tired, etc.), personal/intimate care (i.e. dressing, going to the toilet, getting in and out of bed, etc.) and domestic/household care (i.e. preparing meals, chores outside the house, looking after other children or family, etc.). For this study, we used the mean total YACS score, with higher scores indicating higher caregiving tasks. The YACS reported to be a psychometrically sound measure, with good internal reliability (from .74 to .92) and both convergent and criterion validity. It was validated for Australian young caregivers of age 10 to 25, with parents suffering from various chronic illnesses such as cancer, MS, depression, bipolar disorder and others (Ireland & Pakenham, 2010a).

Youth chronic stress. The Chronic Stress Questionnaire for Children and Adolescents (CSQ-CA) (de Bruin et al., 2017; Hartong et al., 2003) was administered to examine chronic stress levels in youth. It is composed by 19 items with higher scores indicating more chronic stress in the past three months (e.g., "I feel that I have to do too many things at the same time", "I easily over react to situations", and "I often feel relaxed"). All items are rated on a 4-point scale (1 *not true for me at all* to 4 *completely true for me*). The CSQ-CA showed good reliability (α = .87) and convergent and divergent validity (de Bruin et al., 2017).

Psychological flexibility. The short form Avoidance and Fusion Questionnaire for Youth (AFQ-Y8) (Greco et al., 2008; Schweiger et al., 2017) was used to assess youth psychological flexibility. It is a child and adolescents self-report measure that examines the ability to contact the present moment consciously and to change or persist in behavior when doing so serves valued ends. Psychological flexibility supports and maintains well-being, while psychologically inflexible behaviors facilitate the development and maintenance of mental health problems. It is composed of 8 items (e.g., "My life won't be good until I feel happy" and "My thoughts and feelings mess up my life"). All items are rated on a 5-point scale (0 *not at all true* to 4 *very true*). For this study, a total score was obtained by summing the reverse ratings on all items, with higher scores indicating higher psychological flexibility. The scale showed good reliability (α = .90), and incremental, divergent and construct validity (Livheim et al., 2016).

Youth psychosocial adjustment outcomes. The following positive and negative youth psychosocial adjustment outcomes were assessed: internalizing and externalizing problems and psychological well-being.

Internalizing and externalizing problems. The internalizing and externalizing problem scales of the Youth Self-Report (YSR) were used to assess emotional and behavioral functioning of children and adolescents (Achenbach, 1991; Achenbach & Rescorla, 2001). The YSR internalizing problems scale reflects three dimensions: anxious/depressed (i.e., fears, nervousness and feeling of being worthless), withdrawn/depressed scale (i.e., loneliness, shyness and sadness) and somatic complaints (i.e., dizziness, vomiting and headaches). The YSR externalizing scale is composed by two factors: rule-breaking behaviors (i.e., antisocial behaviors, substance use, and lying), and aggressive behaviors (i.e., destructive behaviors, disobedience and acting out). Items are rated on a 3-point scale (0 *not true*, 1 *somewhat or sometimes true* and 2 *very true or often true*) and are summed to obtain a total score for internalizing symptoms and externalizing symptoms, with higher scores indicating more problems. The YSR has demonstrated sound psychometric proprieties including test-retest reliability (.79 to .88), internal consistency (.67 to .83) and good content, criterion-related and construct validity (Achenbach & Rescorla, 2001; Frigerio et al., 2004). Raw scores were used in the analysis as recommended by Achenbach and Rescorla (2001).

Psychological well-being. In order to assess psychological well-being in youth we used the psychological well-being scale of the Kidscreen-27 (The Kidscreen Group Europe, 2006; Ravens-Sieberer et al., 2007). It is a self-report measure assessing youth health-related quality of life in five dimensions: physical well-being, psychological well-being, autonomy and parents, peers and social support and school environment. The psychological well-being subscale is composed by 7 items (e.g., “Have you felt fit and well?”, “Have you been happy with the way you are?” and “Have you been able to rely on your friends?”). Items are rated on a 5-point Likert-scale (0 *not at all* to 4 *extremely* or 0 *never* to 4 *always*) with higher scores indicating greater psychological well-being. Raw scores were used in the analyses to allow for maximum variance (The Kidscreen Group Europe, 2006). The KIDSCREEN-27 was validated in a large population-based sample of youth from several European countries as well as in a sample of children and adolescents whose parents had a physical, mental, or substance abuse illness demonstrating adequate internal consistency, test-retest reliability and convergent and divergent validity (Hagen et al., 2019; Ravens-Sieberer et al., 2007).

4.2.3 Data Analysis

All analyses were performed in IBM SPSS 24 by using the PROCESS macro v.3.4. First, the linear relationships between the key study variables were evaluated using Pearson's correlations. Following the hypothesized tripartite nature of caregiving within the FEF-R, we supposed that illness severity would indirectly influence youth psychosocial adjustment through five causally linked serial multiple mediators: the three components of youth caregiving, youth chronic stress and youth psychological flexibility. We tested for various serial multiple mediation models by switching the sequence of the three components of youth caregiving – i.e., caregiving responsibilities, experiences and tasks – while leaving chronic stress and psychological flexibility in that order as the last two serial mediators. These models were compared in terms of the significant path created by each different causal order of the mediators. Some models yielded none, one or only two indirect paths, whereas the model we selected produced the most numbers of indirect paths and, most importantly, a significant indirect effect in the whole five mediators sequence. Specifically, as depicted in Figure 4.1, we choose the following sequence for the five mediators: caregiving experiences (M1), caregiving tasks (M2), caregiving responsibilities (M3), youth chronic stress (M4), and, finally, youth psychological flexibility (M5).

In sum, we supposed that illness severity (X) would indirectly influence youth psychosocial adjustment (Ys – i.e., internalizing and externalizing problems and psychological well-being) through the abovementioned five serial mediators. Therefore, we performed a serial multiple mediation analysis for each outcome using a customized version of model 6 in the Process macro (Hayes, 2017). To make it coherent with the hypothesized FEF-R, compared to the original Process model 6, the links between illness severity and chronic stress, illness severity and psychological flexibility, caregiving experiences/tasks/responsibilities and psychological flexibility were removed. Model 6 in Process macro allows to test direct and indirect effects in a serial multiple mediation model by generating path coefficients and computing bias corrected 95% confidence intervals (CIs) and five thousand random bootstrap samples (Hayes, 2017; Preacher & Hayes, 2008). Statistical significance is established when zero is not included in the 95% CI.

4.3 Results

4.3.1 Sample Characteristics

The sample consisted of 295 youth of chronically ill parents (42.7% male, with a mean age of 17.61). Parental chronic illnesses or disabilities were classified according to the International Classification of Diseases 11th Revision (ICD-11) (World Health Organization, 2018) into: cancer (37.6%), neurological diseases (18.3%), Type I and II diabetes (13.9%), mental illnesses (12.2%), cardiovascular diseases (3.4%), autoimmune diseases (3.4%), gastrointestinal diseases (2.4%), rheumatic diseases (2.4%), respiratory diseases (1.7%), infectious diseases (1.4%), physical disabilities and musculoskeletal diseases (1.3%), liver diseases (1%) and others (.3 %). Almost all youth (98 %) were native Italian. Seven participants were of Lithuanian, Ukrainian, Romanian or Moroccan nationality.

Means, standard deviations and Pearson correlations among all variables included in the tested models with the addition of youth age and gender are presented in Table 4.2. Illness severity correlated with caregiving experiences (*r* = .20**) and caregiving responsibilities (*r* = -12*) but not with caregiving tasks while the three components of caregiving correlated moderately with each other. Chronic stress was related to caregiving experiences and responsibilities but not with caregiving tasks (*r* = .43** and *r* = .28** respectively). Caregiving experiences and responsibilities – but not caregiving tasks – correlated with each youth outcome variables. Psychological flexibility had a small to moderate correlation with caregiving experiences, responsibilities and was highly correlated with chronic stress, internalizing and externalizing problems and psychological well-being. Youth age exhibited small correlations with chronic stress and psychological well-being while youth gender correlated weakly with caregiving experiences, chronic stress, internalizing problems and psychological well-being – with girls exhibiting higher caregiving experiences and worse psychosocial adjustment for these variables.

Table 4.2 – Means, Standard Deviations, Correlations and Internal Consistency Among All Variables

Variable	Mean (SD)	α	1	2	3	4	5	6	7	8	9	10
1. Illness severity	2.95 (.98)											
2. Caregiving experiences	1.61 (.41)	.78	.20**									
3. Caregiving tasks	1.22 (.52)	.91	.03	.38**								
4. Caregiving responsibilities	1.49 (.78)	.84	.12*	.47**	.39**							
5. Chronic stress	41.48 (8.01)	.85	.09	.43**	.11	.28**						
6. Psychological flexibility	23.19 (5.51)	.77	-.02	-.32**	-.11	-.21**	-.55**					
7. Internalizing problems	14.03 (9.00)	.90	.02	.49**	.11	.33**	.63**	-.66**				
8. Externalizing problems	9.48 (6.24)	.90	.08	.27**	-.01	.22**	.46**	-.44**	.55**			
9. Psychological well-being	26.68 (4.38)	.86	-.06	-.36**	.01	-.17**	-.55**	-.43**	-.55**	-.34**		
10. Youth gender (0 = f, 1 = m)	.43 (.50)		-.01	-.22**	-.16*	-.02	-.25**	.12	-.25**	.04	.17**	
11. Youth age	17.61 (3.)		.04	.06	.02	.04	.16**	-.05	-.01	.04	-.20**	.07

Notes. $^{*}p < .05$, $^{**}p < .01$.

4.3.2 Internalizing Problems

The first model evaluated whether caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and internalizing problems. As shown in Figure 4.2, the direct effects of illness severity on youth internalizing problems ($B = -.30$, $SE = .40$, $t = -.76$, $p = .45$) was not significant.

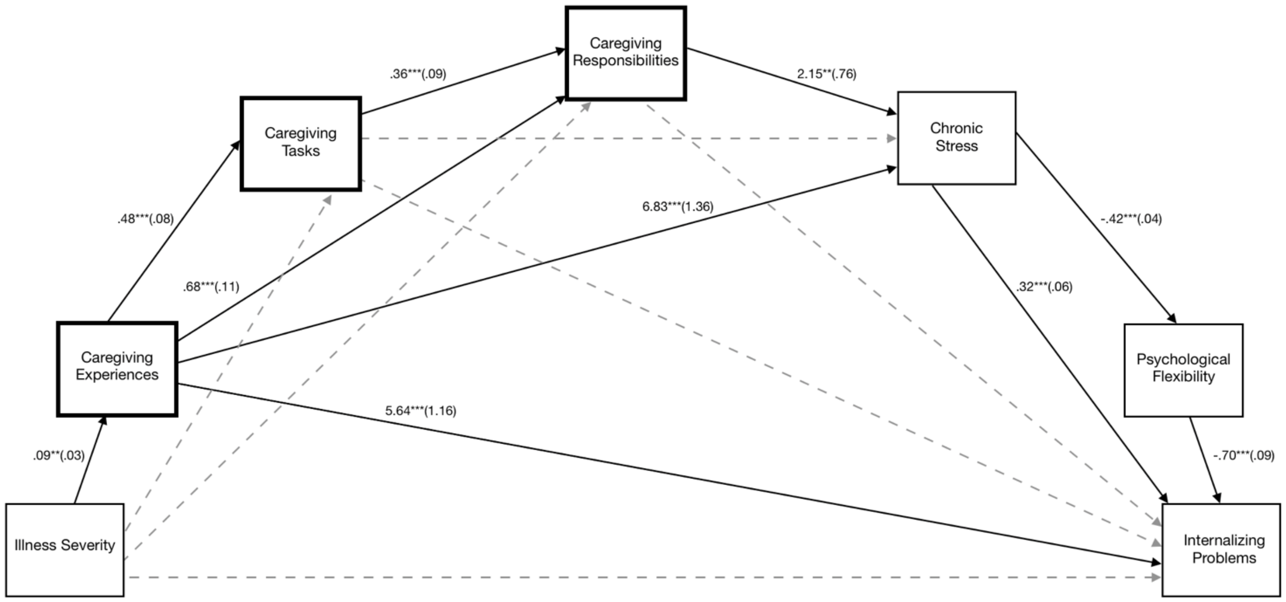

Figure 4.2 – Serial mediation linking illness severity to internalizing problems. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths.* p < .05, ** p < .01, *** p < .001.

The total indirect effect was statistically different from zero, B = 1.01, SE = .30, 95% CI [.445, 1.635] (see Table 4.3). In particular, the indirect effect of illness severity on youth internalizing problems via caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 21 – was significant, B = .01, SE = .01, 95% CI [.002, .025]. This confirms the supposed tri-partite nature of caregiving and its importance in the inclusion within a model examining youth adjustment to parental chronic illness. In fact, this model indicates that an increase in parental illness severity is related to an increase in caregiving experiences (B = .09, SE = .03, *p* < .01), which in turn is associated with an increase in youth caregiving tasks (B = .48, SE = .08, *p* < .001). Sequentially, the increase in youth caregiving tasks is linked to an increase in caregiving responsibilities (B = .36, SE = .09, *p* < .001) which, in turn, is related to an increase in youth chronic stress (B = 2.15, SE = .76, *p* < .01). An increase in chronic stress reflects in a decrease in psychological flexibility (B = -.42, SE = .04, *p* < .001). However, psychological flexibility is ultimately connected to a decrease in youth internalizing problems (B = -.70, SE = .09, *p* < .001).

Table 4.3 – Path Coefficients and 95% Bootstrap Confidence Intervals Predicting Youth Internalizing Problems

	Caregiving Experience (M_1)		Caregiving Tasks (M_2)		Caregiving Responsibilities (M_3)		Chronic Stress (M_4)		Psychological Flexibility (M_5)		Internalizing Problems (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff	95 % CI
Illness severity (X)	.09** (.03)	.03, .14	-.03 (.03)	-.09, .04	.03 (.05)	-.06, .12					-.30 (.40)	-1.09, .49
Caregiving Experience (M_1)			.48*** (.08)	.34, .64	.68*** (.11)	.45, .90	6.83*** (1.36)	4.14, 9.51			5.64*** (1.16)	3.35, 7.92
Caregiving Tasks (M_2)					.36*** (.09)	.18, .54	-1.70 (1.06)	-3.80, .40			-1.45 (.85)	-3.12, .22
Caregiving Responsibilities (M_3)							2.15** (.76)	.65, 3.65			.65 (.61)	-.56, 1.85
Chronic Stress (M_4)									-.42*** (.04)	-.50, -.35	.32*** (.06)	.19, .44
Psychological Flexibility (M_5)											-.70*** (.09)	-.87, -.53
Constant	1.37*** (.09)	1.19, 1.54	.52*** (.15)	.22, .81	-.13 (.21)	-.54, .28	29.51*** (2.02)	25.53, 33.49	40.56*** (1.61)	37.38, 43.74	9.29* (4.22)	.97, 17.60
	$R^2 = .04$, $F(1,221) = 9.96$, $p < .01$		$R^2 = .15$, $F(2,220) = 19.28$, $p < .001$		$R^2 = .28$, $F(3,219) = 28.05$, $p < .001$		$R^2 = .20$, $F(3,219) = 18.25$, $p < .001$		$R^2 = .36$, $F(1,221) = 125.55$, $p < .001$		$R^2 = .62$, $F(6,216) = 57.83$, $p < .001$	

Indirect Effects	Coeff.	95 % CI
Total Indirect Effect	1.01 (.30)	.44, 1.64
Ind 1 X →Experiences (M_1) → Y	.50 (.18)	.18, .89
Ind 2 X → Tasks (M_2)→ Y	.04 (.06)	-.06, .20
Ind 3 X → Responsibilities (M_3)→ Y	.02 (.04)	-.05, .13
Ind 4 X →Experiences (M_1) → Tasks (M_2)→ Y	-.06 (.04)	-.16, .02
Ind 5 X →Experiences (M_1) → Responsibilities (M_3)→ Y	.04 (.04)	-.03, .13
Ind 6 X →Experiences (M_1) → Stress (M_4)→ Y	.19 (.08)	.06, .37
Ind 7 X → Tasks (M_2)→ Responsibilities (M_3)→ Y	-.01 (.01)	-.04, .01
Ind 8 X → Tasks (M_2)→ Stress (M_4)→ Y	.02 (.02)	-.02, .07
Ind 9 X → Responsibilities (M_3)→ Stress (M_4)→ Y	.02 (.03)	-.05, .09
Ind 10 X →Experiences (M_1) → Tasks (M_2)→ Responsibilities (M_3)→ Y	.01 (.01)	-.01, .04
Ind 11 X →Experiences (M_1) → Tasks (M_2)→ Stress (M_4)→ Y	-.02 (.02)	-.06, .00
Ind 12 X →Experiences (M_1) → Responsibilities (M_3)→ Stress (M_4)→ Y	.04 (.02)	.01, .09
Ind 13 X → Experiences (M_1) → Stress (M_4)→ Flex (M_5)→ Y	.18 (.07)	.06, .34
Ind 14 X → Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Y	-.01 (.01)	-.03, .01
Ind 15 X → Tasks (M_2)→ Stress (M_4)→ Flex (M_5)→ Y	.01 (.02)	-.02, .06
Ind 16 X → Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.02 (.03)	-.04, .08
Ind 17 X→ Experiences (M_1)→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Y	.01 (.01)	.00, .03
Ind 18 X→ Experiences (M_1)→ Tasks (M_2)→ Stress (M_4)→ Flex (M_5)→ Y	-.02 (.02)	-.06, .00
Ind 19 X→ Experiences (M_1)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.04 (.02)	.01, .09
Ind 20 X→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	-.01 (.01)	-.03, .01
Ind 21 X→ Experiences (M_1)→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.01 (.01)	.00, .03

Notes. * $p < .05$, ** $p < .01$, *** $p < .001$. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

Of all the other specific indirect effects, the indirect effect of illness severity on internalizing problems via caregiving experiences alone – i.e. path indirect 1 – was significant, B

= .50, SE = .18, 95% CI [.182, .886]. The indirect effect of illness severity on youth internalizing problems via caregiving experiences and chronic stress in serial – i.e. path indirect 6 – was significant as well, B = .19, SE = .08, 95% CI [.064, .366]. Also, the indirect effect of illness severity on youth internalizing problems via caregiving experiences, caregiving responsibilities and chronic stress and in serial – i.e. path indirect 12 – was significant, B = .04, SE = .02, 95% CI [.007, .094]. Moreover, the indirect effect of illness severity on youth internalizing problems via caregiving experiences, chronic stress and psychological flexibility in serial – i.e. path indirect 13 – was significant, B = .18, SE = .08, 95% CI [.062, .344]. The indirect effect of illness severity on youth internalizing problems via caregiving experiences, caregiving tasks, caregiving responsibilities and chronic stress in serial – i.e. path indirect 17 – was also significant, B = .01, SE = .01, 95% CI [.002, .027]. Finally, the indirect effect of illness severity on youth internalizing problems via caregiving experiences, caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 19 – was significant, B = .04, SE = .02, 95% CI [.007, .085].

In addition to the full serial mediation, these analyses revealed that all significant indirect paths ran through caregiving experiences. The overall model accounted for 62% of the variance in the internalizing problems score, R2 = .62, $F(6, 216) = 57.83, p < .001$. In conclusion, the relationship between parental illness severity and youth internalizing problems was fully mediated by youth caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress and psychological flexibility in that order.

4.3.3 Externalizing Problems

The second model evaluated whether caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and externalizing problems.

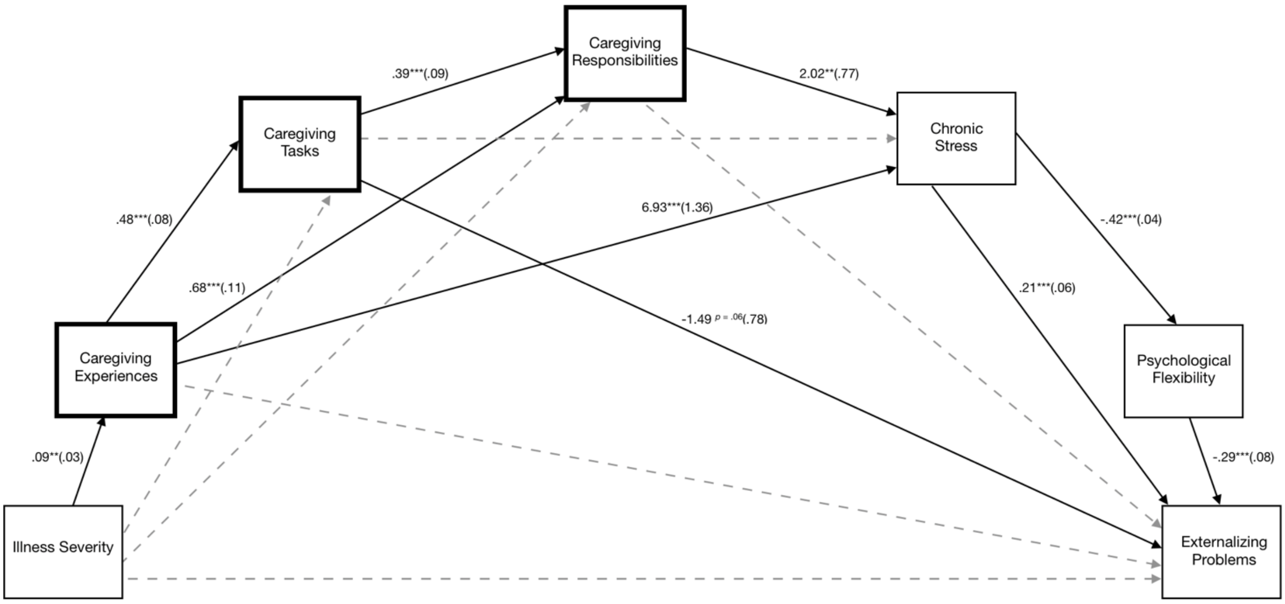

Figure 4.3 – Serial mediation linking illness severity to externalizing problems. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths. * p < .05, ** p < .01, *** p < .001.

As shown in Figure 4.3, the direct effects of illness severity on youth externalizing problems (*B* = .40, *SE* = .37, *t* = 1.08, *p* = .28) was not significant. However, the total indirect effect of illness severity on externalizing problems was statistically different from zero, B = .37, SE = .15, 95% CI [.111, .713] (see Table 4.4). In particular, the indirect effect of illness severity on youth externalizing problems via caregiving experiences, caregiving tasks, caregiving responsibilities chronic stress, and psychological flexibility in series – i.e. path indirect 21 – was significant, B = .004, SE = .03, 95% CI [.0004, .013]. This confirms the supposed tri-partite nature of caregiving for externalizing problems also.

Of all the other specific indirect effects, compared to internalizing problems, the indirect effect of illness severity on externalizing problems via caregiving experiences alone was not significant, while the indirect effect of illness severity on externalizing problems via caregiving experiences and chronic stress in serial – i.e. path indirect 6 – was significant, B = .13, SE = .06, 95% CI [.034, .274].

Table 4.4 – Path Coefficients and 95% Bootstrap Confidence Intervals Predicting Youth Externalizing Problems

	Caregiving Experience (M_1)		Caregiving Tasks (M_2)		Caregiving Responsibilities (M_3)		Chronic Stress (M_4)		Psychological Flexibility (M_5)		Externalizing Problems (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff	95 % CI
Illness severity (X)	.09** (.03)	.03, .14	-.03 (.03)	-.10, .03	.03 (.04)	-.05, .12					-.40 (.37)	-.33, 1.12
Caregiving Experience (M_1)			.48*** (.08)	.32, .63	.68*** (.11)	.46, .90	6.93*** (1.37)	4.24, 9.63			.96 (1.06)	-1.12, 3.05
Caregiving Tasks (M_2)					.39*** (.09)	.21, .57	-1.55 (1.08)	-3.68, .57			-1.49 (.78)	-3.03, .05
Caregiving Responsibilities (M_3)							2.02** (.77)	.49, 3.55			.40 (.57)	-.71, 1.52
Chronic Stress (M_4)									-.42*** (.04)	-.50, -.35	.21*** (.06)	.10, .33
Psychological Flexibility (M_5)											-.29*** (.08)	-.45, -.14
Constant	1.37*** (.09)	1.19, 1.55	.53*** (.15)	.24, .83	-.18 (.21)	-.59, .22	29.37*** (2.03)	25.38, 33.37	40.54*** (1.62)	37.34, 43.74	5.31 (3.84)	-2.25, 12.87
	$R^2 = .04$, $F(1,220) = 9.60$, $p < .01$		$R^2 = .15$, $F(2,219) = 18.82$, $p < .001$		$R^2 = .30$, $F(3,218) = 30.61$, $p < .001$		$R^2 = .20$, $F(3,218) = 18.11$, $p < .001$		$R^2 = .36$, $F(1,220) = 124.22$, $p < .001$		$R^2 = .30$, $F(6,215) = 14.98$, $p < .001$	

Indirect Effects	Coeff.	95 % CI
Total Indirect Effect	.37 (.15)	.11, .71
Ind 1 X →Experiences (M_1) → Y	.08 (.10)	-.10, .30
Ind 2 X → Tasks (M_2)→ Y	.05 (.06)	-.04, .21
Ind 3 X → Responsibilities (M_3)→ Y	.01 (.03)	-.06, .09
Ind 4 X →Experiences (M_1) → Tasks (M_2)→ Y	-.06 (.04)	-.16, -.01
Ind 5 X →Experiences (M_1) → Responsibilities (M_3)→ Y	.02 (.04)	-.04, .10
Ind 6 X →Experiences (M_1) → Stress (M_4)→ Y	.13 (.06)	.03, .27
Ind 7 X → Tasks (M_2)→ Responsibilities (M_3)→ Y	-.01 (.01)	-.03, .01
Ind 8 X → Tasks (M_2)→ Stress (M_4)→ Y	.01 (.02)	-.01, .05
Ind 9 X → Responsibilities (M_3)→ Stress (M_4)→ Y	.02 (.02)	-.02, .06
Ind 10 X →Experiences (M_1) → Tasks (M_2)→ Responsibilities (M_3)→ Y	.01 (.01)	-.01, .02
Ind 11 X →Experiences (M_1) → Tasks (M_2)→ Stress (M_4)→ Y	-.01 (.01)	-.04, .00
Ind 12 X →Experiences (M_1) → Responsibilities (M_3)→ Stress (M_4)→ Y	.03 (.02)	.00, .07
Ind 13 X → Experiences (M_1) → Stress (M_4)→ Flex (M_5)→ Y	.08 (.04)	.02, .16
Ind 14 X → Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Y	-.01 (.01)	-.02, .01
Ind 15 X → Tasks (M_2)→ Stress (M_4)→ Flex (M_5)→ Y	.01 (.01)	-.01, .03
Ind 16 X → Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.01 (.01)	-.01, .04
Ind 17 X→ Experiences (M_1)→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Y	.01 (.01)	.00, .02
Ind 18 X→ Experiences (M_1)→ Tasks (M_2)→ Stress (M_4)→ Flex (M_5)→ Y	-.01 (.01)	-.02, .00
Ind 19 X→ Experiences (M_1)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.02 (.01)	.00, .04
Ind 20 X→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	-.00 (.00)	-.01, .00
Ind 21 X→ Experiences (M_1)→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.004 (.003)	.0004, .01

Notes. * p < .05, ** p < .01, *** p < .001. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

Also, the indirect effect of illness severity on externalizing problems via caregiving experiences, caregiving responsibilities and chronic stress and in serial – i.e. path indirect 12 –

was significant, B = .03, SE = .02, 95% CI [.004, .065]. Moreover, the indirect effect of illness severity on externalizing problems via caregiving experiences, chronic stress and psychological flexibility in serial – i.e. path indirect 13 – was significant, B = .08, SE = .04, 95% CI [.022, .157]. The indirect effect of illness severity on externalizing problems via caregiving experiences, caregiving tasks, caregiving responsibilities and chronic stress in serial – i.e. path indirect 17 – was significant as well, B = .01, SE = .01, 95% CI [.0008, .019]. The indirect effect of illness severity on externalizing problems via caregiving experiences, caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 19 – was also significant, B = .02, SE = .01, 95% CI [.002, .040]. Finally, the indirect effect of illness severity on externalizing problems via caregiving experiences and caregiving tasks in serial – i.e. path indirect 4 – was significant, B = -.06, SE = .04, 95% CI [-.160, -.005].

In sum, besides the full serial mediation, these analyses revealed that all significant indirect paths ran via caregiving experiences – except for the indirect path linking illness severity to externalizing problems via caregiving experiences only. Moreover, compared to internalizing problems, a specific additional indirect effect emerged: the one linking illness severity to externalizing problems via both caregiving experiences and caregiving tasks. This last pathway predicts that an increase in parental illness severity is related to an increase in caregiving experiences (B = .09, SE = .03, $p < .01$) which, in turn, is associated with an increase in youth caregiving tasks (B = .48, SE = .08, $p < .001$). Unexpectedly, an increase in youth caregiving tasks is linked to a decrease in youth externalizing problems (B = -1.49, SE = .78, $p = .06$). However, the beta for this path only approaches statistical significance.

The overall model accounted for 30% of the variance in the externalizing problems score, R2 = .30, $F(6, 215) = 14.98$, $p < .001$. In conclusion, the relationship between parental illness severity and youth externalizing problems was fully mediated by youth caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in that order.

4.3.4 Psychological Well-Being

The third model evaluated whether caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in serial would mediate the relationship between illness severity and youth psychological well-being. As shown in Figure 4.4, the direct effects of illness severity on psychological well-being (*B* = -.24, *SE* = .46, *t* = -.51, *p* = .61) was not significant. However, the total indirect effect of illness severity on psychological well-being was statistically different from zero, B = -.67, SE = .24, 95% CI [-1.187, -.235] (see Table 4.5). In particular, the indirect effect of illness severity on psychological well-being via caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 21 – was significant, B = -.004, SE = .003, 95% CI [-.012, -.0004]. This confirms the supposed tri-partite nature of caregiving for psychological well-being also.

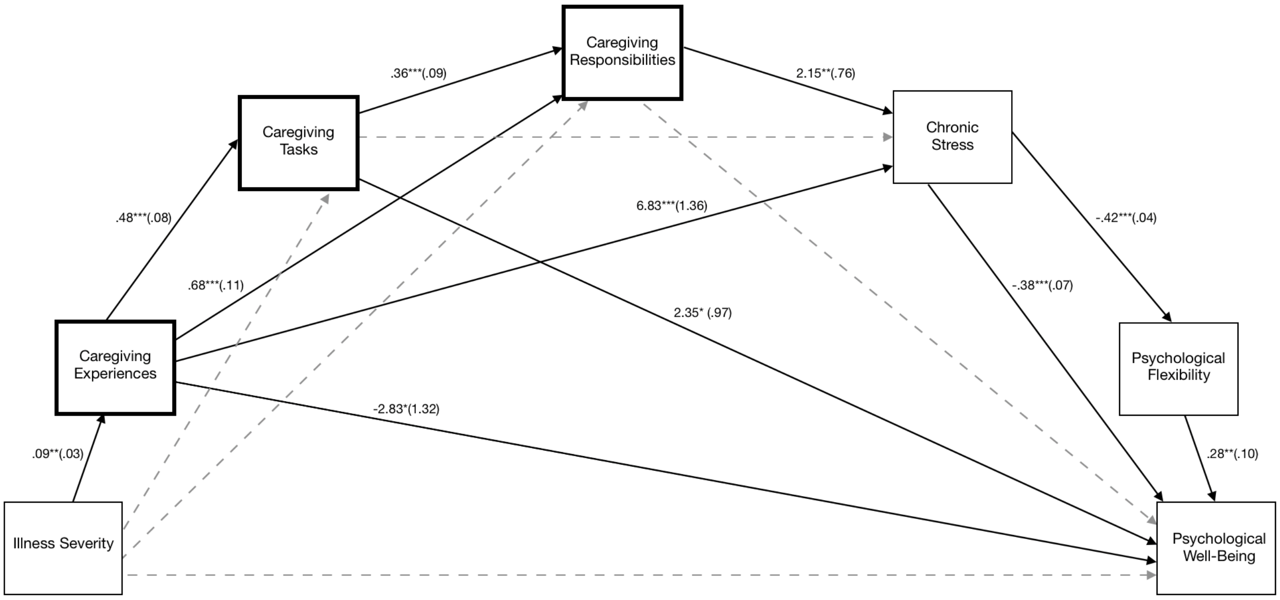

Figure 4.4 – Serial mediation linking illness severity to psychological well-being. Notes: values outside parentheses = path coefficients or unstandardized coefficients; values in parentheses = bootstrapped standard errors (SEs). Dotted lines represent not significant paths. * p < .05, ** p < .01, *** p < .001.

Of all the other specific indirect effects, the indirect effect of illness severity on psychological well-being via caregiving experiences alone – i.e. path indirect 1 – was significant, B = -.25, SE = .14, 95% CI [-.570, -.031]. The indirect effect of illness severity on psychological well-being via caregiving experiences and chronic stress in serial – i.e. path indirect 6 – was significant as well, B = -.23, SE = .10, 95% CI [-.445, -.069]. Also, the indirect effect of illness severity on psychological well-being via caregiving experiences, caregiving responsibilities and chronic stress and in serial – i.e. path indirect 12 – was significant, B = -.05, SE = .03, 95% CI [-.118, -.009]. Moreover, as for internalizing and externalizing problems, the indirect effect of illness severity on psychological well-being via caregiving experiences, chronic stress and psychological flexibility in serial – i.e. path indirect 13 – was significant, B = -.07, SE = .04, 95% CI [-.170, -.013]. The indirect effect of illness severity on psychological well-being via caregiving experiences, caregiving tasks, caregiving responsibilities and chronic stress in serial – i.e. path indirect 17 – was significant as well, B = -.01, SE = .01, 95% CI [-.032, -.002]. The indirect effect of illness severity on psychological well-being via caregiving experiences, caregiving responsibilities, chronic stress and psychological flexibility in serial – i.e. path indirect 19 – was also significant, B = -.02, SE = .01, 95% CI [-.041, -.002]. Finally, the indirect effect of illness severity on psychological well-being via caregiving experiences and caregiving tasks in serial – i.e. path indirect 4 – was also significant, B = .10, SE = .05, 95% CI [.021, .226]. In sum, besides the full serial mediation, like for youth internalizing problems, these analyses revealed that all significant indirect paths ran via caregiving experiences. Furthermore, like for youth externalizing problems, the specific indirect effect linking illness severity to psychological well-being via both caregiving experiences and caregiving tasks was significant as well. This last pathway predicts that an increase in parental illness severity is related to an increase in caregiving experiences (B = .09, SE = .03, $p < .01$) which, in turn, is associated with an increase in youth caregiving tasks (B = .48, SE = .08, $p < .001$). Unexpectedly, an increase in youth caregiving tasks is linked to an increase in psychological well-being (B = 2.35, SE = .97, $p < .05$).

Table 4.5 – Path Coefficients and 95% Bootstrap Confidence Intervals Predicting Youth Psychological Well-Being

	Caregiving Experience (M_1)		Caregiving Tasks (M_2)		Caregiving Responsibilities (M_3)		Chronic Stress (M_4)		Psychological Flexibility (M_5)		Psychological Well-Being (Y)	
	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff.	95 % CI	Coeff	95 % CI
Illness severity (X)	.09** (.03)	.03, .14	-.03 (.03)	-.09, .04	.03 (.05)	-.06, .12					-.24 (.46)	-1.14, .67
Caregiving Experience (M_1)			.48*** (.08)	.33, .64	.68*** (.11)	.45, .90	6.83*** (1.36)	4.14, 9.51			-2.83* (1.32)	-5.44, -.22
Caregiving Tasks (M_2)					.39*** (.09)	.18, .54	-1.70 (1.06)	-3.80, .40			2.35* (.97)	.45, 4.26
Caregiving Responsibilities (M_3)							2.15** (.76)	.65, 3.65			-.70 (.70)	-2.08, .67
Chronic Stress (M_4)									-.42*** (.04)	-.50, -.35	-.38*** (.07)	-.52, -.23
Psychological Flexibility (M_5)											.28** (.10)	.09, .48
Constant	1.37*** (.09)	1.19, 1.54	.52*** (.15)	.23, .81	-.13 (.21)	-.54, .28	29.51*** (2.02)	25.53, 33.49	40.56*** (1.61)	37.38, 43.74	58.74*** (4.82)	49.24, 68.24
	$R^2 = .04$, $F(1,221) = 9.96$, $p < .01$		$R^2 = .15$, $F(2,220) = 19.28$, $p < .001$		$R^2 = .28$, $F(3,219) = 28.05$, $p < .001$		$R^2 = .20$, $F(3,219) = 18.25$, $p < .001$		$R^2 = .36$, $F(1,221) = 125.55$, $p < .001$		$R^2 = .37$, $F(6,216) = 21.15$, $p < .001$	

Indirect Effects	Coeff.	95 % CI
Total Indirect Effect	-.67 (.24)	-1.19, -.24
Ind 1 X →Experiences (M_1) → Y	-.25 (.14)	-.57, -.30
Ind 2 X → Tasks (M_2)→ Y	-.07 (.09)	-.27, .08
Ind 3 X → Responsibilities (M_3)→ Y	-.02 (.05)	-.14, .05
Ind 4 X →Experiences (M_1) → Tasks (M_2)→ Y	.10 (.05)	.02, .23
Ind 5 X →Experiences (M_1) → Responsibilities (M_3)→ Y	-.04 (.04)	-.14, .03
Ind 6 X →Experiences (M_1) → Stress (M_4)→ Y	-.23 (.10)	-.45, -.07
Ind 7 X → Tasks (M_2)→ Responsibilities (M_3)→ Y	.01 (.01)	-.01, .04
Ind 8 X → Tasks (M_2)→ Stress (M_4)→ Y	-.02 (.03)	-.08, .03
Ind 9 X → Responsibilities (M_3)→ Stress (M_4)→ Y	-.02 (.04)	-.12, .05
Ind 10 X →Experiences (M_1) → Tasks (M_2)→ Responsibilities (M_3)→ Y	-.01 (.01)	-.04, .01
Ind 11 X →Experiences (M_1) → Tasks (M_2)→ Stress (M_4)→ Y	.03 (.01)	-.00, .07
Ind 12 X →Experiences (M_1) → Responsibilities (M_3)→ Stress (M_4)→ Y	-.05 (.03)	-.12, -.01
Ind 13 X → Experiences (M_1) → Stress (M_4)→ Flex (M_5)→ Y	-.07 (.04)	-.17, -.01
Ind 14 X → Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Y	.01 (.01)	-.01, .04
Ind 15 X → Tasks (M_2)→ Stress (M_4)→ Flex (M_5)→ Y	-.01 (.01)	-.03, .01
Ind 16 X → Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	-.01 (.01)	-.04, .02
Ind 17 X→ Experiences (M_1)→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Y	-.01 (.01)	-.03, -.002
Ind 18 X→ Experiences (M_1)→ Tasks (M_2)→ Stress (M_4)→ Flex (M_5)→ Y	.01 (.01)	-.00, .03
Ind 19 X→ Experiences (M_1)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	-.02 (.01)	-.04, -.002
Ind 20 X→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	.00 (.00)	-.00, .01
Ind 21 X→ Experiences (M_1)→ Tasks (M_2)→ Responsibilities (M_3)→ Stress (M_4)→ Flex (M_5)→ Y	-.004 (.003)	-.01, -.0004

Notes. * p < .05, ** p < .01, *** p < .001. Coeff. = path coefficient or unstandardized coefficient; value in parenthesis = bootstrapped standard errors (SEs).

The overall model accounted for 37% of the variance in the psychological well-being score, R2 = .37, $F(6, 216) = 21.15, p < .001$. In conclusion, the relationship between parental illness severity and youth psychological well-being was fully mediated by youth caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in that order.

4.4 Discussion

This study confirmed the hypothesized tripartite nature of youth caregiving by exploring the role of the psychosocial caregiving components – i.e. caregiving responsibilities and caregiving experiences – and of specific care tasks in shaping youth adjustment within the FEF-R. The results of path analyses indicated that the adverse effects of parental illness on youth adjustment were serially mediated by youth caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in that order. Including the three components of youth caregiving in the FEF-R – compared to only incorporating caregiving responsibilities – allowed to increase the explained variance in youth adjustment outcomes. In fact, compared to our previous study which only included one of the component of youth caregiving – i.e., caregiving responsibilities (Landi et al., 2019a), considering youth caregiving as a tripartite construct improved the total explained variance of 9% in youth internalizing problems, 6% in youth externalizing problems and .03% in youth psychological well-being.

Noteworthy, *caregiving responsibilities* confirmed its key role in shaping youth psychosocial adjustment. In fact, a significant total indirect effect of the whole five mediators sequence in the tested models emerged only when caregiving responsibilities was the bridge between the tripartite components of caregiving and the other mediators linking illness severity to youth outcomes. Interestingly, an indirect effect of *caregiving experiences* alone appeared only for youth internalizing problems and psychological well-being but not for externalizing problems. Therefore, the differential link between caregiving experiences and youth psychosocial adjustment outcomes should be further investigated. Moreover, the indirect effect of *caregiving tasks* via caregiving experiences was unexpectedly related to an increase in youth psychosocial adjustment – i.e., an increase in caregiving experiences was associated with an increase in caregiving tasks, which in turn was related to a decrease in youth externalizing problems and an increase in psychological well-being. These results reflect the costs and benefits of caregiving that have been previously reported in the young caregiving literature (Ireland & Pakenham, 2010b; Pakenham & Cox, 2014, 2018; Pakenham et al. 2006) and have clinical implications with respect to the need for interventions that mitigate adverse and cultivate positive effect of youth caregiving. Finally, these results confirmed in a broader sample of youth living with chronically ill parents the protective role of psychological flexibility in ameliorating the detrimental effect of parental illness on youth adjustment.

This study has some limitations that should be discussed. First, the present study included a convenience sampling which limits the generalizability of the findings. Second, using the macro PROCESS for path analysis only permitted to test for observed variables and constrained to use mean scores for each of the tripartite components of youth caregiving while other structural equation modeling programs could have permitted to consider the three components of youth caregiving as latent variables (Hayes et al., 2017).

Despite these limitations, this study has several strengths. It was the first in the young carers field to clarify both theoretically and empirically the construct of youth caregiving into three measurable components embedded within a broader conceptual framework of the effects of parental illness on youth. In fact, the Young Caregiver of Parents Inventory-Revised (YCOPI-R) (Cox & Pakenham, 2014; Landi et al., 2019a; Pakenham et al., 2006) and the Youth Activities of Caregiving Scale (YACS) (Ireland & Pakenham, 2010a) confirmed to be standardized and psychometrically solid measures related to important and theoretical formulations of young caregiving. In addition, it was the first study testing in a mixed parental disease sample the simultaneous effects of all three components of youth caregiving on offspring adjustment and supporting the concomitant benefits and costs of youth caregiving.

Future studies should separately analyze each subscale of caregiving experiences and tasks in association with both positive and negative outcomes as well as further disentangle the effect of each caregiving components on each other and their simultaneous impact on youth outcomes. Moreover, the relationship of other possible mediators and moderators to the tripartite components of caregiving within the FEF-R should be explored – for example, the mediating role of benefit finding has only been examined with the caregiving responsibilities component but not with all the other components of youth caregiving at the same time. Finally, future studies should include longitudinal assessment in order to confirm causality of results over time.

4.4.1 Conclusion

This study represents an important advancement in the creation of an empirically supported framework to understand the impact of parental illness on youth psychosocial adjustment. This manuscript innovatively clarified the nature of youth caregiving by examining its tripartite structure within the FEF-R. Results indicated that youth caregiving is a tripartite construct related to both positive and negative youth adjustment outcomes, thereby have clinical implications with respect to the need for interventions that mitigate adverse and cultivate positive effect of youth caregiving.

Chapter 5

General Discussion

5.1 General Discussion

The aims of this PhD dissertation were threefold: (1) to investigate the psychometric properties of the Italian version of the YCOPI-R; (2) to test an expanded model of the effects of parental illness on youth and family functioning derived from the Family Ecology Framework-Revised (Pedersen & Revenson, 2005; Landi et al., 2019a; Pakenham & Cox, 2015) further examining the role of *psychological flexibility* within this model; (3) building on Pakenham and Cox (2015) pioneering research on youth caregiving, to test a refined conceptualization and measurement of youth caregiving.

Results of the first study indicated that the Italian version of the YCOPI-R demonstrated good psychometric properties, maintaining the same factors structure of the original instrument. It also exhibited high internal reliability and discriminant validity, as it significantly differentiated between young caregivers and noncaregivers. Convergent and predictive validity of the Italian YCOPI-R have been supported through evidence of associations between its subscales and measures of caregiving activities, caregiving context variables and youth psychosocial adjustment. One of its subscale, Caregiving Confidence, was also associated with higher levels of health-related quality of life, corroborating the positive and negative nature of youth caregiving.

As a theoretical background, this PhD thesis used a revised version of the Family Ecology Framework (FEF), a model examining how parental illness impacts on youth and families' psychosocial adjustment. Compared to the original FEF, the Family Ecology Framework-Revised (FEF-R) underlines the role of psychological flexibility within this model and includes a refined conceptualization of youth caregiving. The results of the second study supported the proposed serial mediating mechanisms of *psychological flexibility* within the FEF-R. As predicted, the adverse effects of parental illness on youth adjustment and family functioning were serially mediated by youth caregiving responsibilities, chronic stress, and most importantly, psychological flexibility. Therefore, psychological flexibility represents a major protective factor in the link between parental illness severity and youth psychosocial adjustment and family functioning.

Overall, parental illness severity did not exert a direct effect on youth psychosocial adjustment and family functioning, but its impact was fully mediated by caregiving responsibilities, chronic stress and psychological flexibility in serial. The third study included in this PhD dissertation examined the tripartite nature of youth caregiving by exploring the role of each caregiving component – i.e., caregiving responsibilities, caregiving experiences and caregiving tasks – in shaping youth adjustment within the FEF-R. The results of path analyses indicated that the adverse effects of parental illness on youth adjustment were serially mediated by youth caregiving experiences, caregiving tasks, caregiving responsibilities, chronic stress, and psychological flexibility in that order. Including the three components of youth caregiving in the FEF-R, compared to only incorporating caregiving responsibilities, allowed to increase the explained variance in youth adjustment outcomes. Caregiving responsibility confirmed its key role as a bridge between the tripartite components of caregiving and the other mediators linking illness severity to youth outcomes. Caregiving experiences alone mediated the link between parental illness severity and both youth internalizing problems and psychological well-being, while the indirect path via both caregiving experiences and tasks was, unexpectedly, associated with a decrease in youth externalizing problems and an increase in psychological well-being. These results reflect the costs and benefits of caregiving that have been previously reported in the young caregiving literature (Ireland & Pakenham, 2010b; Pakenham & Cox, 2014, 2018; Pakenham et al. 2006).

5.2 Clinical Implications

Even though governments in many counties have started to consider youth caregiving on their social agenda, policy development differs considerably (Pakenham, 2009). Except for some countries, young caregivers' legal rights to recognition, assessments, or support services are still neglected (Becker, 2007; Joseph, Sempik, Leu, & Becker, 2019; Kühne et al., 2013; Pakenham, 2009; Skogøy et al., 2018; Stamatopoulos, 2016; van Doesum et al., 2015). In Italy, young carers' experiences and needs are almost entirely ignored among governmental, health care delivery and societal settings (Leu & Becker, 2017). Nevertheless, the increase in studies indicating that young carers are a high-risk group exposed to adverse psychological outcomes points to the need for more research examining the efficacy of appropriate preventive interventions. Many of the studies examining psychosocial interventions for young caregivers have focused on children of parents with mental illness (Beardslee, Solantaus, Morgan, Gladstone, & Kowalenko, 2013; Thanhäuser, Lemmer, de Girolamo, & Christiansen, 2017; van Doesum, & Hosman, 2009), while others have targeted children of a parent with physical illness/disability – most have focused on cancer, a few on MS, HIV or other specific parental diagnoses (Alexander, O'Connor, Rees, & Halkett, 2019; Coles et al., 2007; Järkestig Berggren & Hanson, 2016; Romer, Barkmann, Schulte-Markwort, Thomalla, & Riedesser, 2002). Most interventions opted for a group format, targeting the child, both children and parents and/or the whole family (Inhestern, Haller, Wlodarczyk, & Bergelt, 2016; Järkestig Berggren & Hanson, 2016; Niemelä, Hakko, & Räsänen, 2010). Others focused on peer support (Wind & Jorgensen, 2019). The main aim of most interventions was to improve family functioning by targeting parents' communication with their children, providing education about parental illness as well as an opportunity to share experiences, and teach each family member's adaptive coping strategies (Romer, Saha, Haagen, Pott, Baldus, & Bergelt, 2007). The value of a 'whole family approach' is becoming largely recognized, especially in order to meet the needs of everyone in the family (Aldridge & Becker, 1993; Frank, & Slatcher, 2010; Gatsou, Yates, Goodrich, & Pearson, 2017; Morley, Li, & Jenkinson, 2016).

In line with these recommendations, this PhD dissertation advocates for a family-centred approach with the purpose of ameliorating the impact of parental chronic illness on youth and the whole family. Hence, it is essential to involve the entire family as well as to consider the broader familiar environment: not only chronically ill parents, their spouses and children, but also economic, pragmatical, and social variables. Nowadays, health care providers' assessment does not include a whole-family approach neither the mental health of adult patients' offspring is routinely examined (Romer et al., 2002). Therefore, a shift toward a biopsychosocial model of health is urgently needed. Education about youth caregiving should also be included in professional settings – e.g., hospitals, general practitioners' offices, nurseries, and schools – and guidelines should be created in order to implement services and interventions aimed at effectively respond to young carers needs.

For all of these reasons, this PhD dissertation targeted children of chronically ill parents in order to inform the development of young carer interventions and to develop an instrument to assess youth caregiving in the Italian context. Results of this PhD thesis confirmed that the YCOPI-R is a sound measure of caregiving responsibilities and experiences in Italian youth and that it could be used to develop and evaluate young carer services in the Italian context. This PhD dissertation also innovatively tested the tripartite nature of youth caregiving indicating that it is a complex construct related to both positive and negative youth adjustment outcomes, thereby having clinical implications concerning the need for interventions that mitigate adverse and cultivate positive effect of youth caregiving. Finally, this thesis also underlined the key protective role of *psychological flexibility* in shaping youth adjustment and family functioning in the context of parental illness pave the way for the creation of tailored interventions programs targeting psychological flexibility in the young carers field.

In light of these results, this PhD dissertation endorses a family-centred approach to increase family resilience and related protective factors – including psychological flexibility especially – in the context of parental chronic illness. Resilience can be defined as a process of positive adjustment to adversity and studies have indicated that it is crucially related to quality of life in people with physical illness/disability (Windle, Bennett, & Noyes, 2011). Recently, a promising intervention was developed with the purpose of increasing resilience: the REsilience for Adults everyDaY (READY) Program is an ACT-informed generic resilience training program that can be tailored to the specific context (Burton, Pakenham, & Brown, 2009). This intervention could be easily adapted to the needs of young caregivers, their chronically ill parents and the whole family. Studies indicated that READY is associated with increase in resilience in people with multiple sclerosis, colorectal cancer survivors and people with diabetes (Hawkes, Pakenham, Chambers, Patrao, & Courneya, 2014; Hawkes et al., 2013; Pakenham, Mawdsley, Brown, & Burton, 2018; Ryan, Pakenham, & Burton, 2019). All in all, fostering resilience and its protective factors – including psychological flexibility, positive interpersonal relationship, mindfulness, subjective well-being, and health behaviors – through READY in young caregivers and their families, will likely ameliorate the detrimental impact of parental chronic illness on the whole family and result in improved HRQoL for all family members.

5.3 Limitations and Strengths

This PhD thesis has some limitations that should be discussed. First of all, the sample used in this dissertation was nonrandomized as participants were recruited only whether they lived with a chronically ill parent. Second, this thesis relied solely on youth self-report data rather than including parental assessment. Given that offspring and their parents might have different perspectives on the impact of parental chronic illness, it is important to collect data from both. In addition, the sample mainly consisted of Caucasian youth with a Western cultural influence, therefore, undermining the generalizability of results across different cultures. Third, the sample of youth used in this dissertation had a wide age range and some of the administered instruments were utilized outside the normative ages – i.e., the Youth Self-Report (YSR). Fourth, given that the original YCOPI-R Part B already required further work, its Italian structure is tentative as well. Fifth, in the studies described in Chapter 3 and Chapter 4, using the Process macro for path analyses only permitted to test for observed variables and one dependent variable at a time while other structural equation modeling programs could have allowed to examine latent variables and an overall model fit.

Despite these limitations, this PhD thesis has several strengths such as the fact that it is the first to validate the YCOPI-R in the Italian population, opening up the possibility to develop and evaluate young carer services and interventions with a solid instrument for the assessment of young caregivers in Italy. This dissertation was also the first in the young carers field to harness a core construct from the flourishing ACT literature and demonstrate its relevance to shaping youth and family functioning in the context of parental illness. Thirdly, this thesis used a mixed parental diagnosis sample and assessed both positive and negative youth psychosocial adjustment outcomes as well as family-level outcomes – while most of the studies in this field have focused on adverse youth outcomes only. Fourth, this dissertation was the first in the young carers field to clarify both theoretically and empirically the construct of youth caregiving into three measurable components embedded within a broader conceptual framework of the effects of parental illness on youth. In fact, it innovatively tested the simultaneous effects of all three components of youth caregiving on offspring adjustment, highlighting the concomitant benefits and costs of youth caregiving.

5.4 Future Research

Young carers are a high-risk group that should receive particular attention in order to inform the development of young carer interventions that target empirically supported mechanisms which ameliorate the detrimental effects of parental illness on youth. Further research examining the effect of youth caregiving is necessary in order to address the unique needs of these youth and their families. Future research should test other possible mediators and moderators within the FEF-R, such as youth coping strategies, social support and benefit finding. While coping strategies and social support have been widely investigated in the caregiving literature, there is a dearth of research on benefit finding and its relationship with youth caregiving. Moreover, the tripartite nature of caregiving within the FEF-R should be further explored in order to elucidate the effect of each caregiving components on each other and their simultaneous impact on youth outcomes and family functioning. Research should also focus on different developmental stages of childhood, examining the distinct impact of parental chronic illness in early, middle and late childhood; up to now, there is a lack of studies focusing on younger children (aged 0-11 years). Future studies should further investigate family dynamics in the context of parental chronic illness and analyze how parental illness influences family interactions in the long term. Longitudinal researches are also needed to confirm causality of results over time. Moreover, the factor structure of the Italian version of the YCOPI-R should be further tested. Finally, randomized controlled trials should explore the efficacy of preventive interventions for young carers and their families – as the proposed adaptation of the READY program – as well as analyze the cost-effectiveness of such tailored individual and family treatments.

5.5 General Conclusions

This PhD project draws attention towards youth of chronically ill parents, a segment of the young population which is presently almost completely neglected in Italy by health policies and healthcare providers. Despite the well-known fact that children of parents with chronic illnesses are a population at risk of developing psychosocial problems (Maybery et al., 2009; Krattenmacher et al. 2014) research is still lacking of individual and family tailored preventive interventions for these families (Morley et al., 2016; Davey et al., 2016). This PhD project originally aimed to increase insight on risk and protective factors in offspring with chronically ill parents in order to inform the development of young carer interventions that target empirically supported mechanisms which ameliorate the detrimental effects of parental illness on youth and to develop specific screening tools for this at-risk population.

To these aims, this dissertation represents an important advancement in the creation of an empirically supported framework to understand the impact of parental illness on youth psychosocial adjustment. It underlined the key protective role of *psychological flexibility* in shaping youth adjustment and family functioning in the context of parental illness, providing a pathway for the creation of tailored interventions programs targeting psychological flexibility in the young carers field. It also innovatively clarified the nature of youth caregiving indicating that it is a tripartite construct related to both positive and negative youth adjustment outcomes, thereby paving the way for interventions that mitigate adverse and cultivate positive effect of youth caregiving. It also confirmed that the YCOPI-R is a sound measure of caregiving responsibilities and experiences in Italian youth and that it could be used to develop and evaluate young carer services and interventions in the Italian context. This PhD project ultimately shed light into the processes through which parental illness results in detrimental youth outcomes and highlighted avenues for targeted interventions that assist this high-risk group of youth.

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