

Outcomes for children who care for a parent with a severe illness or substance abuse

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Children with ill parents: positive and negative outcomes of caring activities

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Author contributions

EKK, BW, TR substantially contributed to the conception and design of the study; EKK performed the statistical analysis, interpretation of data and drafted the manuscript. BW, TR, SB, BVR, KHB, helped with the analysis, interpretation of data and critical revision for important intellectual content. All authors approved the final version to be published.

Ethical approval

The study is approved by the Regional Committee on Medical and Health Research Ethics South-East (reg.no. 2012/1176) and by the Privacy Ombudsman at each of the five health authorities taking part in the study.

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Conflict of interest

The authors declare that they have no conflict of interest.

Outcomes for children who care for a parent with a severe illness or substance abuse

Abstract

Background: Quantitative studies of children's caring activities during parental illness have increased in the past 10 years. However, the various outcomes for these children have been investigated less frequently. In the present study, we investigate whether the children have different outcomes when the parent has a severe physical illness, mental illness or substance abuse, and whether any factors are associated with the positive and negative outcomes of the children's caregiving.

Design: A cross-sectional multicentre study.

Methods: We recruited parents who were out- or inpatients in five public hospitals in Norway and their children. The sample included 246 children aged 8-17 years and 238 of their parents with a severe physical illness, mental illness or substance abuse.

Results: Ten per cent reported negative outcomes at a clinical level of concern, and nearly half of the children reported stress. However, the outcomes were not significantly different between parental illness groups. Positive and negative outcomes were associated with the nature of caring activities (personal care, financial and practical management, household management), social skills and perceived external locus of control.

Conclusion and implications: Health professionals must provide a more comprehensive and overall assessment of both the parents' and the children's needs. In order to recognise the role taken by the child; assessment of children's caring activities and their need for adequate information should be performed. In particular should the children's need for follow-up

regarding caring activities, respite and emotional support be assessed to secure the children necessary skills and feeling of mastery.

Keywords

Young carers, young caregivers, children, adolescents, parental severe physical illness, parental mental illness, parental substance abuse, cross-sectional study.

Introduction

Most children and youth perform chores at home, such as domestic tasks, household management and looking after younger siblings (Becker, 2007; Vaage, 2012). The presence of severe physical illness, mental illness or substance abuse in the family, especially amongst the parents, often increases the extent and nature of caring activities that the children need to undertake (Aldridge, 2017; Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2016; Leu & Becker, 2016; Smyth, Cass, & Hill, 2011; Stamatopoulos, 2015). In the present paper, we use a recent definition from a young carers study by the UK's Department of Education, as it is concise for the current research purposes and recognises several principal dimensions of caring:

A young carer is a child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol. The care provided by children may be long or short term and, when they (and their families) have unmet needs, caring may have an adverse impact on children's health, wellbeing and transitions into adulthood

(Cheesbrough, Harding, Webster, & Aldridge, 2017, p.14)

A small number of Norwegian children and youth in the general population, 1-2%, provide care for ill or elderly adult family members in the household (Vaage, 2012). A study based on the same sample as in the present paper showed that 10% of Norwegian children whose parents have severe illnesses or substance abuse reported a high (5.7%) to very high (4.5%) extent of caregiving, i.e. more than 10 hours a week on average (Kallander et al., 2017). Furthermore, 20% of the parents reported increased caregiving by their children, and 10% of the parents reported that their children have helped them with personal care that they usually would have done themselves. A study of children in Sweden found a 7% prevalence of young carers (Nordenfors & Melander, 2017), and prevalence estimates in Europe, Australia and the US have been reported as 2-8% (Kavanaugh et al., 2016; Leu & Becker, 2016; Smyth et al., 2011). However, studies of prevalence often use various definitions of young carers, age ranges, samples, methods of research and instruments to measure outcomes (Aldridge, 2017; Kavanaugh et al., 2016; Stamatopoulos, 2015). Therefore, reliable cross-national prevalence and outcome data are rare (Aldridge, 2017; Kelly, Devine, & McKnight, 2017; Leu & Becker, 2016).

A selection of types of outcomes of children's caregiving - Previous quantitative outcome studies of children's caring activities mainly based on standardized psychological outcome measures have found increased parent-child conflict, school problems and depression (Kavanaugh, 2014); increased mental health problems (Pakenham & Cox, 2012a, 2012b, 2013, 2014; Shifren & Chong, 2012; Shifren, Hillman, & Rowe, 2014; Van Loon, Van de Ven, Van Doesum, Hosman, & Witteman, 2017), and lower quality of life, life satisfaction and physical symptoms (Lloyd, 2012; Nagl-Cupal, Daniel, Koller, & Mayer, 2014; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Pakenham, Chiu, Bursnall, & Cannon, 2007; Pakenham & Cox, 2012a, 2012b, 2014). Two studies found no significant impact of

role overload, attachment or self-efficacy (Pakenham & Cox, 2013; Remtulla, Charles, & Marshall, 2012). Despite the increase of cross-sectional outcome studies, it is argued that research on both positive and negative outcomes of children's caring activities has been hampered by the lack of appropriate contextually sensitive measures (Aldridge, 2017; Cox & Pakenham, 2014; Joseph, Becker, Becker, & Regel, 2009; Leu & Becker, 2016; Pakenham et al., 2007; Pakenham & Cox, 2012b, 2018). Three context sensitive measures on positive as well as negative experiences reported by the young carers themselves have recently been developed based on qualitative research. These focus on: positive outcomes, such as personal value of the role, increased family cohesion, caregiving confidence and perceived maturity; and negative outcomes, such as stress, worry and guilt, disruption of family cohesion, isolation, lack of social recognition, stigma, and activity, social and school restrictions (Cassidy & Giles, 2013; Cox & Pakenham, 2014; Joseph et al., 2009; Pakenham & Cox, 2018).

Outcomes of children's caregiving across different types of parental illness – A few studies have compared outcomes of children's caregiving across different types of parental illness, such as severe physical illness, mental illness or substance abuse (Cox & Pakenham, 2014; Pakenham & Cox, 2014, 2015). Two previous studies showed that children had more negative outcomes of caregiving when the parent had a mental illness, compared to a physical illness (Ireland & Pakenham, 2010b; Pakenham et al., 2006). However, a recent study, which also included children of parents with substance abuse, found no differences in positive or negative outcomes of children's caregiving between parental physical illness, mental illness and substance abuse (Pakenham & Cox, 2015). The studies are, thus, inconsistent in their findings.

Predictors of caregiving outcomes – Quantitative studies have previously shown association between positive outcome of children’s caregiving and higher levels of social competence, better prosocial behaviour, and empathy (Champion et al., 2009; Ireland & Pakenham, 2010b; Pakenham & Cox, 2018; van der Mijl & Vingerhoets, 2017). Furthermore, both qualitative and quantitative studies have shown the relation between the children’s feeling of external control and negative outcome of caring (Burnett, Jones, Bliwise, & Ross, 2006; Haine, Ayers, Sandler, Wolchik, & Weyer, 2003; Mauseth & Hjälmhult, 2016; Williams & Francis, 2010). Previous studies have also shown that positive outcomes of caring activities were related to increased caring activities, recognition of the caregiving role and social support from family and friends (Cassidy, Giles, & McLaughlin, 2013; Joseph et al., 2009; Nagl-Cupal et al., 2014; Pakenham & Bursnall, 2006; Pakenham et al., 2007; Pakenham & Cox, 2018; Shifren, 2008). Parent’s unmet needs of care and support are associated with negative outcome for the children, such as the parent’s access to care and social support (Pedersen & Revenson, 2005).

Some studies have found more negative outcomes (i.e. more somatisation, less life satisfaction or more stress) if the parent had poorer physical health status, more than one type of illness or if the children perceived a lack of choice in caregiving (Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2012b, 2014, 2015). Demographics, such as the children’s gender, age, ethnicity, and single-parent household, have been shown in several studies to be unrelated to outcomes of caring, with an exception concerning higher number of younger siblings (Pakenham et al., 2006; Pakenham et al., 2007; Pakenham & Cox, 2014; Shifren et al., 2014). There is higher extent of sibling care if there are younger siblings in the family. Pakenham and Cox (2015, 2018) explored whether outcomes of caring activities were associated with parental health status, type of parental illness, demographics and the children’s caring activities based on a family ecology framework for research (Pedersen &

Revenson, 2005). However, the findings of Pakenham & Cox (2015, 2018) displayed that increased caregiving activities were a stronger predictor of outcomes of caregiving than family demographics such as gender, age and single- or two parent family and type of illness.

The *extent* and *nature* of caring activities have been shown to be associated with outcomes in various ways (Joseph et al., 2009; Pakenham & Cox, 2012b, 2015; Razaz, Nourian, Marrie, Boyce, & Tremlett, 2014; Van Loon et al., 2017). Children's personal care for parents with physical illnesses, such as helping with dressing or undressing, washing or showering, has been shown to have a negative effect on the children's outcomes (Bjorgvinsdottir & Halldorsdottir, 2013; Joseph et al., 2009; Lackey & Gates, 2001). Other studies have found that personal care might strengthen the relationship between the child and the parent (East, 2010; Ireland & Pakenham, 2010b; Pakenham & Cox, 2012a). Joseph et al. (2009) found a correlation between emotional care, such as keeping the parent company or making sure the parent is alright, household management and negative outcomes. A recent study has shown that an increased extent of domestic tasks and household management has a negative impact on children's outcomes by increasing their emotional problems (De Roos, De Boer, & Bot, 2017). Overall, some of the studies which have explored association between the nature and extent of caregiving and outcome have shown inconsistent findings.

The few previous quantitative studies with measures of both positive and negative outcomes have indicated that children experience caregiving as more positive than negative (Joseph et al., 2009; Mechling, 2015; Pakenham et al., 2007; Shifren et al., 2014), which seems in line with qualitative studies showing that children overall experience the caregiving as positive (Heyman & Heyman, 2013; McDougall, O'Connor, & Howell, 2018; Nicholls, Patterson, McDonald, & Hulbert-Williams, 2016). If we further explore why some children experience

caregiving as positive while others experience more negative outcomes, we may possibly be able to better identify children affected by parental illness and as young carers in need of interventions developed. So, along with exploring differences of outcome across type of parental illness groups there is also a need to further explore which factors that may predict positive and negative outcome.

The first aim of our study is to investigate the positive and negative outcomes for children who care for a parent with severe physical illness (neurological illness or cancer), mental illness or substance abuse (drug and/or alcohol). The second aim is to investigate differences in positive and negative outcomes of caring activities between the three parental illness groups (physical illness, mental illness and substance abuse). The third aim is to investigate whether the outcomes of the children's caregiving are associated with the type of parental illness, parental health status (physical and mental), family demographics (parental gender, age, income and single- or two-parent family), the parent's access to care and support (home-based services and social support), the family functioning (family cohesion and parenting capacity), the children's characteristics (age, gender, number of siblings, social skills and external LoC), and the children's caring activities (extent and nature).

Methods

Design

This paper reports from a Norwegian explorative and cross-sectional multicentre study.

Sample

The sample consisted of 246 children aged 8-18 years and 238 of their parents, recruited during the treatment of the parent. They were recruited in five public hospitals (health trusts)

located in the south, west and north of Norway. Eight parents were not able to complete the questionnaire due to the severity of their illness. Inclusion criteria (all must be fulfilled to be included) for the parents were: inpatient or outpatient in clinics for neurology, oncology, mental health or substance abuse; having a severe physical illness (PI) in terms of neurological illness or cancer, mental illness (MI) or substance abuse in terms of drug and/or alcohol (SA); at least one biological or adoptive child; parental care for the child at least every second weekend; and understanding the Norwegian language. At each hospital, we recruited patients from two randomly selected outpatient and two randomly selected inpatient units for each of the three parent groups (PI, MI, SA). The patients were recruited only on randomly selected recruitment days or weeks at each unit. We included outpatients and inpatients in a 4:1 ratio in accordance with annual national statistics on distribution of outpatients and inpatients in hospitals.

Instruments and measures

Children/adolescents

Outcomes of caring were measured with the Positive and Negative Outcomes of Caring scales (PANOC-YC20), a 20-item self-report measure consisting of two scales (10 items each) of positive and negative outcomes, respectively (Joseph et al., 2009). Each item is scored on a three-point response scale (never = 0, some of the time=1, a lot of the time = 2). Based on convergent validity data, a sum score of less than 12 on the positive scale and greater than 8 on the negative scale indicates clinical concern. Internal consistency measured by Cronbach's alpha was 0.90 for the positive scale and 0.89 for the negative scale (Joseph et al., 2009), and 0.86 and 0.81, respectively, for the Norwegian version in our study.

Caring activities were assessed with the Multidimensional Assessment of Caring Activities (MACA-YC18), an 18-item self-report measure of extent and nature of caring activities by young people, with a total score (extent) ranging from 0 to 36, and six subscales for domestic tasks, household management, financial/practical management and personal, emotional and sibling care, with a range from 0 to 6 (Joseph et al., 2009). An additional subscale, health care, included three items from the extended MACA-YC42 version (Joseph et al., 2009). The health subscale is not included in the mean or total scores (Tables 4 and 5). The items are answered on a three-point scale (never = 0, some of the time=1, a lot of the time = 2). Cronbach's alpha was 0.78 for the original English version (Joseph et al., 2009) and 0.70 for the Norwegian version in our study.

Locus of control (LoC) was measured with a short version of 14 items from the Nowicki-Strickland Children's Locus of Control Scale (Nowicki & Strickland, 1973). The eight and six items of internal and external LoC, respectively, were answered with dichotomous response categories, yes (scored 1) or no (scored 0). The total sum score, with items on internal control reversed, ranges between 0 to 14. Higher scores indicate an increased level of external LoC. Cronbach's alpha was 0.66 for the original English version (Nowicki & Strickland, 1973) and 0.37 in our study.

Social skills were measured with a 34-item version of the Social Skills Rating System [SSRS] (Gamst-Klaussen, Rasmussen, Svartdal, & Strømgren, 2014; Gresham & Elliott, 1990; Ogden, 2003), which has four subscales for children: co-operation, assertion, self-control and empathy. The Norwegian version is identical to the US version, except for an increase from a three to a four-point scale (never = 0, sometimes = 1, often = 2, almost always = 3). The study used two different versions of the SSRS, one for children aged 8-12 years and another for

children aged 13-18 years, with a Cronbach's alpha of 0.92 (N=151) and 0.90 (N=95), respectively. Cronbach's alpha of child-reported total social skills was 0.83 in a large American sample (Gresham, Elliott, Vance, & Cook, 2011).

Patient parents

Health status was measured with the Health Survey SF-8, a shorter form of the SF-36 (Turner-Bowker, Bayliss, Ware, & Kosinski, 2003; Ware, Kosinski, Dewey, & Gandek, 2001) with a four-item physical component scale (PCS, including physical functioning, role limitations due to physical health problems, bodily pain and general health), and a four-item mental component scale (MCS, including vitality, social functioning, role limitations due to emotional problems and mental health), with a one-week recall period. Each item has a five- or six-point response scale. The SF-8 has been shown to be sensitive to change. The total scores of healthy parents in a previous validation study of the SF-8 were 53.27 (Turner-Bowker et al., 2003), and our study ranged from 25 to 55 with a mean of 42.31. Higher scores indicate better health. Cronbach's alpha for the eight items of the SF-8 has ranged from 0.59 to 0.70 in previous studies (Ware et al., 2001) and was 0.87 in our study.

Parenting capacity during illness in the family was measured with a set of eight questions constructed for the present study. The questions were based on a qualitative study amongst Norwegian families with substance use problems (Haugland, 2005) and a review of research on the impact of substance abuse, mental illness or severe physical illness on parenting capacity (Cleaver & Unell, 2011; Pedersen & Revenson, 2005). The questions ask to what degree the parental illness has a negative influence on the parent's capacity to perform the following activities: do practical work at home; ensure that the child arrives at school in time; follow up on the child's school work; emotionally support the child; maintain structure in

everyday life; follow up on the child's leisure time activities; organise familial social activities; and participate in social activities with the child. Each item is scored on a four-point scale (not at all = 0 to a larger degree = 3), with higher scores indicating lower parenting capacity. Cronbach's alpha was 0.91 in our study.

Family cohesion was measured with a 10-item cohesion subscale of the Family Adaptability and Cohesion Evaluation Scale [FACES III] (Crowley, 1998; Olson, 1986; Olson, Portner, & Lavee, 1985; Vandvik & Eckblad, 1993). Each item is scored on a five-point response scale (almost never = 1 to almost always = 5), with higher scores indicating more cohesion. Cronbach's alpha has been shown to be 0.77 (Olson, 1986) and was 0.93 in our study.

Social support was measured with the Interpersonal Support Evaluation List-12 (ISEL-12), a short form of the longer 40-item version (Cohen & Hoberman, 1983). The items have a four-point response scale (definitely false = 0 to definitely true = 3), and the total sum score ranges from 0 to 36, with higher scores indicating more social support. Cronbach's alpha was 0.70 in a previous study (Merz et al., 2014) and 0.86 in our study.

Access to care was measured by two items designed for our study: "Do you receive home-based services to ensure your own needs?", yes (scored 1) or no (scored 0); and "How many hours a week do you receive home-based services for practical help and/or emotional support?"

Data collection

The inclusion period was 20 months (May 2013 - January 2015). The patients and families were given written and oral information about the study, and written informed consent was

obtained from children and parents. In accordance with The Norwegian Health Research Act, both parents gave consent for children aged between 8 and 15 years, whilst children 16 years or older gave consent by themselves.

Two trained personnel met the family at a time and location chosen by the family, which was usually at the family's home. The personnel were available for clarifications whilst the parent and the child separately answered online questionnaires on individual tablets. Only one child from each family was included in the study. The procedure was as follows:

1. If there was more than one child in the family, we mainly used a lottery drawing to choose which child was included in the survey. This was done by the interviewers in advance by writing a note for each child (name or age) and blindly drawing a note. The child drawn received information in advance and was prepared to complete the questionnaire.
2. If the parent did not want a lottery drawing, but rather preferred to determine which child was included in the survey, the interviewers respected this and noted how the selection was made and the reasons for the selection. The second alternative was seldom in use.

The mean time for completion was 45 minutes for the children and 60 minutes for the parents. The family received two cinema tickets as compensation for their time.

Data Analyses

Data analyses were performed using SPSS 23 (IBM, 2015). Descriptive analyses describe the sample characteristics and positive and negative outcomes of caring activities (Tables 1-3). Analysis of variance (ANOVA) with the Bonferroni post hoc test was performed to examine differences in positive and negative outcomes of caring activities in relation to the three parent groups (PI, MI, SA). Two multiple linear regression analyses were performed, entering

all independent variables simultaneously to examine factors associated with positive and negative outcomes of caring activities, as measured by the PANOC-YC20.

Results

Table 1 shows the characteristics of the children and parents included in the sample.

PLEASE INSERT TABLE 1 HERE

Positive and negative outcomes

Table 2 shows the results on the PANOC, filled in by the children themselves.

PLEASE INSERT TABLE 2 HERE

Positive and negative outcomes across parent groups

The descriptive statistics showed that 28% of the children scored themselves in the clinical range on the positive outcomes total score (< 12), and 10% scored in the clinical range on the negative outcomes total score (> 8) (Table 3). MI children (34%) reported limited positive outcomes more often than PI and SA children (24% and 30%, respectively). SA children (23%) reported negative outcomes on a level of concern more often compared to PI and MI, (7% and 9%, respectively).

The children's scores of positive and negative outcomes of caring activities (PANOC total score/extent) were found not to be significantly different amongst the various parent groups (Table 4).

PLEASE INSERT TABLE 3 AND 4 HERE

Factors associated with positive and negative outcomes of caring activities

The regression analysis (Table 5) showed that better social skills of the child and less household management and personal care for the parent were predictors of more positive outcomes. Higher levels of personal care for the parents, more financial and practical management, poorer social skills and higher external LoC were predictors for more negative outcomes. Both models had moderate explanatory power (positive outcome model: $R^2 = 24\%$; negative outcome model: $R^2 = 35\%$).

PLEASE INSERT TABLE 5 HERE

Sample differences across parent groups

Table 1 shows the characteristics of the three parent groups. Overall, the parents were highly educated with income levels below the general population. However, PI parents had significantly higher levels of education and income compared to MI and SA parents. Furthermore, MI parents had significantly higher income compared to SA parents. SA parents reported single-parent status significantly more frequently than the other two parent groups.

MI parents reported significantly poorer mental health compared to those with PI and SA. No significant differences in physical health were reported. SA parents reported significantly higher parenting capacity to take care of their children compared to PI and MI parents.

The three parent groups also reported differences in access to home-based services, family cohesion and social support. PI parents reported significantly higher family cohesion and social support from the network compared to MI and SA parents. PI parents also received formal care, such as practical home-based services, more often compared to parents in the other two parent groups. Overall, 6% of the parents received home-based services for an average of 1.5 hours a week. The findings of differences across parent groups (PI, MI, SA) are in line with a previous study of demographics, health and quality of life differences

amongst the partners of patients with a somatic illness, mental illness, or substance abuse, based on the same sample as the present study (Birkeland, Weimand, Ruud, Høie, & Vederhus, 2017).

The children reported no significant differences in the external LoC and social skills between parent groups. The extent of social skills was similar to the normal population for children and adolescents in Norway (Ogden, 2003).

Discussion

To summarise: 10% of the children reported negative outcomes at a clinical level of concern, and nearly half of the children reported stress. However, the outcomes were not significantly different between parental illness groups. Positive and negative outcomes were associated with the nature of caring activities the children undertook, their social skills and perceived external LoC.

Positive and negative outcomes

Our findings of more positive outcomes compared to negative outcomes of caregiving activities, assessed by the PANOC, are in line with previous studies (Joseph et al., 2009; Mechling, 2015; Shifren et al., 2014). Joseph et al. (2009) pointed out that their study may have overestimated the positive and negative outcomes, since the sample included children and adolescents who participated in interventions for young carers. The two other studies were based on retrospective experiences of former young carers and emerging young adult carers (Mechling, 2015; Shifren et al., 2014). The mean levels of negative outcomes are lower in the present study than in the three previous PANOC studies and might be explained by the difference in samples. First of all, the children in our study were children of patients in public

hospitals and not identified as young carers or recruited through interventions for young carers, compared to the sample of Joseph et al. (2009). Secondly, the two other studies were retrospective with samples of former young carers between the age of 18-29 years old (Mechling, 2015; Shifren et al., 2014), compared to the present sample of children with a mean age of 12.45 years. Despite finding lower levels of negative outcomes compared to the other studies, our study found that more than 10% of the children experienced negative outcomes at a level of clinical concern, such as reporting that life didn't seem worth living or that they felt so sad that they couldn't handle it. This group of children provided adverse types of care associated with adult responsibility, which may have severely impacted their wellbeing. Thereby, the present study supports the necessity of identifying a group of children who need effective interventions, e.g. adequate information regarding care and the illness trajectory, respite and emotional support (Aldridge, 2017; Bjorgvinsdottir & Halldorsdottir, 2013; De Roos et al., 2017; Hamilton & Cass, 2017; Kavanaugh, Noh, & Studer, 2015; Leu & Becker, 2016; Metzging-Blau & Schnepf, 2008; Moore & McArthur, 2007; Nicholson & Friesen, 2014; Rose & Cohen, 2010).

Positive and negative outcomes across parent groups

There were sample differences across the parent groups (PI, MI, SA) in relation to family demographics, health status, family functioning and access to care and support, both amongst the ill parent and the other parent (Birkeland et al., 2017). In our previous study on the present sample, we also found significant differences between the nature of caring activities across the three groups (PI, MI, SA), in that children living with PI parents took on significantly more domestic and emotional care than children living with SA parents (Kallander et al., 2017). Despite these differences in the groups, we did not find that the children's positive and negative outcomes of caregiving differed between children living with PI, MI or SA parents.

A few studies have shown more negative outcomes of children's caregiving when parents have mental illnesses compared to physical illnesses. However, the lack of significant differences in perceived positive and negative outcomes of caring between PI, MI and SA children in our study is consistent with findings from a recent study (Pakenham & Cox, 2015). Based on these findings, we found it important to further explore which factors may be associated with which outcomes.

Factors associated with positive and negative outcomes of caring activities

The family demographics, such as the parent's age, gender, income and single-parent status, and the children's characteristics, such as gender, age and number of siblings, were not associated with either positive or negative outcomes of children's caring activities in our study. Even if their parents were overall highly educated, their family income was lower than for the general population, and this had no association with the outcomes. This finding of no association with family demographics as described above is in line with the findings of Pakenham et al. (2006) and Pakenham and Cox (2014, 2018). Older age in children has been shown to be associated with more negative outcomes and a higher extent of caring activities (Ireland & Pakenham, 2010a; Joseph et al., 2009). In line with our findings, other studies have shown no such association between age and outcome (Pakenham et al., 2007; Pakenham & Cox, 2012a, 2018).

Overall, the parents in our study had poorer health than adults in the general population. However, parental health status was not associated with the children's outcomes of caring activities. This finding is inconsistent with Pakenham & Cox (2015, 2018), which found that a more serious illness of the parent was associated with more negative outcomes of caring activities and better parental physical health with more positive outcome. The parents rarely

received any home-based services. Nevertheless, parental access to care and social support was not significant associated with outcomes of caring or family functioning.

As we predicted, our results showed that better *social skills* were also associated with more positive outcomes and less negative outcomes. However, providing caring activities in itself has been shown to lead to the development of new skills, knowledge and perceived maturity, in terms of a sense of independence and personal growth (Cox & Pakenham, 2014; Pakenham et al., 2006; Pakenham & Cox, 2012a; Razaz et al., 2014). Some studies argue that the children need social skills, such as empathy to take on emotional caregiving, and that the skills in itself may serve as an indicator of positive outcome (Champion et al., 2009; Mauseth & Hjälmhult, 2016; van der Mijl & Vingerhoets, 2017). Whether the positive outcomes of caring activities in the present study were due to previously learned social skills, or whether the positive outcomes contributed to the development of better social skills, remains unclear. However, it has been argued that young carers need the ability to develop skills, mastery and social support in the relation to the care they provide (Kavanaugh, Howard, & Banker-Horner, 2018).

Taking on caregiving may provide a feeling of possibility to take control over an uncontrolled situation (Burnett et al., 2006; Kallander et al., 2017; Mauseth & Hjälmhult, 2016). However, in line with previous research the higher external *locus of control* the children reported the more negative outcomes of caregiving (Williams & Francis, 2010). These findings may indicate that caregiving in itself did not necessarily gave them the feeling of control.

Children's social skills enable them to take on caring activities and to cope, but poor social skills to perform the caring activities and the feeling of lack of control may severely impact their wellbeing.

Previous quantitative studies have found that the extent and nature of caring activities are associated with positive and negative outcomes (Cassidy & Giles, 2013; Joseph et al., 2009; Pakenham & Cox, 2015, 2018; Razaz et al., 2014; Van Loon et al., 2017). In the present study, extent was not associated with any outcome, but our study showed that the *nature* of caring activities was related to positive and negative outcomes. Personal care for the parent was associated with less positive and more negative outcomes. Additionally, less household management was associated with positive outcomes, and less financial and practical management with negative outcomes. In contrast to Joseph et al. (2009), we found no association between emotional care and outcomes, positive or negative, or sibling care, domestic tasks or extent of caregiving. However, a qualitative study from Iceland found that the children who provide intimate physical and emotional care for their parents felt it was demanding, embarrassing and quite difficult whilst feeling unsupported and left alone with inescapable responsibility (Bjorgvinsdottir & Halldorsdottir, 2013). Thereby, findings in previous research combined with our study findings support the need for research that further explores these factors.

Strengths and limitations of our study

Major strengths are linked data between the child and the ill parent, data on three parent groups (physical and mental illness, substance abuse), efforts to recruit a representative sample from five public hospitals serving one third of Norway, use of mostly well-established questionnaires, and lack of missing data for most questions due to the required answers in the online data collection. However, the LoC questionnaires showed a low Cronbach's alpha in the Norwegian version used in the current study.

The main limitations were an unknown inclusion rate of eligible families and that the sample was probably skewed with a lower illness severity of the patients with mental illness and substance abuse. Many eligible patients in mental health outpatient clinics were probably not informed of the study because the therapists were reluctant to inform the patients, considered the patients too ill to participate or forgot to inform them. Many patients with substance abuse were not eligible because they did not have custody of their children, and the health of the substance abuse patients presently in treatment was probably better than in periods without treatment. Due to these circumstances, the situation of families, the extent and the outcomes of caring activities of children with ill parents are probably less positive than our study shows.

Conclusion

Despite the mostly positive outcomes of children's caring activities, some children provided adverse types of care associated with adult responsibilities, such as personal care and financial and practical-, and household management. These caring activities, poorer social skills and the feeling of lack of control were associated with negative outcomes.

Implications for research and practice

The study's findings support the need to further explore how different types of caring activities and factors may impact on outcome of caregiving, and especially children's feeling of control and skills to identify triggers of negative outcome. Health professionals must provide a more comprehensive and overall assessment of both the parent's and the children's needs. In order to recognise the role taken by the child; assessment of children's caring activities and their need for adequate information should be performed. In particular should

the children's need for follow-up regarding caring activities, respite and emotional support be assessed to secure children the necessary skills and feeling of mastery.

Author contributions

EKK, BW, TR substantially contributed to the conception and design of the study; EKK performed the statistical analysis, interpretation of data and drafted the manuscript. BW, TR, SB, BVR, KHB, helped with the analysis, interpretation of data and critical revision for important intellectual content. All authors approved the final version to be published.

Ethical approval

The study was approved by the Regional Committee on Medical and Health Research Ethics South-East (reg.no. 2012/1176) and by the Privacy Ombudsman at each of the five health authorities taking part in the study.

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References

- Aldridge, J. (2017). Where are we now? Twenty-five years of research, policy and practice on young carers. *Critical Social Policy*, 1-11. doi: 10.1177/0261018317724525
- Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy*, 7(1), 23-50. doi: 10.1177/1468018107073892
- Birkeland, B., Weimand, B. M., Ruud, T., Høie, M. M., & Vederhus, J.-K. (2017). Perceived quality of life in partners of patients undergoing treatment in somatic health, mental health, or substance use disorder units: a cross-sectional study. *Health Qual Life Outcomes*, 15(1), 172.

- Bjorgvinsdottir, K., & Halldorsdottir, S. (2013). Silent, invisible and unacknowledged: Experiences of young caregivers of single parents diagnosed with multiple sclerosis. *Scandinavian Journal of Caring Sciences*. doi: 10.1111/scs.12030
- Burnett, G., Jones, R. A., Bliwise, N. G., & Ross, L. T. (2006). Family unpredictability, parental alcoholism, and the development of parentification. *The American journal of family therapy*, 34(3), 181-189.
- Cassidy, T., & Giles, M. (2013). Further exploration of the Young Carers Perceived Stress Scale: Identifying a benefit-finding dimension. *British Journal of Health Psychology*, 18(3), 642-655. doi: 10.1111/bjhp.12017
- Cassidy, T., Giles, M., & McLaughlin, M. (2013). Benefit finding and resilience in child caregivers. *British Journal of Health Psychology*. doi: 10.1111/bjhp.12059
- Champion, J. E., Jaser, S. S., Reeslund, K. L., Simmons, L., Potts, J. E., Shears, A. R., & Compas, B. E. (2009). Caretaking behaviors by adolescent children of mothers with and without a history of depression. *Journal of Family Psychology*, 23(2), 156.
- Cheesbrough, S., Harding, C., Webster, L., & Aldridge, J. (2017). The lives of young carers in England: Omnibus survey report. London: Department for Education.
- Cleaver, H., & Unell, I. (2011). *Children's needs-parenting capacity: child abuse, parental mental illness, learning disability, substance misuse, and domestic violence*: The Stationery Office.
- Cohen, S., & Hoberman, H. M. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, 13(2), 99-125.
- Cox, S. D., & Pakenham, K. I. (2014). Confirmatory factor analysis and invariance testing of the Young Carer of Parents Inventory (YCOPI). *Rehabilitation Psychology*, 59(4), 439-452. doi: 10.1037/a0035860
- Crowley, S. L. (1998). A psychometric investigation of the FACES-III: Confirmatory factor analysis with replication. *Early education and development*, 9(2), 161-178.
- De Roos, S. A., De Boer, A. H., & Bot, S. M. (2017). Well-being and need for support of adolescents with a chronically ill family member. *Journal of child and family studies*, 26(2), 405-415.
- East, P. L. (2010). Children's provision of family caregiving: Benefit or burden? *Child Development Perspectives*, 4(1), 55-61.
- Gamst-Klaussen, T., Rasmussen, L.-M. P., Svartdal, F., & Strømgen, B. (2014). Comparability of the social skills improvement system to the social skills rating system: A Norwegian study. *Scandinavian Journal of Educational Research*, 60(1), 20-31. doi: 10.1080/00313831.2014.971864
- Gresham, F. M., & Elliott, S. N. (1990). *Social skills rating system (SSRS)*: American Guidance Service.
- Gresham, F. M., Elliott, S. N., Vance, M. J., & Cook, C. R. (2011). Comparability of the Social Skills Rating System to the Social Skills Improvement System: Content and psychometric comparisons across elementary and secondary age levels. *School Psychology Quarterly*, 26(1), 27-44. doi: 10.1037/a0022662
- Haine, R. A., Ayers, T. S., Sandler, I. N., Wolchik, S. A., & Weyer, J. L. (2003). Locus of control and self-esteem as stress-moderators or stress-mediators in parentally bereaved children. *Death Studies*, 27(7), 619-640.
- Hamilton, M. G., & Cass, B. (2017). Capturing the centrality of age and life-course stage in the provision of unpaid care. *Journal of Sociology*, 53(1), 79-93. doi: 10.1177/1440783315625117
- Haugland, B. S. M. (2005). Recurrent disruptions of rituals and routines in families with paternal alcohol abuse. *Family Relations*, 54(2), 225-241.

- Heyman, A., & Heyman, B. (2013). 'The sooner you can change their life course the better': The time-framing of risks in relationship to being a young carer. *Health, Risk & Society*, 15(6-07), 561-579. doi: 10.1080/13698575.2013.830080
- IBM, C. (2015). Released 2015. IBM SPSS Statistics for windows, Version 22.0.
- Ireland, M. J., & Pakenham, K. I. (2010a). The nature of youth care tasks in families experiencing chronic illness/disability: Development of the Youth Activities of Caregiving Scale (YACS). *Psychology & Health*, 25(6), 713-731. doi: 10.1080/08870440902893724
- Ireland, M. J., & Pakenham, K. I. (2010b). Youth adjustment to parental illness or disability: the role of illness characteristics, caregiving, and attachment. *Psychology, Health & Medicine*, 15(6), 632-645. doi: 10.1080/13548506.2010.498891
- Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child: Care, Health and Development*, 35(4), 510-520. doi: 10.1111/j.1365-2214.2009.00959.x
- Kallander, E. K., Weimand, B. M., Becker, S., Van Roy, B., Hanssen-Bauer, K., Stavnes, K., . . . Ruud, T. (2017). Children with ill parents: Extent and nature of caring activities. *Scandinavian Journal of Caring Sciences*. doi: 10.1111/scs.12510
- Kavanaugh, M. S. (2014). Children and adolescents providing care to a parent with Huntington's disease: Disease symptoms, caregiving tasks and young carer well-being. *Child & Youth Care Forum*, 43(6), 675-690. doi: 10.1007/s10566-014-9258-x
- Kavanaugh, M. S., Howard, M., & Banker-Horner, L. (2018). Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS. *Social Work in Health Care*, 57(1), 1-12.
- Kavanaugh, M. S., Noh, H., & Studer, L. (2015). "It'd be nice if someone asked me how I was doing. Like, 'cause I will have an answer": Exploring support needs of young carers of a parent with Huntington's disease. *Vulnerable Children and Youth Studies*, 10(1), 12-25. doi: 10.1080/17450128.2014.980370
- Kavanaugh, M. S., Stamatopoulos, V., Cohen, D., & Zhang, L. (2016). Unacknowledged Caregivers: A Scoping Review of Research on Caregiving Youth in the United States. *Adolescent Research Review*, 1(1), 29-49.
- Kelly, G., Devine, P., & McKnight, M. (2017). Lost in translation? The challenges of measuring informal care among children and young people. *International Journal of Care and Caring*, 1(3), 388-406.
- Lackey, N. R., & Gates, M. F. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing*, 34(3), 320-328.
- Leu, A., & Becker, S. (2016). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, 1-13. doi: 10.1080/13676261.2016.1260698
- Lloyd, K. (2012). Happiness and Well-Being of Young Carers: Extent, Nature and Correlates of Caring Among 10 and 11 Year Old School Children. *J Happiness Stud*, 14(1), 67-80. doi: 10.1007/s10902-011-9316-0
- Mauseth, T., & Hjalmlhult, E. (2016). Adolescents' experiences on coping with parental multiple sclerosis: a grounded theory study. *Journal of Clinical Nursing*, 25(5-6), 856-865.
- McDougall, E., O'Connor, M., & Howell, J. (2018). "Something that happens at home and stays at home": An exploration of the lived experience of young carers in Western Australia. *Health & social care in the community*.

- Mechling, B. M. (2015). A cross-sectional survey of the effect on emerging adults living with a depressed parent. *Journal of Psychiatric and Mental Health Nursing*, 22(8), 570-578.
- Merz, E. L., Roesch, S. C., Malcarne, V. L., Penedo, F. J., Llabre, M. M., Weitzman, O. B., . . . Gallo, L. C. (2014). Validation of interpersonal support evaluation list-12 (ISEL-12) scores among English- and Spanish-speaking Hispanics/Latinos from the HCHS/SOL Sociocultural Ancillary Study. *Psychological Assessment*, 26(2), 384-394. doi: 10.1037/a0035248
- Metzing-Blau, S., & Schnepf, W. (2008). Young carers in Germany: To live on as normal as possible—a grounded theory study. *BMC Nursing*, 7(1), 15.
- Moore, T., & McArthur, M. (2007). We're all in it together: supporting young carers and their families in Australia. *Health and Social Care in the Community*, 15(6), 561-568. doi: 10.1111/j.1365-2524.2007.00719.x
- Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and effects of caregiving on children. *Journal of Advanced Nursing*, 70(10), 2314-2325. doi: 10.1111/jan.12388
- Nicholls, W., Patterson, P., McDonald, F. E., & Hulbert-Williams, N. J. (2016). Unmet needs in young adults with a parent with a chronic condition: A mixed-method investigation and measure development study. *Scandinavian Journal of Caring Sciences*. doi: 10.1111/scs.12320
- Nicholson, J., & Friesen, B. J. (2014). Developing the evidence base for families living with parental psychiatric disabilities: Crossing the bridge while we're building it. *Psychiatric rehabilitation journal*, 37(3), 157-161. doi: 10.1037/prj0000092
- Nordenfors, M., & Melander, C. (2017). Young carers in Sweden - A short overview. Sweden, Borås: Swedish Family Care Competence Centre (Nka).
- Nowicki, S., & Strickland, B. R. (1973). A locus of control scale for children. *Journal of Consulting and Clinical Psychology*, 40(1), 148.
- Ogden, T. (2003). The Validity of Teacher Ratings of Adolescents' Social Skills. *Scandinavian Journal of Educational Research*, 47(1), 63-76. doi: 10.1080/00313830308605
- Olson, D. H. (1986). Circumplex model VII: Validation studies and FACES III. *Family Process*, 25(3), 337-351.
- Olson, D. H., Portner, J., & Lavee, Y. (1985). FACES III. Family social science. *University of Minnesota*, 290.
- Pakenham, K. I., & Bursnall, S. (2006). Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple sclerosis and comparisons with children of healthy parents. *Clinical Rehabilitation*, 20(8), 709-723.
- Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology*, 51(2), 113.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, 12(1), 89-102.
- Pakenham, K. I., & Cox, S. (2012a). The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the associations between caregiving activities and youth adjustment overtime. *Psychology & Health*, 27(3), 324-346. doi: 10.1080/08870446.2011.563853

- Pakenham, K. I., & Cox, S. (2012b). Test of a model of the effects of parental illness on youth and family functioning. *Health Psychology, 31*(5), 580-590. doi: 10.1037/a0026530
- Pakenham, K. I., & Cox, S. (2013). Comparisons between youth of a parent with MS and a control group on adjustment, caregiving, attachment and family functioning. *Psychology & Health, 29*(1), 1-15. doi: 10.1080/08870446.2013.813944
- Pakenham, K. I., & Cox, S. (2014). The effects of parental illness and other ill family members on the adjustment of children. *Annals of Behavioral Medicine, 48*(3), 424-437. doi: 10.1007/s12160-014-9622-y
- Pakenham, K. I., & Cox, S. (2015). The effects of parental illness and other ill family members on youth caregiving experiences. *Psychology & Health, 30*(7), 857-878. doi: 10.1080/08870446.2014.1001390
- Pakenham, K. I., & Cox, S. (2018). Effects of Benefit Finding, Social Support and Caregiving on Youth Adjustment in a Parental Illness Context. *Journal of child and family studies, 1*-16.
- Pedersen, S., & Revenson, T. A. (2005). Parental illness, family functioning, and adolescent well-being: A family ecology framework to guide research. *Journal of Family Psychology, 19*(3), 404.
- Razaz, N., Nourian, R., Marrie, R. A., Boyce, W. T., & Tremlett, H. (2014). Children and adolescents adjustment to parental multiple sclerosis: A systematic review. *BMC Neurology, 14*(1), 107.
- Remtulla, Y., Charles, G., & Marshall, S. (2012). An analysis of responsibility, attachment security, and relationship efficacy among young carers. *Relational Child & Youth Care Practice, 25*(2).
- Rose, H. D., & Cohen, K. (2010). The experiences of young carers: a meta-synthesis of qualitative findings. *Journal of Youth Studies, 13*(4), 473-487. doi: 10.1080/13676261003801739
- Shifren, K. (2008). Early caregiving: Perceived parental relations and current social support. *Journal of Adult Development, 15*(3-4), 160.
- Shifren, K., & Chong, A. (2012). Health-related behaviors: A study among former young caregivers. *Journal of Adult Development, 19*(2), 111-121.
- Shifren, K., Hillman, A., & Rowe, A. (2014). Early caregiver experiences, optimism, and mental health: Former young caregivers and emerging adult caregivers. *International Journal of Psychology Research, 9*(4), 361.
- Smyth, C., Cass, B., & Hill, T. (2011). Children and young people as active agents in caregiving: Agency and constraint. *Children and Youth Services Review, 33*(4), 509-514. doi: 10.1016/j.childyouth.2010.05.009
- Stamatopoulos, V. (2015). One million and counting: the hidden army of young carers in Canada. *Journal of Youth Studies, 18*(6), 809-822. doi: 10.1080/13676261.2014.992329
- Turner-Bowker, D. M., Bayliss, M. S., Ware, J. E., & Kosinski, M. (2003). Usefulness of the SF-8™ Health Survey for comparing the impact of migraine and other conditions. *Quality of Life Research, 12*(8), 1003-1012.
- Vaage, O. F. (2012). Tidene skifter. Tidsbruk 1971-2010 (Changing Times. Time Use 1971-2010). Oslo, Kongsvinger: Statistics Norway.
- van der Mijl, R. C., & Vingerhoets, A. J. (2017). The Positive Effects of Parentification: An Exploratory Study among Students. *Psihologiske teme, 26*(2), 417-430.
- Van Loon, L., Van de Ven, M. O., Van Doesum, K., Hosman, C. M., & Witteman, C. L. (2017). Parentification, stress, and problem behavior of adolescents who have a parent with mental health problems. *Family Process, 56*(1), 141-153.

- Vandvik, I. H., & Eckblad, G. F. (1993). FACES III and the Kvebaek Family Sculpture Technique as measures of cohesion and closeness. *Family Process*, 32(2), 221-233.
- Ware, J. E., Kosinski, M., Dewey, J. E., & Gandek, B. (2001). *How to score and interpret single-item health status measures: a manual for users of the SF-8 health survey*. Boston: QualityMetric Incorporated.
- Williams, K., & Francis, S. E. (2010). Parentification and psychological adjustment: Locus of control as a moderating variable. *Contemporary Family Therapy*, 32(3), 231-237.

Table 1 Descriptive statistics for characteristics of the children and patient/parents

<i>Variable</i>	Total	Physical illness (PI)	Mental illness (MI)	Substance abuse (SA)
<i>Child characteristics (N)</i>	246	140	76	30
Age	12.45 (2.85)	12.74 (2.61)	11.97 (3.05)	12.33 (3.32)
Gender (Female %)	56.9 %	56.4 %	60.5 %	50 %
Number of siblings	1.63 (0.93)	1.49 (0.90)	1.76 (0.95)	1.90 (0.96)
External Locus of control	4.33 (2.08)	4.31 (2.12)	4.16 (2.02)	4.87 (2.04)
Social skills (standardized)	0.00 (0.99)	0.09 (0.84)	-0.17 (1.20)	0.01 (1.07)
<i>Caring activities (MACA-YC18)</i>				
Domestic activity	3.24 (1.43)	3.40 (1.34)	3.15 (1.59)	2.70 (1.29)
Household management	2.89 (1.31)	2.95 (1.26)	2.80 (1.34)	2.86 (1.50)
Financial and practical management	0.50 (0.86)	0.50 (0.89)	0.40 (0.69)	0.76 (1.07)
Personal care	0.31 (0.80)	0.38 (0.89)	0.22 (0.62)	0.20 (0.76)
Emotional care	2.05 (1.59)	2.31 (1.55)	1.82 (1.56)	1.40 (1.63)
Sibling care	1.10 (1.45)	1.07 (1.49)	1.02 (1.31)	1.48 (1.60)
Health care (MACA-YC42)	0.41 (0.84)	0.44 (0.80)	0.33 (0.70)	0.47 (1.25)
Total score (extent)	10.00 (4.16)	10.52 (4.18)	9.35 (4.00)	9.26 (4.17)
<i>Family demographic (N)</i>	238	135	75	28
Age	42.62 (5.81)	44.25 (5.61)	40.08 (5.17)	41.57 (5.85)
Ethnicity (Norwegian %)	93.3 %	94.8 %	88 %	100 %
Gender (Female %)	72.7 %	71.1 %	85.3 %	46.4 %
Education High	43.7 %	54.8 %	32 %	21.4 %
Middle	40.8 %	34.8 %	48 %	50.0 %
Low	15.5 %	10.4 %	20 %	28.6 %
Family income pr year (NOK)	820 366.8	1 009 031.8	618 000.0	452 785.7
Very high	30.3 %	39.3 %	24.0 %	3.6 %
High	24.8 %	28.9 %	22.7 %	10.7 %
Middle	17.6 %	15.6 %	14.7 %	35.7 %
Low	16.0 %	11.1 %	21.3 %	25.0 %
Very low	11.3 %	5.2 %	17.3 %	25.0 %
Single-parent family (%)	17.2 %	11.9 %	20.0 %	35.7 %
<i>Parental illness characteristics</i>				
Duration of illness (Years)	7.86 (10.9)	4.96 (11.25)	10.41 (8.80)	15.00 (9.60)
Perceived unpredictability (Yes %)	74.4 %	81.5 %	76.0 %	35.7 %
<i>Parental health status (SF-8)</i>	42.31 (6.26)	42.74 (6.05)	40.42 (6.14)	45.28 (6.18)
Physical Component Scale (PCS)	40.27 (10.10)	39.43 (10.52)	40.24 (9.76)	44.40 (7.95)
Mental Component Scale (MCS)	42.00 (11.67)	44.45 (10.16)	36.56 (12.33)	44.79 (12.13)
<i>Family functioning</i>				
Parenting capacity	1.25 (0.84)	1.28 (0.86)	1.43 (0.76)	0.67 (0.73)
Family cohesion (FACES III)	40.83 (7.10)	42.08 (5.35)	39.40 (8.83)	38.61 (8.24)
<i>Parental access to care and support</i>				
Social support (ISEL-12)	25.88 (7.64)	26.66 (7.70)	24.01 (7.75)	27.41 (5.77)
Home-based services (%)	6.3 %	8.1 %	4.0 %	3.6 %
Hours practical help	1.73	1.45	3.33	0
Hours emotional support	0.53	0.36	1.00	1.00

Note: Unless otherwise noted, estimates are mean (standard deviation)

Table 2 Descriptive statistics of children’s PANOC scores (N=246)

<i>Items^a</i>	Never	Some of the time	A lot of the time
	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>
<i>Positive outcome</i>			
1. ...I feel I am doing something good	9 (3.7)	98 (39.8)	139 (56.5)
2. ...I feel that I am helping	10 (4.1)	111 (45.1)	125 (50.8)
3. ...I feel closer to my family	26 (10.6)	101 (41.1)	119 (48.4)
4. ...I feel good about myself	26 (10.6)	115 (46.7)	105 (42.7)
7. ...I feel that I am learning useful things	28 (11.4)	139 (56.5)	79 (32.1)
8. ...My parents are proud of the kind of person I am	17 (6.9)	98 (39.8)	131 (53.3)
15. ...I like who I am	36 (14.6)	80 (32.5)	130 (52.8)
18. ...I feel I am better able to cope with problems	48 (19.5)	148 (60.2)	50 (20.3)
19. ...I feel good about helping	11 (4.5)	90 (36.6)	145 (58.9)
20. ...I feel I am useful	29 (11.8)	201 (41.5)	115 (46.7)
<i>Negative outcome</i>			
5. ...I have to do things that make me upset	151 (61.4)	80 (32.5)	15 (6.1)
6. ...I feel stressed	131 (53.3)	101 (41.1)	14 (5.7)
9. ...I feel like running away	212 (86.2)	29 (11.8)	5 (2.0)
10. ...I feel very lonely	181 (73.6)	54 (22.0)	11 (4.5)
11. ...I feel like I can’t cope	204 (82.9)	35 (14.2)	7 (2.8)
12. ...I can’t stop thinking about what I have to do	163 (66.3)	72 (29.3)	11 (4.5)
13. ...I feel so sad I can hardly stand it	210 (85.4)	32 (13.0)	4 (1.6)
14. ...I don't think I matter	188 (76.4)	47 (19.1)	11 (4.5)
16. ...life doesn’t seem worth living	218 (88.6)	22 (8.9)	6 (2.4)
17. ...I have trouble staying awake	189 (76.8)	46 (18.7)	11 (4.5)

^aEach item starts with “Because of caring...”

PANOC = positive and negative outcome of caring activities (Joseph et al., 2009)

Table 3 Number of children who scored in clinical range on positive and negative outcome measured with PANOC

	Total	Parent groups		
		Physical illness	Mental illness	Substance abuse
	N = 246	N = 140	N = 76	N = 30
<i>Positive scale total score</i>				
Clinical group (total score ≤ 11)	87 (28,0)	46 (24,3)	30 (34,2)	11 (30,0)
Non Clinical group (total score ≥ 12)	159 (72,0)	94 (75,7)	46 (65,8)	19 (70,0)
<i>Negative scale total score</i>				
Non Clinical concern (total score ≤ 7)	122 (90,2)	130 (92,9)	69 (90,8)	23 (76,7)
Clinical concern (total score ≥ 8)	24 (9,8)	10 (7,1)	7 (9,2)	7 (23,3)

No missing. PANOC = positive and negative outcome of caring activities (ref).

Cut-off scores for clinical groups measured with PANOC are from Joseph et al. (2009)

Table 4 Mean and SD of children’s positive and negative PANOC scores.
 Test of differences between parental illness groups (ANOVA)

	Total N = 246	Parent groups			F	df	P
		Physical illness N = 140	Mental illness N= 76	Substance abuse N = 30			
<i>Variable</i>	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)			
Positive	13.65 (4.25)	13.89 (3.84)	13.22 (4.71)	13.60 (4.84)	0.61	2, 243	0.54
Negative	2.88 (3.17)	2.60 (2.85)	3.04 (3.00)	3.77 (4.65)	1.82	2, 243	0.16

PANOC = positive and negative outcome of caring activities (Joseph et al., 2009)

Table 5 Multiple regression analysis of associated factors of positive and negative outcome of caring activities (PANOC)

<i>Variable</i>	Positive		Negative	
	β	<i>p</i>	β	<i>p</i>
<i>Children's characteristics</i>				
Age	-.102	.132	.105	.093
Gender	.046	.485	-.049	.419
Number of siblings	.083	.290	.023	.753
Locus of control (LoC)	-.028	.698	.295	<.001***
Social skills (stand.val.) (SSRS)	.450	<.001***	-.232	.001*
<i>Caring activities (MACA-YC18)</i>				
Domestic	-.227	.112	.135	.302
Household	-.279	.047*	.197	.127
Financial/Practical	-.019	.856	.188	.048*
Personal	-.212	.037*	.313	.001**
Emotional	-.005	.974	.115	.427
Siblings (n=221)	-.064	.452	.152	.054
Health (MACA-YC42)	.003	.971	.007	.922
Total score (extent)	.593	.094	-.289	.374
<i>Family demographics</i>				
Gender	-.068	.299	-.028	.643
Family income (groups)	-.132	.151	-.107	.206
Single parent family	.124	.163	.030	.711
<i>Type of illness</i>				
Mental illness v physical#	-.006	.933	.031	.637
Substance v physical#	.104	.159	.031	.650
<i>Parental health status</i>				
Health status (SF-8)	.054	.495	-.106	.149
<i>Family functioning</i>				
Family cohesion (FACES III)	.015	.826	.030	.639
Parental capacity	.041	.607	-.015	.833
<i>Parental access to care and support</i>				

Social support (ISEL-12)	-.027	.679	-.039	.513
Home-based services	-.010	.879	-.001	.991

	$R^2 = 0.32$	$R^2 = 0.42$
	Adjusted $R^2 = 0.24$	Adjusted $R^2 = 0.35$

#Relative to physical illness * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$