Who cares?

Identifying young caregivers, their problem behavior and need of support

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Contents

Abstract

Children undertaking caring responsibilities for their ill or disabled parents have been referred to as young caregivers. Research presents an inconsistent picture about how to define a young caregiver and how youth is affected by caregiving. We aim to (1) generate accurate cut-off values to identify young caregivers and non-caregivers, (2) investigate differences in problem behavior between these two groups and (3) gain insight into caregivers' need of support. In this Dutch study, a series of self-report measures were completed by 161 adolescent children (51.6% girls, mean age = 15.1) with parents with a chronic medical condition. Two questionnaires, the Dutch Caregiving Inventory and the Young Caregiver of Parents Inventory, were used to measure the extent to which the adolescent provides care for the ill parent. Problem behavior was assessed using the Youth Self Report. Cut-off values of caregiving variables were generated based on previous quantitative and qualitative research. Once caregivers and non-caregivers were identified, differences in their problem behavior were analyzed. Finally, this study revealed a number of 67 caregivers (39.8% girls, mean age = 15.5) and 94 non-caregivers (60.2% girls, mean age = 14.8). Young caregivers displayed higher internalizing problem behavior than non-caregivers. Qualitative examination of young caregivers' need of support indicate their wish for opportunities to be heard. To initiate support for young caregivers, instruments identifying them must be developed. Recommendations are made for increasing awareness and understanding towards the needs and lives of adolescents affected by parental illness.

1. Introduction

> It's too late for me now. My dad died and I'm no longer a 'young carer', but for all those other kids out there who are in the same situation I was, then something should be done to help them. (. . .) help them care without worrying, without being frightened. (Jimmy, personal communication, September, 1992)

1.1 Young Caregiving

Parental illness disrupts family functioning and may frequently be accompanied by great caregiving responsibilities for adolescents (Ireland & Pakenham, 2010). Caregiving responsibilities and involvement in household chores are generally encouraged during childhood; the extent of such, however, must be congruent with age and maturity (Bjorgvinsdottir & Halldorsdottir, 2014). Children providing care for their ill or disabled parents receive increased attention in research, health and social services (Aldridge, 2008). Recent austerity measures, which have led to decreased financial support for ill people in several European countries, put high pressure on families to provide care at home (Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, 2011). Since January 2015, Dutch municipalities are responsible for providing care for their citizens themselves rather than the state (Rijksoverheid, 2015). Due to this decentralization in healthcare and extensive cutbacks in specialist health expenses (algemene wet bijzondere ziektekosten), the municipalities have to fulfill more tasks with less money (Van der Bles, 2013). Effects on healthcare by the new system remain to be seen, but it is indeed a concern currently discussed in the Netherlands. In the case of money shortages or the failure of municipalities to provide the care required, children with parental illness might not receive the support necessary to prevent them from adopting the role of a caregiver.

Who is a young caregiver? Although research on young caregivers has increased within the last 10 years, there is still no universal agreement regarding the definition. Some define young caregivers in a detailed manner according to the intensity or level of responsibilities they assume as well as resulting restrictions in their activities (Pakenham, Chiu, Bursnall & Cannon, 2006). Others use broader definitions, emphasizing the risk of stringent definitions excluding those who would benefit from services (Newman, 2002). For the purpose of this study, the following definition applies: Young caregivers are adolescents between 10 and 20 years of age providing assistance on a regular basis to their parents who need help because of a chronic medical condition. Young caregivers experience activity restrictions and feel responsible in terms of providing care for the ill parent. The extent to which they provide care is higher than in youth with healthy parents (Carers National Association, 1998; Pakenham et al., 2006; Siskowski, 2006).

In order to conduct research on the impact of young caregiving, understanding of the underlying issues is necessary. Caregiving ranges from domestic care, general support and emotional support to personal care and care for siblings (Lackey & Gates, 2001). According to several studies, young caregivers perform more household chores than non-caregivers (Hunt, Levine, & Naiditch, 2005; Nagl-Cupal, Daniel, Koller, & Mayer, 2014). According to Warren (2007) the extent of involvement in significant tasks, such as helping with intake of medication or personal hygiene, distinguishes caregivers from non-caregivers the most. Also, caregiving is time-consuming and may prevent adolescents from engaging in social activities (Aldridge & Becker, 1999; Bjorgvinsdottir & Halldorsdottir, 2014; Lackey & Gates, 2001). Accordingly, young people express the need for social support due to feelings of isolation, which are found to be a strong predictor of young caregivers' adjustment to parental illness (Aldridge & Becker 1993; Ireland & Pakenham, 2010). Based on these empirical findings, we identify young caregivers based on the extent of involvement in caregiving tasks, caregiving responsibilities, activity restrictions and feelings of isolation. In this study, adolescents of parents with a chronic medical condition, fulfilling caregiving corresponding to youth with healthy parents are referred to as non-caregivers. According to Warren (2007) adolescents who do not assume the caregiving role typically prepare light meals and tidy or dust their own room but rarely perform other household chores. Non-caregivers also rarely provide personal care and when they do, they are more likely to assist with intake of medication or healthcare, rather than participating in intimate care tasks such as bathing or using the toilet (Warren, 2007).

1.2 Prevalence

Changes in healthcare systems including cuts in home care, shorter hospital stays and higher life expectancy are associated with an increase in the number of young caregivers (Cohen, Greene, Toyinbo & Siskowski, 2012; Gates & Lackey, 2001). Additionally, several demographic trends such as decreasing family size, high divorce rates and a higher number of single parents lead to fewer adults spending fewer hours in the home resulting in a shift of family care onto children and adolescents (East, 2010). Likewise, the fact that parents are conceiving children at an older age, which is related to elevated vulnerability for chronic diseases, seems to increase early caregiving experiences (Kacharek & Shifren, 2003; Korneluk & Lee, 1998).

Most studies giving insight into the situation of young caregivers provide qualitative data, whereas quantitative data, especially estimated prevalence, appears to be rare (Nagl-Cupal et al., 2014). In the Netherlands, 13.2% of children have a parent with a chronic illness (Goldschmeding, Van de Looij-Jansen, & Butte, 2006). How many of those children provide care for their parents, however, was not yet examined. The Office for National Statistics (2003) presented a prevalence of 1.6% of young caregivers aged 5 to 17 in the UK. This study restricted caregiving as being unpaid or providing care for 20 hours or more per week. The National Alliance for Caregiving in the U.S. reports 3.2% of young caregivers aged 8 to 17. This survey defined a caregiver as “anyone who provides unpaid help or care to anyone in the household or any relative, whether or not the relative lives with the caregiver. The care may include help with personal needs, meals, household chores, shopping, paperwork, medication, getting around, or visiting regularly to see how the care receiver is doing” (Hunt et al., 2005, p.11). The New Zealand Census of 2006 identifies 4.2% of children aged 15 to 18 years as young caregivers (McDonald, Cumming, & Dew, 2009). This high prevalence, within a small age range, could be explained by a rather broad definition: A caregiver is anyone who, within the past four weeks, looked after a member of his or her own household who was ill or had a disability. A recent study in Austria revealed 3.5% of caregiving children aged 5 to 18 years (Nagl-Cupal et al., 2014). This study emphasized any age below 18 and identified caregivers based on the extent of their caregiving activities. This list of prevalence rates shows that their discrepancy may be linked to different definitions of a caregiver. Hence, estimating the actual number of young caregivers is challenging due to lack of standardized criteria required to define a young caregiver (Newman, 2002). Pakenham et al. (2007) explain this difficulty of estimating the actual prevalence through the tendency for young caregivers to stay hidden and to not identify themselves as such. Bjorgvinsdottir and Halldorsdottir (2013) found that young people feel invisible, unacknowledged and unsupported as caregivers. Most of them, however, seem to be reluctant to draw attention to their role as a caregiver due to fear of being ridiculed or making the situation worse (Banks et al., 2002).

1.3 Young Caregiving and Sociodemographic Factors

Various aspects influence the impact of caregiving on adolescents. According to Nagl-Cupal et al. (2014), the average age of young caregivers is around 12 years, although the number of young caregivers increases with time. Most caregivers are female (Lackey & Gates, 2001). Eley (2004) describes a 'hierarchy of care', determining that those who in fact become caretakers is dependent on age and gender. Moreover, the presence of siblings may interact with the caregiving experience. Caregiving responsibilities may be shared between siblings or, dependent on age, may be taken over by one adolescent providing care for both their younger siblings and ill parent (Pakenham et al., 2006). Accordingly, this study controlled for sociodemographic factors including gender, age and presence of siblings.

1.4 Young Caregiving and Problem Behavior

The impact of young caregiving on youth is not well understood so far. Johnston, Gumaer, Martin and Martin (1992) found increased self-dependence, readiness to help others and tolerance, with respect to diseases, in youth caring for their ill parents. Additional positive outcomes were found including increased maturity (Pakenham, Bursnall, Chiu, Cannon & 2006), confidence, self-esteem, resilience (Ryan & Fox, 2003), closer family relationships and greater skill development such as greater sensitivity, sharing, empathy and patience. For instance, in a study by Banks et al. (2001), parents reported that their child had gained understanding of the possible limitations of people, learned to be patient and could therefore easily accept and help others. Likewise, a young caregiver reported that caring for his mother felt like a positive reward as it made life less stressful for her (Banks et al., 2001). The majority of studies, however, report an adverse impact of youth taking over caregiving responsibilities on their functioning, including emotional or physical health, school performance and psychosocial adjustment (Cohen et al., 2012; East, 2010; Ireland & Pakenham, 2010; Ryan & Fox, 2003; Shifren, 2008; Siskowski, 2006). In Frank's survey (1995), young caregivers report feelings of resentment, anger, emotional exhaustion and feelings of isolation. Examples of negative outcomes include a decrease of participation in social activities, a decrease of friends visiting or ability to meet friends during leisure time.

Also, some children report tiredness and fear of bullying associated with school (Banks et al., 2001).

1.5 Need of Support

The main focus of most services lies with the care receiver, thus, many caregivers wish for increased attention and the opportunity to talk about their needs and opinions (Banks et al., 2010). Aldridge and Becker (1993) described the needs of young caregivers regarding support as very modest but clear. Youth providing care for ill parents want someone they can trust in order to talk about concerns or fears. Retrospective research by Lackey & Gates (2001) showed that former caregivers repeatedly emphasized the necessity of providing support. They reported that they wished that someone had told them what was going on with the ill parent and had received information about the diagnosis, prognosis and instructions regarding care. Becker et al. (1998) suggest that families and young caregivers in particular could benefit from professional guidance that takes the interests of all family members into account. Support for families with parental illness comes in a number of guises (Banks et al., 2010). Services provided for young caregivers usually offer counseling as well as leisure activities enabling a break from caring. Access to such services however, depends on the location and knowledge about their existence. Throughout the UK, the Carers National Association (1998) estimated about 110 projects supporting young caregivers; but their network only actively knew of a few young caregivers. Furthermore, Aldridge and Becker (1993) reported that professionals who were in touch with families affected by parental illness failed to talk to children about their role or did not identify them as young caregivers. A recent finding of Bjorgvinsdottir and Halldorsdottir (2013) also revealed that most of the young caregivers were never asked or consulted about the nature or experience of their caregiving role.

1.6 Aim

Most research so far has focused on the impact of parental illness on youth without taking into account the caregiving role these children potentially assume (Pakenham et al. 2006). Current research and theory is characterized by differing views regarding the impact of caring at a young age. Adolescents are a vulnerable group, potentially facing significant difficulties when engaging in the role of a caregiver (Carers Australia, 2001). Young people may fulfill several caretaking responsibilities leading to excessive demands and overwhelming emotions

(Ireland & Pakenham, 2010; Siskowski, 2006). Findings of how caregivers differ from non-caregivers are inconsistent (Nagl-Cupal et al., 2014). Young caregiving is initiated by the onset or presence of parental illness. Yet, not all adolescents with ill parents will inevitably become caregivers, because families often receive enough external support (Aldridge & Becker, 1999). Many studies, however, conducted their research adopting this view. Therefore, this study investigates solely adolescents with parental illness, intending to identify caregivers based on their self-reported caregiving tasks and caregiving experience. Hence, our first aim is to generate cut-off values revealing a group of caregivers and a group of non-caregivers. Research displays inconsistent findings regarding the impact young caregiving has on adolescents with parental illness. Thus, our second aim is to investigate the differences across the groups of caregivers and non-caregivers in terms of problem behavior. Finally, this study aims at gaining insight into caregivers' support needs. This includes investigating their agreement on receiving support as well as which kind of support they desire.

1.7 Research Question

This study will focus on adolescents with chronically, physically ill parents and associated caregiving in children from the ages of 10 – 20 years. Once identified as a young caregiver, the question of interest is how young caregivers differ in their problem behavior and their need of support compared to non-caregivers.

1.8 Hypotheses

This study assumes that adolescents identified as young caregivers differ from non-caregivers in terms of involvement in caregiving tasks and caregiving experience (H1). Furthermore, based on the fact that the majority of studies show adverse consequences, we hypothesize that young caregivers show increased externalizing problem behavior (H2) as well as internalizing problem behavior (H3) compared to non-caregivers. Finally, we hypothesize that more caregivers are in need of support than non-caregivers (H4).

2. Method

2.1 Data

This research is based on data collected in the context of dissertational research *The Impact of Parents' Chronic Medical Condition on Children* by Sieh (2012). Data was gathered between 2008 and 2012. Research-related literature was found through database search engines including *PubMed*, *Google Scholar* and *Web of Science* from the digital library of Leiden University. Additional and complementary information was found using the ancestry approach. Search terms included *young caregiving*, *young carers*, *young caregivers*, *youth caregivers*, *illness* and *chronic* combined with *internalizing*, *externalizing*, *problem*, *adjustment*, *consequences* and *impact*.

2.2 Participants

We included adolescent girls and boys between 10 and 20 years of age living together with at least one parent with a chronic medical condition (CMC). In this study, CMC was restricted to somatic conditions. Parental CMC was defined as the impairment of one or more organ systems by a disease or injury impairing health for at least 6 months (Brown et al. 2007; Livneh and Antonak 2005). Medical conditions involved multiple sclerosis, rheumatoid arthritis, brain damage, muscle disease, spinal cord injury, inflammatory bowel disease, Parkinson disease and diabetes type I with physical complications (Sieh, 2012). Children were excluded from participation in case of severe somatic or psychiatric disorder, insufficient knowledge of Dutch language or residency outside of the Netherlands (Sieh, 2012).

2.3 Procedure

Across the Netherlands, families with parental CMC were recruited at general practitioners, health organizations, rehabilitation and community centers, hospitals, schools, and public places. Recruiting procedures involved brochures and posters containing information about the project. When interested in participation, families contacted the researchers by e-mail or phone. Participants completed several questionnaires administered by research assistants at the families' home. After completion, adolescents received a gift worth 10 Euro. The project manager had designed a research protocol, guiding the assistants after training them.

2.4 Informed Consent and Ethical Approval

The study was approved by the ethics committee of the Research Institute of Child Development and Education at the University of Amsterdam in June 2008. Active informed consent was obtained from all participating patients and children (Sieh, 2012).

2.5 Measures

Caregiving Variables

The extent of caregiving was determined by self-report data based on two aspects: *Caregiving tasks* and *caregiving experience*. Caregiving tasks provided by youth included the frequency of household chores, such as taking out garbage or cleaning the house and significant tasks, such as supporting the parent with eating or intake of medication. Caregiving tasks were measured using the Dutch Caregiving Inventory (DCI). Sixteen items were answered on a 5-point scale (i.e., *not at all*, *less than once a week*, *1–3 times a week*, *3–6 times a week* and *daily*). Higher scores indicated more chores reported by young participants (Meijer, Oostveen, & Stams, 2008). Cronbach's alpha within the items of caregiving tasks was $\alpha = .75$. Caregiving experience was determined by the extent of caregiving responsibilities, activity restriction and feelings of isolation. Caregiving experience ($\alpha = .84$) was measured using the Young Caregiver of Parent Inventory (YCOPI) by Pakenham et al. (2006). Youth filled in three subscales measuring *caregiving responsibilities* (8 items; Cronbach's alpha = .84), *activity restriction* (8 items; $\alpha = .87$) and *feelings of isolation* (3 items, $\alpha = .78$). Example items are "Others expect me to help my parents", "I feel as though I am missing out on things" and "I sometimes feel alone", respectively (Sieh, 2012). Accordingly, they rated the extent to which they agreed on each item, using a 5-point scale ranging from *strongly disagree* (0) to *strongly agree* (4).

Identifying Caregivers

Regarding the first aim of this study, identifying young caregivers, a mixed methods approach was elected. Mixed methods research is increasingly recognized as the third major research approach, combining elements of quantitative and qualitative research in order to answer research questions (Johnson, Onwuegbuzie & Turner, 2007). To identify caregivers and distinguish them from non-caregivers, this study defined a double-staged cut-off point as illustrated in Table 1.

Criterion 1: For the process of identifying caregivers and non-caregivers based on caregiving tasks the mixed methods approach allowed us to generate adequate cut-off values based on qualitative data derived from research by Warren (2007), highlighting differences between young caregivers and non-caregivers. Corresponding to Warren (2007), cut-off values were generated for the domains of household chores and significant tasks, respectively.

Criterion 2: Participants rated their caregiving experience based on caregiving responsibilities, activity restriction and feelings of isolation. The cut-off values for this criterion derived from research by Pakenham et al. (2006); normative caregiving experience in adolescents with healthy parents were measured. Corresponding to these measures, a caregiver has to score at least one standard deviation above the mean of a non-caregiver.

Table 1

Identifying young caregivers

	Criteria
1. Caregiving tasks	Criterion 1: A minimum of *1 hour per week on average* spending on household chores OR a minimum of *1 hour per week* spending on at least one significant task
2. Caregiving experience	Criterion 2: Caregiving responsibility: $M \geq 1.84$ AND Activity restriction: $M \geq 1.48$ AND Feelings of isolation: $M \geq 2.73$

Note. M = Mean; means and standard deviations for cut-off scores derived from “The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers,” by K. I. Pakenham, S. Bursnall, J. Chiu, T. Cannon and M. Okochi, 2006, *Rehabilitation Psychology*, *51*, 113–126.

Adolescent Problem Behavior

For the purpose of this study, problem behavior is operationalized as emotional and behavioral difficulties, involving internalizing and externalizing problems. Externalizing problems refer to aggressive or delinquent behavior; internalizing problems refer to behavior directed toward the self, such as anxiety, withdrawn behavior or somatic complaints. Problem Behavior was determined by one of the most widely used self-report screening tools for behavioral and emotional problems in adolescents. The Youth Self-Report (YSR) from Achenbach (1991) operationalized internalizing problem behavior (31 items) and externalizing problem behavior (30 items). Adolescents rated their behavioral problems on a 3-point Likert scale (0 = *absent*, 1 = *occurs sometimes*, 2 = *occurs often*). Sieh (2012) reported satisfactory to good reliability for externalizing subscales *aggressive behavior* and *rule-breaking behavior* (α = .60 and α = .79, respectively). The same applied for internalizing subscales *withdrawn behavior*, *somatic complains* and *anxiety/depression* (α = .65, α = .71, and α = .86, respectively). Internal reliability for the total problem behavior scale was excellent (α = .92). Example items include "I would rather be alone than with others", "I feel dizzy or lightheaded", "I am too fearful or anxious" within the internalizing scale and "I destroy things belonging to others" and "I break rules at home, school, or elsewhere" within the externalizing scale. Descriptive and psychometric data for all measures are summarized in Table 2.

Table 2

Descriptive and Psychometric Properties of Scales

	No.	Young caregivers		Non - caregivers	
	items	*M*(*SD*)	*Range*	*M*(*SD*)	*Range*
Caregiving tasks	16	9.41 (3.46)	1 – 19	5.11 (3.22)	0 – 20
Household chores	8	9.41 (3.46)	1 – 19	5.11 (3.22)	0 – 20
Significant tasks	8	2.54 (3.64)	0 – 18	0.67 (1.45)	0 – 9
Caregiving experience	16	48.84 (9.31)	33 – 74	35.43 (9.03)	19 – 65
Caregiving responsibilities	8	23.42 (4.39)	16 – 36	18.52 (5.59)	8 – 31
Activity restriction	8	17.48 (4.96)	12 – 31	11.04 (4.29)	8 – 33
Problem Behavior	61	21.03 (12.66)	4 – 65	14.31 (11.34)	1 – 71
Externalizing problems	30	8.34 (5.23)	0 – 24	6.70 (5.62)	0 - 32
Internalizing problems	31	12.69 (9.18)	1 – 42	7.61 (7.58)	0 –39

Note. Scale scores obtained by summing across items.

Need of Support

Young caregiver's need of support was measured and investigated based on three levels: Whether the adolescent agreed on receiving support, which kind of support they would wish for and (optionally) what they consider to be the most important support for youth with parental illness. Participants could choose up to nine different support aspects including (1) talking about the disease and its consequences, (2) talking about the best coping strategies, (3) talking about how to get help-care, (4) talking about everyone's well-being, (5) looking for possible solutions, (6) looking for strengths within the family and support them, (7) help with financial issues, (8) help with the household and (9) organizing a qualified person to take over caregiving tasks. Multiple choices were possible.

2.6 Statistical Analysis

This study checked the data for accuracy by correcting incomplete, inconsistent and ambiguous answers. After conducting a missing values analysis, we used expectation maximization at random to substitute missing values. The statistical analysis was completed using IBM Statistics, version 22; *p*-value was set at .05, two-tailed. Bivariate correlations between caregiving variables, problem behavior, age, gender and presence of siblings were analyzed by inspecting the correlation matrix. Correlations were compared across both groups by calculating *Z*-values (Field, 2013). Gender and presence of siblings were converted into dummy variables using the value 1 for boys, 2 for girls; 1 for presence of siblings, 2 for no siblings. Adolescents were assigned to either the group of caregivers or the group of non-caregivers through computing caregiving variables, calculating the means and finally recoding them into different variables according to the cut-off values illustrated in Table 1. For the purpose of identifying group membership, we used the value 1 for caregivers and 0 for non-caregivers. Finally, to test whether our analysis was accurate at identifying group membership, a discriminant analysis was conducted. The dichotomous variable of caregiving or not caregiving was entered as the grouping variable; our predictor variables, caregiving tasks and caregiving experience, were entered as independent variables. Accordingly, to capture the performance of our method predicting group membership Youden's Index J was calculated (J = sensitivity + specificity – 1). The index combines information about sensitivity, that is the proportion of caregivers correctly identified as such and specificity, the proportion of non-caregivers correctly identified as such (Youden, 1950).

Methods of descriptive statistics, including frequencies, were used to analyze characteristics of young caregivers. Whether young caregivers differed from non-caregivers on demographics was determined by carrying out a one-way ANOVA's on age; chi-square analyses on gender and presence of siblings. Corresponding to our hypotheses, ANCOVA's were conducted to determine whether young caregivers differed from non-caregivers in problem behavior. The dependent variables entered were externalizing and internalizing problem behavior, respectively. The fixed factor was the dichotomous variable of group membership, representing the independent variable. Age, gender and presence of siblings were entered as covariates. Before starting the analysis of covariance, the following assumptions were examined (Field, 2013): We examined normal distribution through using the Kolmogorov – Smirnov analysis and inspecting Normal Quantile-Quantil Plots (Q-Q Plot). We also assessed homogeneity of regression slopes between the covariates and dependent variables. Filtering methods were used to reduce error variance and provided us with a clearer picture of our analysis. For the same purpose, the relations of covariates with the independent and dependent variable were investigated. Prior to controlling for any covariate, we explored the main effect for problem behavior in respect of caregiving or non-caregiving groups using univariate analyses.

Subsequently, this study took a closer look at five caregivers displaying very high caregiving scores. Demographic characteristics including age, gender, presence of siblings and type of parental illness were investigated. Additionally, raw score means were calculated for these cases within the scales of household chores, significant tasks, caregiving responsibilities, activity restriction, externalizing and internalizing problem behavior. Frequency methods were used to investigate the extent of agreement with need of support. Finally, caregivers’ answers to the optional question about their considerations on the most important support needed were investigated in a qualitative manner by collecting and then clustering them according to overlapping themes. Answers were assigned to either of the following levels: individual, family or context. The former included support directly associated with the personal and emotional desires within the individual. Support on the family level addressed needs and interrelations within the family. The contextual level addressed support associated with the social structure including social services, school and healthcare systems.

3. Results

3.1 Sample Characteristics

The sample of this study consisted of 161 young people with an ill parent; all participants were Dutch. The age ranged from 10 – 20 years. The mean age of the children was 15.09 years, with a standard deviation of 2.33. The overall sample consisted of 51.6% female children. Fifty-two children were only-children (32.3%).

3.2 Identifying Caregivers

Based on 8 items measuring the extent of household chores, the analysis yielded the cut-off value of $M \geq 1$, exposing every adolescent who spent at least one hour per week on average exerting household chores. Based on 8 items measuring significant caregiving tasks, the analysis yielded a cut-off value of $X \geq 1$, exposing adolescents who reported engaging in at least one significant caregiving task for a minimum of one hour peer week. Our analysis of caregiving tasks revealed 66 (41%) adolescents to be caregivers based on household chores and 78 (48.4%) caregivers based on significant caregiving tasks. Together, by Criterion 1 of caregiving tasks, 104 (64.6%) young caregivers were identified. Our analysis of caregiving responsibilities revealed 132 (82%) and activity restriction revealed 91(56%) caregivers. Based on the three items of feelings of isolation, no caregivers were identified; so this scale was excluded from the analysis. Children scored 0.84 on average; a mean of 2.73 was required to be a caregiver. Hence, by Criterion 2 of caregiving experience, over half of the children (n=86, 53.4%) were identified as caregivers. The total number of caregivers in this study, fulfilling both criteria 1 and 2, was 67 adolescents (41.6%). The average age of young caregivers was 15.46 years (SD=2.28).

The test of equality of group means shows that caregivers significantly differ from non-caregivers on both the predictor variables, that is caregiving tasks and experience [$F(1, 159) = 65.74, p < .05$; $F(1, 159) = 84.02, p < .05$], respectively. Hence, our first hypothesis was confirmed. The corresponding correlation of .68 suggests that our analysis has a moderate effect ($d = .46$) on the grouping variable, that is whether an adolescent is a caregiver or not. Wilks' Lambda shows that our caregiving variables predicted group membership ($p < .05$). Standardized canonical discriminant function coefficients revealed caregiving experience to have a slightly higher importance as a predictor ($\beta = .71$) than caregiving tasks had ($\beta = .60$). Cross-validated classification results showed that we were able to correctly predict 76.1% (sensitivity) adolescents as caregivers and 87.2% (specificity) as non-caregivers. Our calculation of the Youden's Index yielded a value of $J = .63$.

Table 3

Demographic Characteristics of Sample after Categorization into Caregivers and Non-Caregivers

Demographics	Young caregivers % (*N*)	Non-caregivers % (*N*)
Caregiving tasks	**64.6 (104)**	**35.4 (57)**
Female	61.4 (51)	38.6 (32)
Male	67.9 (53)	32.1 (25)
Siblings	67.9 (74)	32.1 (35)
Caregiving experience	**53.4 (86)**	**46.6 (75)**
Female	55.4 (46)	44.6 (37)
Male	51.3 (40)	48.7 (38)
Siblings	55.0 (60)	45.0 (49)
Total	**41.6 (67)**	**58.4 (94)**
Female	39.8 (33)	60.2 (50)
Male	43.6 (34)	56.4 (44)
Siblings	43.1 (47)	56.9 (62)

Table 4

Means, Standard deviations and Range of Age in Caregivers and Non-Caregivers

	Young caregivers		*Non-caregivers*	
	M (*SD*)	*Range*	*M* (*SD*)	*Range*
Caregiving tasks	15.26 (2.34)	10-20	14.78 (2.31)	10-19
Caregiving experience	15.43 (2.24)	10-20	14.71 (2.39)	10-20
Total	**15.46 (2.28)**	**10-20**	**14.83 (2.34)**	**10-20**

Note. *SD* = Standard deviation.

Table 3 and Table 4 summarize the demographic findings of young caregivers and non-caregivers. Results of the one-way ANOVA [F(1, 159) = 2.83, *p* = .093] displayed that the young caregiver's age did not significantly differ from non-caregiver's age (*M*=14.83, *SD*=2.34). Of identified caregivers, 39.8% were female and 43.1% had siblings. Chi-square tests showed that neither gender nor presence of siblings showed significant association with group membership ($p > .05$). Externalizing problem behavior highly correlated with internalizing problem behavior in both groups. Also in both groups, the relationship between externalizing problem behavior and caregiving experience displayed large effect sizes. In caregivers, caregiving experience displayed a moderate correlation with internalizing problem behavior. For caregivers, the presence of siblings and caregiving tasks showed a strong significant correlation. Within the group of non-caregivers, adolescent gender highly correlated with caregiving experience. Table 5 displays correlations between variables for caregivers and non-caregivers, respectively. Internalizing problem behavior was correlated with age in caregivers, r (67) = .34, $p < .05$, but not in non-caregivers, r (94) = .00. The difference between these correlations was statistically significant, $Z = 2.17$, $p < .05$.

Table 5

Bivariate Correlations between Variables for Caregivers and Non-Caregivers

	1 *cg / n-cg*	2 *cg / n-cg*	3 *cg / n-cg*	4 *cg / n-cg*	5 *cg / n-cg*	6 *cg / n-cg*
1 *Cg tasks*	-					
2 *Cg experience*	.24 / .08	-				
3 *ExtP*	.11 / -.13	.23 / .24*	-			
4 *IntP*	.16 / -.01	.47* / .48**	.51** / .46**	-		
5 *Age*	.32** / .11	.29* / .08	.18 / .11	.34* / -.00	-	
6 *Gender*	.09 / .04	.12 / .03	-.19 / -.08	.16 / .28**	.26* / -.19	-
7 *Siblings*	-.17 / .08	.23 / .10	.06 / .13	.07 / .00	-.00 / .00	-.01 / -.04

Note. *cg* = caregivers; n-cg = non-caregivers; *ExtP* = Externalizing Problem Behavior; *IntP* = Internalizing Problem Behavior. For variables of caregivers N = 67, variables of non-caregivers N = 94, * $p < .05$ (two-tailed), ** $p < .01$(two-tailed).

3.3 Comparison between caregivers and non-caregivers on problem behavior

Externalizing problem behavior

Kolmogorov Smirnov analysis confirmed normal distribution of the interval covariate across both groups yielding a *p*-value greater than .05. However, distribution of externalizing problem behavior in non-caregivers deviated from normality ($p < .05$). We did not consider this a violation of assumptions, as normal distribution of the dependent variable is less crucial, particularly in large samples (Tabachnick & Fidell, 2007). The requirement of homogeneity for regression slopes was satisfied, as there was no significant interaction between the caregiving groups and covariates ($p > .05$). Age, presence of siblings and gender did not significantly vary across the groups of caregivers and non-caregivers ($p > .05$); age, however, did significantly correlate with externalizing problem behavior [$F(1, 159) = 6.94, p = .01$]. Gender and presence of siblings did not significantly correlate with externalizing problem behavior and could therefore not be included in the analysis of covariance (Mayers, 2013). The univariate analysis, prior to ANCOVA adjustments, indicated that externalizing problem behavior scores did not significantly differ between the caregiving groups ($p > .05$). This was also the case after controlling for age; ANCOVA revealed no significant difference in externalizing problem behavior between caregivers and non-caregivers ($F(1, 158) = 2.72$, $p > .05$, so we rejected our second hypothesis.

Internalizing problem behavior

According to Kolmogorov-Smirnov analysis and visual inspection of normal Q-Q plots, distribution of internalizing problem behavior deviated from normality in both groups ($p < .05$). There was no significant interaction between caregiving groups and presence of siblings or gender ($p > .05$). Prior to controlling for covariates, the univariate analysis indicated that internalizing problem behavior scores did significantly differ between caregiving groups ($p < .05$). After controlling for covariates, the analysis of covariance showed statistically significant effects for internalizing problem behavior in respect of caregiving groups [$F(1, 158) = 12.82, p < .05$], hence, we confirmed our third hypothesis.

3.4 Single Cases

Table 6 illustrates characteristics of five selected cases of caregiving adolescents, who displayed particularly high scores on caregiving variables. In three cases, adolescents' parents suffered from multiple sclerosis, the remaining two adolescents had parents suffering from brain damage and rheumatoid arthritis. Three cases had siblings and two cases were male. Case 2 agreed on need for support in the form of offering talks about adequate coping strategies. Case 4 wished for support in terms of talking about the disease and its consequences, everyone's well-being and about potential solutions for the situation. Case 5 also wished for help on how to cope with the situation, to talk about everyone's well-being and support with financial issues. Cases 1 and 3 did not answer the optional, open question.

Table 6

Demographic characteristics and raw score means of single caregiver cases (N = 5)

	1	2	3	4	5
Age	16.09	15.78	15.35	11.86	14.67
Gender	Female	Female	Male	Male	Female
Siblings	No	No	Yes	Yes	Yes
Parental Illness	MS	RA	MS	MS	BD
Household tasks *Range*: 0.07 – 2.50	1.38	1.38	2.50	0.88	0.88
Significant tasks *Range*: 0.13 – 2.13	2.00	2.13	0.75	0.38	0.13
Caregiving responsibility *Range*: 1.00 – 4.50	2.63	2.38	2.63	4.50	2.88
Activity restriction *Range*: 1.00 – 4.13	2.13	2.13	1.00	1.50	4.13
Externalizing problems *Range*: 0.00 – 1.03	0.03	0.43	0.00	0.30	0.30
Internalizing problems *Range*: 0.00 – 1.36	0.16	0.39	0.29	0.58	0.61

Note. MS = Multiple sclerosis, RA = Rheumatoid arthritis, BD = Brain damage.

3.5 Need of Support

Not more caregivers agreed on the need of support than non-caregivers did ($p > .05$). Frequency methods displayed a number of 25 caregivers and a number of 17 non-caregivers expressing a need for support. Caregivers most frequently selected support in the form of counseling meetings within the family, enabling talks about everyone's well-being. Table 7 summarizes caregiver's considerations on most important support aspects for adolescents with parental illness.

Table 7
Support aspects considered as important by Caregivers

Individual level	Family level	Context level
Trauma support	Counseling meetings with the whole family discussing current or future situations and improving family relationships	Support with financial issues and family allowance
Finding peers with same experience	Support to entertain family such as organizing activities	Increased attention and awareness towards youth with parental illness
Psychological support from the onset of the illness on; steady guidance from person of trust or coach		General information in schools about diseases, in order to increase knowledge and respect
External reassurance for their caregiving role		Support in the household

4. Discussion

4.1 General discussion

The first aim of this study was to develop a feasible method to identify caregivers. A mixed method approach was employed as cut-off values were generated based on both, qualitative and quantitative research. Caregivers were identified according to 1) the extent they performed caregiving tasks and 2) their experience of caregiving. Caregiving tasks included household chores and significant caregiving tasks. Caregiving experience included the perceived responsibility in caregiving and activity restriction. In the study of Pakenham et al. (2006), feelings of isolation appeared to be the strongest predictor of youth adjustment to parental illness, but in this study, every participant in this study scored within the norm. Hence, feelings of isolation, originally intended to be included in the method of identifying caregivers, were excluded. In total, 41.6% of our sample was identified as caregivers based on their involvement and experience in terms of providing care for the ill parent. Overall, subsequent analyses suggested the approach used in this study to be fairly accurate in identifying caregivers. Results showed that young caregivers might assume a wide array of caregiving duties as the level of involvement in caregiving tasks is significantly higher in caregivers than in non-caregivers. Likewise, the way they experience caregiving also significantly differs across the two groups. Caregiving responsibilities measured the caregiver's evaluation of their family's reliance and expectations regarding caretaking. Caregiving responsibility significantly correlated with both externalizing and internalizing problem behavior. This corresponds with earlier research displaying perceived choice of caregiving as the strongest correlate of caregivers' adjustment to parental illness (Pakenham et al., 2007). Aldridge and Becker (1993) reported that perceiving little or no choice in providing care, as well as feeling forced into taking over family responsibilities may subject young caregivers to a risk of psychological or social difficulties, like abandoning personal ambitions or few opportunities to develop social contacts. Furthermore, a higher sense of responsibility to assume a caregiving role may derive from socio-economic difficulties, restricting the family to receive external support (Aldridge & Becker, 1993).

The second aim of this study was to examine the effect of caregiving on young people with parental illness by assessing adolescent problem behavior. Hence, differences in problem behavior between caregivers and non-caregivers were of interest. The prediction that caregivers would display increased internalizing problem behavior compared to non-caregivers was supported. This indicates that adolescents considered caregivers show greater levels of withdrawn behavior, somatic complaints and anxiety or depression. Higher levels of somatic complaints correspond to findings of elevated somatization among adolescents with parental illness reported by Lester et al. (2003). Increased internalizing problems may also be associated with the withdrawn nature of young caregivers. According to Bjorgvinsdottir and Halldorsdottir (2013) adolescents feel invisible, unacknowledged and unsupported in their role as a caregiver, possibly leading to the suppression of one's own needs expressed through somatic complaints and anxious or depressive feelings. In contrast, caregivers did not differ from non-caregivers in terms of externalizing problem behavior involving rule-breaking and aggressive behavior. Low levels of externalization could reflect the positive impact of caregiving existent in several studies, such as maturity or increased tolerance which may buffer against engaging in aggressive or rule-breaking behavior on a conspicuous level (Pakenham et al., 2006; Ryan & Fox, 2003). These findings may also reflect their reluctance in drawing attention to themselves, avoiding to stress their role as a caregiver and to show their fear of making the situation worse (Banks et al., 2002). Caregivers may try to prevent any additional burden for their parents and therefore intend to stay out of trouble. These inconsistent findings (high levels of internalization and low levels of externalization in caregivers) correspond with the inconsistent picture throughout literature, reporting both positive and negative effects of caregiving, reflecting the complex nature of this issue.

The third aim of this study was to gain insight into the caregiver's perception regarding the need for support. Compared to non-caregivers, not significantly more caregivers agreed on the need of support. This finding may correspond with the fact that many young caregivers do not identify themselves as such and the decision to accept or seek help is a complex one (Banks et al., 2010). If young caregivers agreed on the need of support, they most frequently selected the option of someone leading counseling meetings within their family. Answers to the optional, open question about what caregivers consider very important when coping with parental illness involved support on an individual, family and contextual level. Examples included the desire to find peers with similar experiences, organizing activities or support with financial issues. Overall, young caregivers considerations about important support reflected the wish to be heard. These findings correspond to previous research, suggesting that caregivers feel invisible, unacknowledged and desire opportunities to talk about their situation (Banks et al., 2010; Bjorgvinsdottir & Halldorsdottir, 2013). Clearly, support for both, care recipient and caregiver is necessary, indicating that every family member is affected by parental illness and that support for the family as a whole is critical.

4.2 Limitations

This study possesses a number of strengths and limitations. The research question required exploration drawn from different data sources. The mixed method approach allowed to do so and combined strengths from both qualitative and quantitative research. An additional strength of this study is its focus on self-reported caregivers' needs. Lastly, strengths lie within a relatively large sample and the inclusion of a non-caregiver comparison group. However, this study also exhibits some limitations that have to be taken into account. For one, there is no concrete definition of what constitutes a 'normal' amount of providing care for an ill parent at a young age; it varies across cultural and social norms (Nagl-Cupal et al., 2014).

Also, the perspective of caregivers regarding their role, that is whether they perceive themselves as caregivers, could not be considered in this study. Furthermore, throughout the analysis of covariance regarding internalizing problem behavior, homogeneity of regression slopes was violated. As alternative analyses were beyond the scope of this research, results ought to be interpreted with caution. The study's results rely on adolescent perceptions, thus, accuracy of participants' answers could not be determined. Additionally, the cross-sectional design of this study did not allow insight into baseline problem behavior of adolescents before onset of illness. Another method-related limitation regards splitting the sample in two groups, reducing the sample sizes and possibly reducing variance (Field, 2013). Finally, it is necessary to keep in mind that caregiving incorporates several issues such as children's rights and well-being, ill people's rights, interpersonal relationships and family obligations (Banks et al., 2010). Thus, caregiving occurs on multiple levels within the family context rather than in isolation. Clearly, the fact that this study solely investigated the level of the child presents a limitation of this research.

4.3 Conclusions and Future implications

Adolescents providing care for family members in case of illness is a worldwide phenomenon (Nagl-Cupal et al., 2014). The role adolescents may play in case of parental illness needs to be recognized and validated by those working with children and families. Support desired by young people caring for an ill family member cannot be provided as long as adolescents stay declared as 'hidden' caregivers. Within our sample, 48.5% reported involvement in significant tasks, such as assisting with medication intake or body hygiene. According to Warren (2007), involvement in significant tasks distinguishes caregivers from non-caregivers the most. Considering that almost half of the participants in this study reported involvement in significant tasks, it may serve as an essential factor in terms of identification of young caregivers. Healthcare professionals, schools and hospitals should induce awareness and action towards identifying youth assuming a caregiving role. Our analyses of caregiving variables found caregiving experience, that is the extent to which adolescents feels responsible for providing care and restricted in their activities, to be slightly more important than caregiving tasks, that is involvement in household chores and significant tasks. This finding highlights the importance of including the child's experience in their role as a caregiver in future definitions.

Once identified as a caregiver, Aldridge and Becker (1999) emphasize a whole-family approach, integrating everyone's wishes. Society, especially healthcare providers need to assess family and children's needs in a holistic manner. Considering the reluctance of young caregivers to identify themselves as such, support must be provided on the basis of the requirements in a non-intrusive manner (Banks et al., 2010). In times where large proportions of young people have access to the Internet, it could be a way to provide various forms of support, ensuring the preservation of individual's anonymity. Information pages and opportunities to reach out to others in similar situations can be set up without forcing individuals to identify themselves as young caregivers (Banks et al., 2010). Need of support expressed by caregivers themselves addresses several levels involving policy, schools, social services and healthcare. Results suggest that interventions should build on social support systems and family education. Caregiving variables used by this study to identify caregivers illustrate areas to be targeted by support systems. Social and health services could provide assistance at home, offer counseling or organize leisure activities for adolescents. As the number of young caregivers is likely to increase, evidence-based interventions need to be developed in order to prevent adverse outcomes for children providing care for their ill parent.

In terms of future implications, youth should be taken into account within development of support services designed for ill or disabled parents. The overall awareness ought to grow and environments where young caregivers feel confident to talk about their needs and problems should be formed. Future research should include caregivers providing care to other family members such as grandparents or siblings. Furthermore, research should collect data from different perspectives on caregiving such as parents, peers or teachers. Also, future studies should gain additional insight into potential long-term effects of providing care at a young age through longitudinal study designs. Aldridge and Becker (1993) suggest that caregiving within families should be considered as mutual obligation and right. However, where is the line between normal expectations within a family environment and the point of children being adversely affected by providing care at a young age? This is a question that needs to be addressed in future research and practice, working towards a more sensitive and responsive environment for children who care.

In conclusion, this study shows that adolescents with parental illness do not inevitably become caregivers. In order to identify those who are indeed caregivers, we suggest the inclusion of both, adolescents' involvement in caregiving tasks and how they experience the provision of care for their ill family member. Being identified as a young caregiver appears to be associated with higher levels of withdrawn behavior, somatic complaints and anxiety or depression. Our recommendation is to increase awareness towards young people's potential role and needs in case of parental illness. Early screening of caregiving variables may contribute to problem prevention in adolescents with ill parents.

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