





Factors associated with quality of life for children affected by parental illness or substance abuse

Ellen Katrine Kallander MSc, PhD (Researcher)^{1,2,3} , Bente M. Weimand RN, RPN, PhD (Professor)^{1,4} , Ketil Hanssen-Bauer MD, PhD (Head of Department, Associate Professor)^{1,2} , Betty Van Roy MD, PhD (Head of Department)⁵ and Torleif Ruud MD, PhD (Professor Emeritus)^{1,2} 

¹Division of Mental Health Services, Akershus University Hospital, Lørenskog, Norway, ²Institute of Clinical Medicine, University of Oslo, Oslo, Norway, ³Fafo Research Foundation, Oslo, Norway, ⁴Faculty of Health Sciences, Department of Nursing and Health Promotion, OsloMet – Oslo Metropolitan University, Oslo, Norway and ⁵Department of CAMHS, Clinic of Children and Adolescent Medicine, Akershus University Hospital, Lørenskog, Norway

Scand J Caring Sci; 2020

Factors associated with quality of life for children affected by parental illness or substance abuse

Background: There have been inconsistent findings from studies examining factors associated with quality of life (QoL) for children affected by parental illness.

Aim: The aim of this study was to explore factors associated with self-reported QoL in children affected by parental illness or parental substance abuse.

Design: A cross-sectional multicentre study.

Methods: The sample included 246 families with children 8–18 years recruited via ill parents who received treatment for severe physical illness, mental illness or substance abuse in specialised health services. We performed multiple linear regression analyses to examine factors associated with the children's self-reported QoL.

Main outcome measure: KIDSCREEN-27.

Results: The children's self-reported QoL was positively associated with the ill parent's self-reported physical health, the children's self-reported social skills, the degree to which other adults took over the ill parent's

responsibilities, provision of sibling care, provision of health care for the ill parent and positive outcome of caregiving. The children's QoL was negatively associated with the children's self-reported responsibilities due to parental illness, provision of emotional care for the ill parent, negative outcomes of caregiving and external locus of control. The model explained 63% of the variance (adjusted R^2) in children's total QoL.

Study limitations: Sampling bias may have occurred during recruitment.

Conclusions: The findings suggest factors of importance for the children's QoL. Clinicians should assess whether an ill parent's physical health may influence negatively on their ability to perform daily responsibilities at home and care for their children, and clinicians can use children's self-reported QoL to identify children who are most negatively affected.

Keywords: quality of life, young carers, young caregivers, parental severe physical illness, parental mental illness, parental substance abuse, cross-sectional study.

Submitted 19 August 2019, Accepted 13 April 2020

Introduction

Assessing children's quality of life may serve as an early indicator of psychosocial problems and indicate needs, and it may add significant information undetected by assessments of psychosocial adjustment (1-5). The term 'quality of life' (QoL) used in this paper is defined as a multidimensional construct that covers children's self-reported well-being in various dimensions such as physical well-being, psychological well-being, autonomy and parent relations,

social support and peers, and school environment (4,6). Well-being and QoL are closely related and even overlapping. Both concepts were developed within separate traditions, often identified as multidimensional and also used in combination. The Organisation for Economic Co-operation and Development (OECD) (7) operationalises the concept of children's well-being in two broad groups: (1) the well-being conditions of families where children live, which relate to the level of family income, housing conditions and the quality of the environment; and (2) child-centred well-being factors, which include their own health status, educational and social outcomes, including their own subjective perceptions of QoL.

Pedersen and Revenson's family ecology framework to guide research on parental illness, family functioning and

Correspondence to:

Ellen Katrine Kallander, Mental Health Services, Akershus University Hospital, Box 1000, 1478 Lørenskog, Norway.
E-mail: Ellen.Katrine.Kallander@ahus.no

children's well-being (8) supports the development of effective interventions based on evidence. For children, parental illness may negatively impact their everyday life with peer, school and family relationships. Research has shown that family role redistribution is the most common coping mechanism used by families experiencing parental illness (8-11). Important for these children's well-being were their daily hassles, stress responses and their parents' capacity of parenting (8). Daily hassles were related to the extent to which parental illness increased difficulties in daily life (e.g. increased responsibility at home). Children's stress responses to an uncontrollable life event such as parental illness may result from illness demands associated with family role redistribution. More severe parental illness often impaired the parenting capacity and demanded more from other family members (8,12). Differences in illness, such as diagnosis, severity, duration, predictability and level of stigmatisation, affect children differently (8,12). Important factors at individual and family levels are child and parent's age, gender, coping style and psychological resources. Other relevant factors external to the family are social support, access to care and cultural norms (8).

Based on Pedersen and Revenson's guide to research, quantitative studies began from the late 2000s to explore the impact of parental illness inspired by this model (11,13), and impact for the children across different types of illnesses, such as physical illness, mental illness and substance abuse (14-16). Krattenmacher and colleagues indicated that type of parental disease and the parent's subjective health status had no direct effect on children's adjustment (16). Giannakopoulos and colleagues found that parents' good mental health status, and not parental physical illness, was associated with better quality of life for adolescents (15). To the author's knowledge, the only study which included parental substance abuse in addition to physical and mental health found that the risk of adjustment problems for children was elevated if the ill parent was mentally ill or abused substances (17).

In 2010, Norway amended the Health Personnel Act requiring healthcare personnel to clarify whether patients have children and to ensure that the children's need for information and appropriate services are met. This amendment included children under 18 who are next-of-kin to parents with severe physical illness, mental illness or substance abuse (18,19). With knowledge about common, and illness-specific, needs among children affected by parental illness, and about factors that are associated with QoL, more targeted interventions may be developed. This paper is part of a larger multicentre project that aimed to provide new knowledge about the situation and adjustment of children whose parents were patients in specialised health services. The larger project included experiences and descriptions of the family situation reported by both the children and parents (20-23), and

examined how well the specialised health services identified the children and how the legislative amendment from 2010 had been implemented (24-26).

In the general population, lower child QoL is associated with parental socioeconomic factors such as lower levels of parental education and family income (5-6,27-29), and single-parent family (27,30,31). Higher QoL is associated with child personal characteristics such as internal locus of control and social skills, and social factors, such as social support (32,33).

Factors associated with lower QoL among children whose parents have cancer have included female parent, single parent, older child and the child needing additional support (34), poor parental mental health (35,36), reduced parental physical and mental health status (34,37), and poor family functioning (34,36,37). Four studies found no association between parental cancer and child QoL (34,37-39), while one indicated better QoL compared with norms in this population, although children with support needs had lower QoL (34).

Factors associated with lower QoL among children of parental mental illness have included parental depression (40) and other types of parental illness, such as injury, death or substance abuse (41). A study of parental substance abuse and parent-rated child QoL showed significantly higher levels of physical and psychological well-being compared with European normative data (42). Another study found that parental mental illness, but not parental physical illness, was positively associated with child QoL (15). One study found that the child's social life during parental mental illness was positively associated with life satisfaction (43), which is a subjective well-being measure within the QoL concept (44). A previous study with the same sample of children and QoL measure as in our study (21) found that the children with ill or substance-abusing parents had significantly lower physical well-being compared with European normative data, and found no significant QoL differences between children in different parental illness groups. Compared with girls and older children, boys and younger children report significantly greater physical and psychological well-being, as along with peer and social support. Younger children also reported significantly greater well-being at school compared with older children (21).

A few quantitative studies indicated lower QoL in young carers compared with young noncarers (45-49). A young carer is a person under 18 who provides care for someone physically or mentally ill, disabled, or abusing drugs or alcohol (50-52). A recent Swiss prevalence study of young carers indicated no association between extent and nature of caregiving and overall QoL, and pointed out lack of research on the association between caregiving and various QoL dimensions, namely physical well-being, psychological well-being, autonomy and parent relations, social support and peers, and school environment (49).

The mixed results on factors associated with children's QoL during parental illness and parental substance (37-38,53-55) may be explained by different sampling and methodological variations in the research. International research has demonstrated that descriptions of children's condition and situation regarding the impact of parental illness, their mental health or quality of life will often differ systematically between respondents, whether the respondent is the child, the parent or the teacher (44,53,56-60). Discrepancies between children and parent self-reporting have been repeatedly acknowledged in the literature and are often understood as part of a proxy problem (61). This may limit the generalisability of the results to a broader target population (10,62).

To summarise, factors that according to previous research may be associated with self-reported QoL of children affected by parental illness are family socio-demographic factors (i.e. ill parent's gender, single-parent family, level of education and income), parental illness characteristics and severity (i.e. health status and mental health), family functioning (i.e. family cohesion), child characteristics (i.e. age, gender and social skills), child stress response to parental illness (locus of control) and children's caregiving for ill parents. No studies have explored the association between these children's self-reported QoL and parenting capacity, parental access to care and support (i.e. home-based services and social support), family role redistribution, daily hassles in terms of time spent on provision of care and child stress response to parental illness (i.e. positive and negative outcomes of caregiving). There is a need to explore whether these factors are associated with the QoL for children affected by parental illness.

Academic and clinical disciplines (i.e. psychology, sociology, family therapy) have described and investigated how parental illness affects children differently within the research paradigms. The factors summarised above are also included in the family ecology framework that Pedersen and Revenson (2005) developed to guide research (8), the OECD's (2016) operationalisation of the concept of children's well-being, the research of QoL for young carers and existing QoL literature (7).

Aim

The aim of this paper was to explore factors associated with self-reported QoL in children affected by parental illness or parental substance abuse. These factors include family socio-demographics (i.e. ill parent's gender, single-parent family, level of education and family income), parental illness characteristics and severity (i.e. illness duration, unpredictability, health status, mental health), family functioning (i.e. family cohesion, parental capacity), parental access to care and support (i.e. home-based services, parental social support), children's characteristics

(age, gender, social skills), family role redistribution (i.e. increased responsibilities), daily hassles (i.e. nature of caregiving) and child stress responses (i.e. outcome of caregiving and feeling of control).

Methods

Design

This is a cross-sectional multicentre study conducted in five of 19 health trusts in three of four health regions of Norway.

Sample and recruitment

The sample included 246 families with children 8–18 years recruited via ill parents in treatment for severe physical illness (N = 135, neurological illness or cancer), mental illness (N = 75) or substance abuse (N = 28). The present study used data from 246 children aged 8–18 and from 238 of their parents. Eight ill parents were unable to complete the questionnaire. Inclusion criteria were having parental care for at least one child and understanding Norwegian. Written informed consent was obtained from both children and parents. The ill parents were recruited from randomly selected outpatient units and inpatient units on randomly selected days or weeks, with outpatient and inpatient ratio of 4 : 1, reflecting national distribution in health services.

Measures

Self-reported by the children

Dependent variable (QoL). Children's self-reported QoL was measured with the Norwegian version of KIDSCREEN-27 (6). This instrument measures physical well-being (five items), psychosocial well-being (seven items), peer relations and social support (four items), autonomy and parent relations (seven items) and school environment (four items). Each item is scored on a five-point scale ('Not at all' = 1 to 'Very much' = 5) (63). Rasch scores were computed from the sum of items' raw score for each dimension, and t-scores were calculated (mean = 50; standard deviation [SD] = 10) for comparison with European normative data (63). Higher scores indicate greater QoL. In the present study, Cronbach's alpha was 0.94 for the total scale and from 0.79 to 0.90 for the subscales. (31). KIDSCREEN-27 (4,64) functions satisfactory for the target groups, as shown in an earlier paper on our sample (31) and in other studies (21,30,65).

Independent variables. Child characteristics—Social skills were measured with a 34-item version of the Social Skills

Rating System (SSRS) for children (66,67) with four subscales: co-operation, assertion, self-control and responsibility. The Norwegian version has a four-point scale (never = 0, sometimes = 1, often = 2, almost always = 3) (68). Higher scores indicating better social skills. Two versions of SSRS were used in our study: one for children 8–12 and another for 13–18 years old. These had Cronbach's alphas of 0.92 (N = 151) and 0.90 (N = 95), respectively.

Family role redistribution—Three questions were designed for our study on the children's perception of *family role redistribution* of responsibilities: (1) 'Do you undertake more responsibilities at home, due to parental illness?' (2) 'When your parent is ill, are there other adults who take on the responsibilities your ill parent usually provides?' These were answered using a four-point scale ('Never' = 0, 'Some' = 1, 'Often' = 2, 'A lot' = 3). Question 3) 'Do you experience too much responsibilities at home?' was answered using a three-point scale ('Never' = 1, 'Sometimes' = 2, 'Often or very often' = 3). Higher scores indicate higher levels of family role redistribution.

Daily hassles—Extent and nature of caregiving was measured using the 18 items self-report measure Multidimensional Assessment of Caring Activities for young carers (MACA-YC18) (69,70). Each item is scored on a three-point scale ('Never' = 0, 'Some of the time' = 1, 'A lot of the time' = 2), resulting in a total score range 0–36. MACA-YC18 has six subscales: domestic tasks such as cleaning and cooking, household management such as shopping, financial and practical management such as helping to pay bills, personal care such as helping to dress or wash, emotional care such as keep company and make sure the person is alright and sibling care, each ranging from 0 to 6 (69). Three items (i.e. make sure that a person take their medicines) from the extended MACA-YC42 version (69) was added as an additional subscale on health care. Higher scores indicate higher extent of caregiving. The questionnaire was translated from English to Norwegian using appropriate back-translation procedures. MACA-YC18 was designed to be completed by young carers, but we used a version modified for young people in general (22,23). Cronbach's alpha was 0.70 for the Norwegian version used here.

Hours spent on caregiving was assessed with 'How many hours do you help out or take responsibility at home during an ordinary week?' and scored on a five-point scale ('1–4 hours = 0', '5–9 hours = 1', '10–19 hours = 2', '20–49 hours = 3', '50 hours or more = 4').

Child stress response—Outcomes of caregiving were measured with the Positive and Negative Outcomes of Caring scales (PANOC-YC20), a 20-item self-report measure for young

people with subscales (10 item each) for positive and negative outcomes (69). Each item is scored on a three-point scale ('Never' = 0, 'Some of the time' = 1, 'A lot of the time' = 2). The questionnaire was translated from English to Norwegian using appropriate back-translation procedures. PANOC-YC18 was originally designed for young carers, but we used a version modified for young people in general (23). Cronbach's alphas for the positive and negative scales were 0.86 and 0.81, respectively, for the Norwegian version.

Locus of control (LoC) was measured with 14 items (8 for internal and 6 for external LoC) from the 40-item Nowicki–Strickland Children's Locus of Control Scale (71). Items are scored dichotomously ('Yes' = 1, 'No' = 0), with reverse coding for internal control items. Total score ranges from 0 to 14, with higher scores indicating higher external LoC. The questionnaire was translated from English to Norwegian using appropriate back-translation procedures. Cronbach's alphas were 0.66 for the original English version (71) and 0.41 for the shorter version used in our study.

Filled out by the ill parents

Parental illness characteristics and severity. The parents' perception of *illness duration* and *predictability* of illness were two questions designed for our study: (1) 'For how long have you been ill or having substance abuse problems?' This item is scored numerically by months and years. (2) 'Is it difficult to know how the illness will progress in the future?' This item is scored dichotomously ('Yes' = 1, 'No' = 0).

Health status of the parent was measured with Health Survey SF-8, a short version of SF-36 (72,73). SF-8 includes a four-item physical component scale (PCS) (physical functioning, role limitations due to physical health problems, bodily pain and general health) and a four-item mental health component scale (MCS) (e.g. vitality and social functioning, role limitations due to emotional problems and mental health). Each item is scored for the previous week on a five- or six-point scale. SF-8 has been shown to be sensitive to change (73). Higher scores indicate better health. Cronbach's alphas were 0.82 and 0.80 for PCS-8 and MCS-8, respectively, in our study.

Mental health of the parent was also measured by Hopkins Symptom Check List 10 (SCL-10) (74), with four items on anxiety and six on depression, with a one-week scoring period on a four-point scale (from 1 = 'Not at all' to 4 = 'Extremely'), mean scores above 1.85 indicating significant symptoms. Cronbach's alpha was 0.91 in our study.

Family functioning. *Family cohesion* was measured with the 10-item cohesion subscale of the Family Adaptability and Cohesion Evaluation Scale (FACES III) (75–78). Each

item is scored on a five-point scale ('Almost never' = 1 to 'Almost always' = 5), with higher scores indicating more cohesion. Cronbach's alpha has been reported to be 0.77 (76) and 0.93 in our study.

Parenting capacity during illness was measured with eight questions constructed for this study based on a qualitative study of Norwegian families with substance use problems (79) and a review of available research on the impact of substance abuse, mental illness and/or severe physical illness on parenting capacity (8,80). These questions measure to which degree the parents' illness has a negative influence on their capacity to perform: practical work at home, ensuring the child arrives at school on time, follow-up of the child's schoolwork, emotionally supporting the child, maintaining structure in everyday life, follow-up of the child's leisure time activities, organising family social activities and participating in social activities with the child. Each item is scored on a four-point scale ('Not at all' = 0 to 'A larger degree' = 3), higher scores indicating lower parenting capacity. Cronbach's alpha was 0.91.

Parental access to care and social support. *Access to care* was measured with three questions regarding access to home-based services 'Do you receive home-based services to ensure your own needs?' ('Yes' = 1, 'No' = 0). Two items of practical help and emotional support were scored numerically by hours per week.

Social support was measured with Interpersonal Support Evaluation List-12 (ISEL-12), a short form of the 40-item version (81). Each item is scored on a four-point scale ('Definitely false' = 0 to 'Definitely true' = 3). Total sum score ranges from 0 to 36, higher scores indicating more social support. Cronbach's alpha was 0.86 in our study.

Data collection

Inclusion period was 20 months (May 2013 to December 2014) carried out by research personnel. Patients and families were given written and verbal information about the study, written informed consent was obtained from both children and parents. Both parents gave consent for children 8–15 years, while children over 16 years consented themselves. Data collection was conducted where the family wanted, usually in their home. Parent and child separately completed online questionnaires on tablets with two researchers present to be available to answer any questions. Completing the questionnaires took on average 45 minutes for children and 60 minutes for parents. Each family received two cinema tickets as compensation for their time.

Statistical analyses

We present the sample characteristics using descriptive statistics (Table 1). We conducted six multiple linear regression analyses with children's reported QoL

measured by KIDSCREEN-27 (total scores and the five dimensions) as the six dependent variables. First, we conducted a bivariate regression analysis of association with total QoL of each independent variable considered to be relevant based on previous studies or lack of previous studies. Independent variables with a bivariate association with a p value below 0.20 were included in the multilevel regression analysis, following the lax criterion recommended by Altman (82). Due to previous research, the independent variables on children's caregiving were considered important and included in the multiple regression analyses regardless of significance of the bivariate associations (49).

All KIDSCREEN scores were standardised according to the KIDSCREEN manual, and mean t-scores were used for each of the five KIDSCREEN-27 dimensions (63). We controlled that none of the included independent variables were strongly correlated and that the dependent variables had acceptable normal distributions. We entered all independent variables simultaneously into the regression analyses. The adjusted R square (R^2) values were used to assess the fit of the statistical models. Analyses of variables were considered to be statistically significant at $p < 0.05$. Data analyses were performed using SPSS 23, IBM, 2015.

Ethical approval

The study was approved by the Regional Committee on Medical and Health Research Ethics (Reg. no. 2012/1176) and by the Privacy Ombudsman at each of the five health trusts.

Results

Descriptive statistics for the characteristics of the children and ill parents are presented in Table 1. The bivariate and multilevel regression analyses are presented in Table 2.

The children's *general QoL* (total score) had a positive association with ill parent's self-reported physical health status. There were also positive associations with the children's self-reported social skills, being a boy, experience of other adults taking over the responsibilities of the ill parent, provided health care for ill parent and experienced positive outcome of their caregiving at home and for the ill parent. QoL indicated negative association with children's self-reported higher age, more responsibilities due to parental illness, provision of emotional care for ill parent, negative outcome of caregiving at home and for the ill parent, and external LoC. This model explained 63% (adjusted R^2) of the variance.

The *physical well-being dimension* had a positive association with children's self-reported social skills and negative associations with higher age and negative outcome

Table 1 Characteristics of the sample

Variables	Total M (SD)	Physical illness M (SD)	Mental illness M (SD)	Substance abuse M (SD)
Reported by the children				
Child characteristics (N)	246	140	76	30
Age (years)	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%
Social skills (SSRS) ^a	0.00 (0.99)	0.09 (0.84)	-0.17 (1.20)	0.01 (1.07)
Family role redistribution				
More responsibility due to parental illness (some/a lot)	55%	66%	44%	30%
Too much responsibilities due to parental illness (some/a lot)	34%	37%	26%	40%
Other adults take over the responsibilities (a lot)	29%	28%	29%	30%
Daily hassles (i.e. nature/extent of caregiving) (MACA)				
Domestic activity ^b	3.24 (1.43)	3.40 (1.34)	3.15 (1.59)	2.70 (1.29)
Household management ^b	2.89 (1.31)	2.95 (1.26)	2.80 (1.34)	2.86 (1.50)
Financial and practical management ^b	0.50 (0.86)	0.50 (0.89)	0.40 (0.69)	0.76 (1.07)
Personal care ^b	0.31 (0.80)	0.38 (0.89)	0.22 (0.62)	0.20 (0.76)
Emotional care ^b	2.05 (1.59)	2.31 (1.55)	1.82 (1.56)	1.40 (1.63)
Sibling care ^b	1.10 (1.45)	1.07 (1.49)	1.02 (1.31)	1.48 (1.60)
Health care ^c	0.41 (0.84)	0.44 (0.80)	0.33 (0.70)	0.47 (1.25)
Hours spent on caregiving (N)				
1–4	84	52	20	12
5–9	59.5%	63.5%	60.0%	41.7%
10–19	28.6%	32.7%	15.0%	33.3%
20–49	9.5%	3.8%	20.0%	16.7%
≥50	1.2%		5.0%	8.3%
Child stress response				
Positive outcomes of caregiving (PANOC-YC20)	13.65 (4.25)	13.89 (3.84)	13.22 (4.71)	13.60 (4.84)
Negative outcomes of caregiving (PANOC-YC20)	2.88 (3.17)	2.60 (2.85)	3.04 (3.00)	3.77 (4.65)
External locus of control (LoC)	4.33 (2.08)	4.31 (2.12)	4.16 (2.02)	4.87 (2.04)
Quality of life (KIDSCREEN-27) ^a				
Physical well-being	47.05 (10.55)	47.59 (10.62)	45.85 (10.36)	47.61 (10.81)
Psychological well-being	49.02 (11.22)	49.06 (10.33)	48.59 (11.61)	49.96 (14.22)
Autonomy and parental relationships	50.62 (11.51)	51.72 (11.00)	48.35 (11.77)	51.21 (12.70)
Peers and social support	50.32 (11.68)	50.52 (11.53)	49.47 (12.27)	51.56 (11.10)
Well-being at school	51.05 (11.76)	50.91 (11.06)	51.48 (12.91)	50.58 (12.23)
Reported by the ill parents				
Family socio-demographics (N)				
Gender (female)	238	135	75	28
Education High	72.7%	71.1%	85.3%	46.4%
Middle	43.7%	54.8%	32%	21.4%
Low	40.8%	34.8%	48%	50.0%
Single-parent family (%)	15.5%	10.4%	20%	28.6%
Family income per year (in NOK 1000)	17.2%	11.9%	20.0%	35.7%
Very high (<900)	820 (972)	1 009 (1 232)	618 (321)	452 (217)
High (700–899)	30.3%	39.3%	24.0%	3.6%
Middle (450–699)	24.8%	28.9%	22.7%	10.7%
Low (280–449)	17.6%	15.6%	14.7%	35.7%
Very low (<280)	16.0%	11.1%	21.3%	25.0%
Very low (<280)	11.3%	5.2%	17.3%	25.0%
Parental illness characteristics and severity				
Duration of illness (years)	7.86 (10.9)	4.96 (11.25)	10.41 (8.80)	15.00 (9.60)
Unpredictability of illness (yes)	74.4%	81.5%	76.0%	35.7%
Health status (SF-8) ^a				
Physical component scale	40.27 (10.10)	39.43 (10.52)	40.24 (9.76)	44.40 (7.95)
Mental component scale	42.00 (11.67)	44.45 (10.16)	36.56 (12.33)	44.79 (12.13)
Mental health (SCL-10)	0.97 (0.73)	0.70 (0.58)	1.46 (0.76)	0.96 (0.65)

Table 1 (Continued)

Variables	Total M (SD)	Physical illness M (SD)	Mental illness M (SD)	Substance abuse M (SD)
Family functioning				
Family cohesion (FAS III) ^a	40.83 (7.10)	42.08 (5.35)	39.40 (8.83)	38.61 (8.24)
Parenting capacity ^a	1.25 (0.84)	1.28 (0.86)	1.43 (0.76)	0.67 (0.73)
Parental access to care and support				
Social support (ISEL-12) ^a	25.88 (7.64)	26.66 (7.70)	24.01 (7.75)	27.41 (5.77)
Family access to home-based services (yes)	6.3%	8.1%	4.0%	3.6%
Hours practical help per hours a week	1.73	1.45	3.33	0
Hours emotional help per hours a week	0.53	0.36	1.00	1.00

Unless otherwise noted, estimates are mean (standard deviation; SD). PANOC: positive and negative outcomes of caring. MACA = multidimensional assessment of caring activities.

^aStandardised values.

^bSubscale of MACA-YC18.

^cThree items (one subscale) from MACA-YC42 that are not part of MACA-YC18.

of caregiving. This model explained 28% (adjusted R^2) of the variance.

The *psychological well-being dimension* had positive associations when children self-reported being a boy, experience of other adults taking over the responsibilities of the ill parent, provision of personal care and health for ill parent, and experienced positive outcome of caregiving. Psychological well-being was negatively associated with the children's self-reported higher age, more responsibilities due to parental illness and negative outcome of caregiving. This model explained 50% (adjusted R^2) of the variance.

The *autonomy and parent relation dimension* had a positive association with children's self-reported positive outcome of caregiving and negative associations with provision of sibling care and negative outcome of caregiving. This model explained 24% (adjusted R^2) of the variance.

The *social support and peers dimension* had positive associations with the children's self-reported social skills and experience of other adults taking over the responsibilities of the ill parent, and negative association with negative outcome of caregiving. This model explained 23% (adjusted R^2) of the variance.

The *school environment dimension* had positive associations with children's self-reported social skills and provision of sibling care and negative association with negative outcome of caregiving. This model explained 26% (adjusted R^2) of the variance.

Sample differences across parent groups

Table 1 shows the characteristics of the three-parent groups. Overall, parents were highly educated with income levels below the general population. Parents with physical illness had significantly higher levels of education and incomes compared to parents with mental

illness and parents with substance abuse. Furthermore, parents with mental illness had significantly higher incomes compared to parents with substance abuse. Parents with substance abuse reported single-parent status significantly more frequently than the other two parent groups. Parents with mental illness reported significantly poorer mental health compared to those with physical illness and substance abuse. No significant differences in physical health were reported. Parents with substance abuse reported significantly higher parenting capacity when it came to caring for the children, compared to parents with physical illness and mental illness.

The three-parent groups also reported differences in access to home-based services, family cohesion and social support. Parents with physical illness reported significantly higher family cohesion and social support compared to parents with mental illness or substance abuse. Parents with physical illness also received more formal care, such as practical home-based services, compared with parents in the two other parent groups. Overall, 6% of the parents received home-based services for an average of 1.5 hours a week.

The children reported no significant differences in the external LoC and social skills between parent groups.

Discussion

Children's self-reported QoL (total score) was positively associated with the ill parent's self-reported physical health status, child being a boy, the children's self-reported social skills, that other adults take over the responsibilities for the ill parents, provision of health care for the ill parent and positive outcome of the caregiving. QoL was negatively associated with children's higher age, self-reported increased responsibilities due to parental illness, provision of emotional care, negative outcome of caregiving and external locus of control.

Table 2 Multiple regression analyses of associated factors with quality of life (KIDSCREEN-27)

Independent variables	Total score		Total score ^d		Physical well-being ^d		Psychological well-being ^d		Parent relation and autonomy		Social support and peers ^d		School environment ^d	
	Unadjusted ^a	p	Adjusted ^b	p	β^b	p	β^b	p	β^b	p	β^b	p	β^b	p
Self-reported by the children (N = 246)														
Child characteristics														
Age	-1.210	0.002	-0.965	0.001	-0.044	<0.001	-0.025	0.001	-0.008	0.388	-0.009	0.324	-0.003	0.762
Gender (girl = reference)	7.069	0.002	3.617	0.026	0.040	0.496	0.118	0.007	0.078	0.130	0.039	0.462	0.001	0.986
Social skills (SSRS) ^d	10.665	<0.001	6.704	<0.001	0.119	0.001	0.014	0.578	0.057	0.064	0.132	<0.001	0.131	<0.001
Family role redistribution														
More responsibility due to parental illness	-4.921	<0.001	-2.843	0.005	-0.060	0.098	-0.067	0.015	-0.023	0.471	-0.018	0.578	-0.046	0.141
Other adults take over the responsibilities	3.836	<0.001	2.349	0.002	0.022	0.413	0.069	0.001	0.036	0.116	0.063	0.009	-0.008	0.731
Too much responsibility due to parental illness	-11.681	<0.001	0.358	0.834	0.060	0.335	0.051	0.273	-0.044	0.418	0.006	0.918	0.043	0.431
Daily hassles (i.e. nature/extent of caregiving)														
Domestic tasks (MACA-YC18)	.108	0.893	0.444	0.497	0.013	0.582	-0.011	0.512	0.048	0.179	-0.010	0.630	-0.011	0.607
Household management "	-0.323	0.711	-0.785	0.261	-0.048	0.057	-0.025	0.174	-0.032	0.145	-0.024	0.304	0.007	0.763
Financial or practical management "	-0.969	0.465	0.253	0.800	0.14	0.693	-0.025	0.356	0.008	0.795	0.061	0.066	0.036	0.262
Personal care "	-0.987	0.488	-0.432	0.717	-0.054	0.222	0.097	0.003	-0.044	0.261	0.007	0.864	0.003	0.940
Emotional care "	-0.238	0.740	-1.315	0.019	0.012	0.566	-0.025	0.101	-0.008	0.638	0.000	0.995	0.000	0.984
Sibling care (N = 221) "	-1.069	0.197	-0.673	0.219	0.010	0.622	0.018	0.231	-0.037	0.033	-0.013	0.463	0.035	0.048
Health care (MACA-YC42)	0.188	0.890	3.967	0.001	-0.014	0.756	0.082	0.011	0.061	0.112	0.011	0.787	-0.009	0.811
Hours spent on caregiving (N = 84) ^c	-7.224	<0.001												
Child stress response														
Positive outcome of caregiving (PANOC-YC20)	1.815	<0.001	0.680	0.002	0.13	0.127	0.015	0.015	0.014	0.040	0.008	0.290	0.011	0.113
Negative outcome of caregiving (PANOC-YC20)	-3.221	<0.001	-1.609	<0.001	-0.028	0.017	-0.055	<0.001	-0.023	0.021	-0.023	0.028	-0.027	0.006
External locus of control (LoC)														
Self-reported by the ill parents (N = 238)	-3.729	<0.001	-1.181	0.008	0.008	0.610	-0.023	0.052	-0.012	0.397	-0.007	0.652	-0.010	0.469
Family socio-demographics														
Ill parents gender	2.789	0.285												
Single-parent family	2.498	0.056												
Level of education	2.148	0.185												
Level of family income (groups)	1.977	0.020	1.061	0.096	0.000	0.996	0.023	0.173	0.025	0.212	0.002	0.928	0.017	0.414

Table 2 (Continued)

Independent variables	Total score		Total score ^d		Physical well-being ^d		Psychological well-being ^d		Parent relation and autonomy		Social support and peers ^d		School environment ^d	
	Unadjusted ^a	p	Adjusted ^b	p	β ^b	p	β ^b	p	β ^b	p	β ^b	p	β ^b	p
Parental illness characteristics and severity														
Mental illness (relative to physical illness)	-3.477	0.160												
Substance abuse (relative to physical illness)	-0.302	0.931												
Illness duration	0.082	0.445												
Unpredictability	-3.903	0.142												
Health status (SF-8) ^d														
Physical component scale	0.312	0.006	0.203	0.009	0.005	0.071	0.003	0.172	0.001	0.801	0.003	0.225	-0.001	0.733
Mental component scale	0.123	0.217												
Mental health (SCL-10)	-0.370	0.018	-0.091	0.404	0.001	0.764	-0.002	0.476	-0.003	0.394	0.002	0.557	0.006	0.094
Family functioning														
Family cohesion (FACES III)	-0.024	0.885												
Parenting capacity	-2.081	0.129												
Parental access to care and support														
Home-based services	-6.465	0.176												
Social support (ISEL-12)	0.026	0.886												
Explained variance (R ²)			R ² = 0.67		R ² = 0.35		R ² = 0.55		R ² = 0.31		R ² = 0.30		R ² = 0.33	
			Adjusted		Adjusted		Adjusted		Adjusted		Adjusted		Adjusted	
			R ² = 0.63		R ² = 0.28		R ² = 0.50		R ² = 0.24		R ² = 0.23		R ² = 0.26	

^aUnstandardised bivariate coefficients.

^bUnstandardised multivariate coefficients.

^cNot included in the multiple regression analyses due to high amount of missing data.

^dStandardised values.

Child QoL and association with factors related to conditions of the families

The multilevel regression analysis indicated that among the factors related to conditions of the families, only physical health of the ill parents was positively associated with QoL. Factors related to significant differences in the sample's three-parent groups, in terms of family socio-demography (i.e. parental education, income, single-parent status), illness characteristics (i.e. mental health), family functioning (i.e. higher parenting capacity, family cohesion) and access to care and support (i.e. access to home-based services, social support), were not associated with the children's overall QoL in the multilevel regression analysis. Mental health and family income were positively associated with QoL only in the bivariate analysis. Six previous studies have shown that parental mental health (e.g. anxiety and depression) is negatively associated with QoL (15,35-36,40,83,84). Two studies have indicated positive association between parental physical and mental health status (e.g. physical and mental functioning and role limitation) and QoL (34,37). The ill parents reported family income levels somewhat below the general population and some differences in income across the parental illness groups, as previously described in papers based on the present sample (20,22,23). However, income was not associated with QoL in the multiple linear regressions.

Child QoL and association with child-centred well-being factors

As summarised above, the children's QoL was mainly associated with child-centred well-being factors. Results related to *child characteristics* were in line with an earlier KIDSCREEN study (32), and *social skills* were positively associated with overall QoL, and in this study the dimensions physical well-being, social support and peers, and school environment. Two previous papers on present sample indicated positive association between social skills and extent and nature of caring activities (22), and positive outcome of caregiving (23). These findings suggest that social skills are an important child-centred well-being factor. In line with another paper on the present sample, older *age* was negatively associated with physical and psychological well-being and being a *boy* positively associated with physical well-being (21).

Family redistribution in terms of children's reports of more responsibilities due to parental illness was negatively associated with their general QoL and the dimensions of psychological well-being. The experience of other adults taking over the ill parent's responsibilities was positively associated with their general QoL, and the dimensions of psychological well-being, social support and peers. More than half of the children reported more

responsibilities due to parental illness, and one third reported too much (Table 1). However, only one third reported that they experienced that other adults took over the responsibilities of the ill parent (Table 1).

Our results related to *daily hassles* (MACA) indicated no association between nature of caring activities and KIDSCREEN-27 in the bivariate analysis, in line with the Swiss study of Leu and colleagues (49) using MACA and KIDSCREEN-10 scores. However, our multiple linear regression analyses of the KIDSCREEN-27 five well-being dimensions indicated that *personal care* was positively associated with the psychological well-being. Qualitative findings on children's provision of personal care found that children experienced the provision in a negative way (85,86), while some studies found positive association between good relationship between the child and the ill parent when children provided personal care (11,46,87). *Health care* was positively associated with general QoL. However, qualitative research findings found that children experience various challenges related to follow-up of their parent's medication (88,89). *Emotional care* was negatively associated with general QoL, which is in line with one study which included association between negative outcome of caregiving and emotional care (69). Two studies found that children's contribution in families and at home, emotional and instrumental, was beneficial for the children (90,91). A previous study based on the present sample as in this paper (22) indicated that provision of emotional care by children affected by parental illness or parental substance abuse, particularly physical illness, is just as commonly provided as in a general population of children in a Swedish study (92), measured by MACA. Children's emotional caregiving is underexplored, but have been found to be most prevalent among adolescents with strong family obligation values (91). *Sibling care* was negatively associated with autonomy and parent relation and positively to the school environment. It might be that the children do not want to take care of their siblings. Besides, findings suggest that sibling care increase skills that may benefit them in school.

Results related to *children's stress response* indicated that positive outcome of caregiving was positively associated with QoL in general, psychological well-being, autonomy and parent relation. However, a previous paper on the present sample indicated that the children with ill or substance-abusing parents had significantly lower physical well-being compared with European normative data and no significant QoL differences between children in different parental illness groups (21). Negative outcome of caregiving was negatively associated with child QoL in general and all five dimensions. An Irish Time survey (48) and Swiss study (49), which both used KIDSCREEN-10, indicated slightly lower QoL among young carers compared with children who had no caring

responsibilities. External LoC was negatively associated with QoL, but this finding may be uncertain as the LoC questionnaire had a poor reliability in our study. This finding is supported by a Norwegian qualitative study of adolescents whose parents have multiple sclerosis (93). Our findings are consistent with previous studies indicating positive association between social skills and QoL and that more negative outcome of caregiving was associated with lower QoL (43,45-46,94). This suggests that it may not be the role of children affected by parental illness or the role as a child caregiver which may negatively impact their QoL, but the negative consequences of caregiving.

Methodological considerations

Main strengths of the study are the relatively large sample size, linked data between children and ill parents, broad recruitment from five health trusts, use of mostly well-established questionnaires and few missing data. However, the LoC questionnaires showed a low Cronbach's alpha in the Norwegian version used in the current study. Main limitations are uncertain and probably skewed representability, especially of families affected by mental illness or substance abuse, indicating that our results may be positively biased in these two parental illness groups. Also, there was no testing of co-morbidity such as parents with physical illness which also had mental illness. Another limitation is the cross-sectional design where no causal inference may be assumed from parental illness per se. Attrition analysis was not possible due to lack of data on which patients were informed about the study by clinicians. The regression models explained moderate parts of the variance.

Implications

Overall, in Norway as in other countries, except UK (50-52,95), there has been little recognition of children's involvement in care and work at home, and has seldom been addressed in contrast to the division of labour between men and women over the last decades, in research and in political and public debate (96-98). The findings suggest that it is insufficient to assess just the extent or nature of children's caregiving to determine possible positive or negative outcome. Provision of caring activities at the expense of QoL should be considered. A suggestion for further research is to explore children's

involvement in care and work at home in relation to their QoL.

Conclusions

When parents are ill, clinicians should consider assessing whether parents' physical health functioning may negatively influence their ability to perform daily activities, regardless of main illness. Findings also suggest that interventions to support families' unmet needs and to reduce children's negative outcome of caregiving responsibilities are particularly important. Assessing QoL might identify struggling children with an ill parent or a parent with substance abuse. Effects of such assessments of both parents and children should be investigated in future research.

Acknowledgements

We gratefully thank all of the children and parents who participated in this study and the coordinators, research assistants and PhD students who collected the study data. We also thank the institutions that made it possible for us to recruit these participants. Finally, we also thank Jonas Christoffer Lindstrøm PhD candidate at Health Services Research Unit, Akershus University Hospital, for statistical advice in analysing the data.

Conflict of interest

The authors declare that they have no conflict of interest.

Author contributions

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

Funding

This study was funded by the Research Council of Norway (ID: 213477), the Norwegian Directorate of Health and the participating partners in the study.

References

- 1 Bisegger C, Cloetta B, von Rueden U, Abel T, Ravens-Sieberer U, the European KIDSCREEN Group. Health-related quality of life: gender differences in childhood and adolescence. *Soz Praventivmed* 2005; 50: 281-91.
- 2 Jozefiak T, Larsson B, Wichstrom L, Wallander J, Mattejat F. Quality of life as reported by children and parents: a comparison between students and child psychiatric outpatients. *Health Qual Life Outcomes* 2010; 8: 136.
- 3 Meade T, Dowswell E. Adolescents' health-related quality of life (HRQoL)

- changes over time: a three year longitudinal study. *Health Qual Life Outcomes* 2016; 14: 14.
- 4 Ravens-Sieberer U, Auquier P, Erhart M, Gosch A, Rajmil L, Bruil J, Power M, Duer W, Cloetta B, Czemy L, Mazur J, Czimbalmos A, Tountas Y, Hagquist C, Kilroe J. The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Qual Life Res* 2007; 16: 1347–56.
 - 5 Vella SA, Magee CA, Cliff DP. Trajectories and predictors of health-related quality of life during childhood. *J Pediatr* 2015; 167: 422–7.
 - 6 Ravens-Sieberer U, Herdman M, Devine J, Otto C, Bullinger M, Rose M, Klasen F. The European KIDSCREEN approach to measure quality of life and well-being in children: development, current application, and future advances. *Qual Life Res* 2014; 23: 791–803.
 - 7 OECD. *Enhancing child well-being to promote inclusive growth*. Paris: OECD Publishing; 2016. Available from: [http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/ELSA\(2016\)7/REV1&doclang=en](http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/ELSA(2016)7/REV1&doclang=en).
 - 8 Pedersen S, Revenson TA. Parental illness, family functioning, and adolescent well-being: a family ecology framework to guide research. *J Fam Psychol* 2005; 19: 404–19.
 - 9 Rolland JS. Parental illness and disability: a family systems framework. *J Fam Ther* 1999; 21: 242–66.
 - 10 Sieh DS, Meijer AM, Oort FJ, Visser-Meily JM, Van der Leij DA. Problem behavior in children of chronically ill parents: a meta-analysis. *Clin Child Fam Psychol Rev* 2010; 13: 384–97.
 - 11 Pakenham KI, Cox S. Test of a model of the effects of parental illness on youth and family functioning. *Health Psychol* 2012; 31: 580–90.
 - 12 Torvik FA, Rognmo K. Barn av foreldre med psykisk lidelse og alkoholmisbruk; omfang og konsekvenser [Norwegian Institute of Public Health] Oslo: Folkehelseinstituttet; 2011. 1-50]. Available from: <https://www.fhi.no/globalassets/dokumenterfiler/rapporter/2011/rapport-20114-pdf.pdf>.
 - 13 Sieh DS, Visser-Meily JM, Oort FJ, Meijer AM. Risk factors for problem behavior in adolescents of parents with a chronic medical condition. *Eur Child Adolesc Psychiatry* 2012; 21: 459–71.
 - 14 Pakenham KI, Cox S. The effects of parental illness and other ill family members on youth caregiving experiences. *Psychol Health* 2015; 30: 857–78.
 - 15 Giannakopoulos G, Dimitrakaki C, Pedeli X, Kolaitis G, Rotsika V, Ravens-Sieberer U, Tountas Y. Adolescents' wellbeing and functioning: relationships with parents' subjective general physical and mental health. *Health Qual Life Outcomes* 2009; 7: 100.
 - 16 Krattenmacher T, Kuhne F, Halverscheid S, Wiegand-Grefe S, Bergelt C, Romer G, Möller B. A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life. *J Psychosom Res* 2014; 76: 213–20.
 - 17 Pakenham KI, Cox S. The effects of parental illness and other ill family members on the adjustment of children. *Ann Behav Med* 2014; 48: 424–37.
 - 18 Helsedirektoratet. *Barn som pårørende [The Norwegian Directorate of Health]*. Oslo: Helsedirektoratet; 2010.
 - 19 Helse- og omsorgsdepartementet. *Om lov om endringer i helsepersonelloven m.m. (oppfølging av born som pårørende) [The Norwegian Ministry of Health and Care Services]*. Oslo: Helse- og omsorgsdepartementet; 2009.
 - 20 Birkeland B, Weimand BM, Ruud T, Hoie MM, Vederhus JK. 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* 2017; 15: 172.
 - 21 Hagen KA, Hilsen M, Kallander EK, Ruud T. Health-related quality of life (HRQoL) in children of ill or substance abusing parents: examining factor structure and sub-group differences. *Qual Life Res* 2018; 28: 1063–1073.
 - 22 Kallander EK, Weimand BM, Becker S, Van Roy B, Hanssen-Bauer K, Stavnes K, Faugli A, Kufas E, Ruud T. Children with ill parents: extent and nature of caring activities. *Scand J Caring Sci* 2018; 32: 793–804.
 - 23 Kallander EK, Weimand BM, Ruud T, Becker S, Van Roy B, Hanssen-Bauer K. Outcomes for children who care for a parent with a severe illness or substance abuse. *Child Youth Serv* 2018; 39: 228–249.
 - 24 Skogøy BE, Sorgaard K, Maybery D, Ruud T, Stavnes K, Kufas E, Peck GC, Thorsen E, Lindstrøm JC, Ogden T. Hospitals implementing changes in law to protect children of ill parents: a cross-sectional study. *BMC Health Serv Res* 2018; 18: 609.
 - 25 Skogøy BE, Maybery D, Ruud T, Sorgaard K, Peck GC, Kufas E, Stavnes K, Thorsen E, Ogden T. Differences in implementation of family focused practice in hospitals: a cross-sectional study. *Int J Ment Health Syst* 2018; 12: 77.
 - 26 Skogoy BE, Ogden T, Weimand B, Ruud T, Sorgaard K, Maybery D. Predictors of family focused practice: organisation, profession, or the role as child responsible personnel? *BMC Health Serv Res* 2019; 19: 793.
 - 27 Bradshaw J, Keung A, Rees G, Goswami H. Children's subjective well-being: International comparative perspectives. *Child Youth Serv Rev* 2011; 33: 548–56.
 - 28 Ravens-Sieberer U, Horka H, Illyes A, Rajmil L, Ottova-Jordan V, Erhart M. Children's quality of life in Europe: national wealth and familial socioeconomic position explain variations in mental health and well-being—a multilevel analysis in 27 EU countries. *ISRN Public Health* 2013; 2013: 1–9.
 - 29 von Rueden U, Gosch A, Rajmil L, Bisegger C, Ravens-Sieberer U. Socioeconomic determinants of health related quality of life in childhood and adolescence: results from a European study. *J Epidemiol Community Health* 2006; 60: 130–5.
 - 30 Berman AH, Liu B, Ullman S, Jadback I, Engstrom K. Children's quality of life based on the KIDSCREEN-27: child self-report, parent ratings and child-parent agreement in a Swedish random population sample. *PLoS ONE* 2016; 11: 1–15.
 - 31 Kvarme LG, Haraldstad K, Helseth S, Sorum R, Natvig GK. Associations

- between general self-efficacy and health-related quality of life among 12–13-year-old school children: a cross-sectional survey. *Health Qual Life Outcomes* 2009; 7: 85.
- 32 Detmar SB, Bruil J, Ravens-Sieberer U, Gosch A, Bisegger C, the European KIDSCREEN Group. The use of focus groups in the development of the KIDSCREEN HRQL questionnaire. *Qual Life Res* 2006; 15: 1345–53.
- 33 Gaspar T, Ribeiro JP, de Matos MG, Leal I, Ferreira A. Health-related quality of life in children and adolescents: subjective well Being. *Span J Psychol* 2012; 15: 177–86.
- 34 Bultmann JC, Beierlein V, Romer G, Moller B, Koch U, Bergelt C. Parental cancer: Health-related quality of life and current psychosocial support needs of cancer survivors and their children. *Int J Cancer* 2014; 135: 2668–77.
- 35 Götze H, Ernst J, Braehler E, Romer G, von Klitzing K. Predictors of quality of life of cancer patients, their children, and partners. *Psychooncology* 2015; 24: 787–95.
- 36 Beierlein V, Bultmann JC, Moller B, von Klitzing K, Flechtner HH, Resch F, Herzog W, Brähler E, Führer D, Romer G, Koch U, Bergelt C. Measuring family functioning in families with parental cancer: reliability and validity of the German adaptation of the Family Assessment Device (FAD). *J Psychosom Res* 2017; 93: 110–7.
- 37 Kuhne F, Krattenmacher T, Bergelt C, Ernst JC, Flechtner HH, Führer D, Herzog W, Klitzing KV, Romer G, Möller B. Parental palliative cancer: psychosocial adjustment and health-related quality of life in adolescents participating in a German family counselling service. *BMC Palliat Care* 2012; 11: 21.
- 38 Krattenmacher T, Kuhne F, Führer D, Beierlein V, Braehler E, Resch F, Klitzing KV, Flechtner H-H, Bergelt C, Romer G, Möller B. Coping skills and mental health status in adolescents when a parent has cancer: a multi-center and multi-perspective study. *J Psychosom Res* 2013; 74: 252–9.
- 39 Jeppesen E, Bjelland I, Fossa SD, Loge JH, Dahl AA. Health-related quality of life in teenagers with a parent with cancer. *Eur J Oncol Nurs* 2016; 22: 46–53.
- 40 Dittrich K, Fuchs A, BERPohl F, Meyer J, Führer D, Reichl C, Reck C, Kluczniok D, Kaess M, Hindi Attar C, Möhler E, Bierbaum A-L, Zietlow A-L, Jaite C, Winter SM, Herpertz SC, Brunner R, Bödeker K, Resch F. Effects of maternal history of depression and early life maltreatment on children's health-related quality of life. *J Affect Disord* 2018; 225: 280–8.
- 41 Coker TR, Elliott MN, Wallander JL, Cuccaro P, Grunbaum JA, Corona R, Saunders AE, Schuster MA. Association of family stressful life-change events and health-related quality of life in fifth-grade children. *Arch Pediatr Adolesc Med* 2011; 165: 354–9.
- 42 Comiskey CM, Milnes J, Daly M. Parents who use drugs: the well-being of parent and child dyads among people receiving harm reduction interventions for opiate use. *J Subst Use* 2017; 22: 206–10.
- 43 Fraser E, Pakenham KI. Resilience in children of parents with mental illness: relations between mental health literacy, social connectedness and coping, and both adjustment and caregiving. *Psychol Health Med* 2009; 14: 573–84.
- 44 Wallander JL, Koot HM. Quality of life in children: A critical examination of concepts, approaches, issues, and future directions. *Clin Psychol Rev* 2016; 45: 131–43.
- 45 Pakenham KI, Bursnall S, Chiu J, Cannon T, Okochi M. The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and non-caregivers. *Rehabil Psychol* 2006; 51: 113–26.
- 46 Pakenham KI, Cox S. 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. *Psychol Health* 2012; 27: 324–46.
- 47 Chikhradze N, Knecht C, Metzging S. Young carers: growing up with chronic illness in the family - a systematic review 2007–2017. *J Compassionate Health Care* 2017; 4: 12.
- 48 Lloyd K. Happiness and well-being of young carers: Extent, nature and correlates of caring among 10 and 11 year old school children. *J Happiness Stud* 2012; 14: 67–80.
- 49 Leu A, Frech M, Wepf H, Sempik J, Joseph S, Helbling L, Moser U, Becker S, Jung C. Counting young carers in Switzerland—a study of prevalence. *Child Soc* 2019; 33: 53–67.
- 50 Aldridge J. Where are we now? Twenty-five years of research, policy and practice on young carers. *Crit Soc Policy* 2017; 38: 155–65.
- 51 Leu A, Becker S. A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *J Youth Stud* 2016; 20: 750–62.
- 52 Joseph S, Sempik J, Leu A, Becker S. Young carers research, practice and policy: an overview and critical perspective on possible future directions. *Adolesc Res Rev* 2019; 5: 77–89.
- 53 Bee P, Berzins K, Calam R, Prymachuk S, Abel KM. Defining quality of life in the children of parents with severe mental illness: a preliminary stakeholder-led model. *PLoS ONE* 2013; 8: e73739.
- 54 Morley D, Selai C, Schrag A, Jahan-shahi M, Thompson A. Adolescent and adult children of parents with Parkinson's disease: incorporating their needs in clinical guidelines. *Parkinsons Dis* 2011; 2011: 951874.
- 55 Sieh DS, Meijer AM, Visser-Meily JM. Risk factors for stress in children after parental stroke. *Rehabil Psychol* 2010; 55: 391–7.
- 56 Berg-Nielsen TS, Solheim E, Belsky J, Wichstrom L. Preschoolers' psychosocial problems: in the eyes of the beholder? Adding teacher characteristics as determinants of discrepant parent-teacher reports. *Child Psychiatry Hum Dev* 2012; 43: 393–413.
- 57 Eiser C, Varni JW. Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *Eur J Pediatr* 2013; 172: 1299–304.
- 58 Jonsson U, Alaie I, Lofgren Willeus A, Zander E, Marschik PB, Coghill D, Bölte S. Annual research review: Quality of life and childhood mental and behavioural disorders - a critical review of the research. *J Child Psychol Psychiatry* 2017; 58: 439–69.

- 59 Jozefiak T, Larsson B, Wichstrom L, Mattejat F, Ravens-Sieberer U. Quality of life as reported by school children and their parents: a cross-sectional survey. *Health Qual Life Outcomes* 2008; 6: 34.
- 60 Quitmann J, Rohenkohl A, Sommer R, Bullinger M, Silva N. Explaining parent-child (dis)agreement in generic and short stature-specific health-related quality of life reports: do family and social relationships matter? *Health Qual Life Outcomes* 2016; 14: 150.
- 61 Sattoe JN, van Staa A, Moll HA. On Your Own Feet Research Group. The proxy problem anatomized: child-parent disagreement in health related quality of life reports of chronically ill adolescents. *Health Qual Life Outcomes* 2012; 10: 10.
- 62 Najman JM, Williams GM, Nikles J, Spence S, Bor W, O'Callaghan M, Le Brocque R, Andersen MJ. Mothers' mental illness and child behavior problems: cause-effect association or observation bias? *J Am Acad Child Adolesc Psychiatry* 2000; 39: 592-602.
- 63 The KIDSCREEN Group Europe. *The KIDSCREEN questionnaires - Quality of life questionnaires for children and adolescents. Handbook.* 2006, Pabst Science Publishers, Lengerich, Germany.
- 64 Andersen JR, Natvig GK, Haraldstad K, Skrede T, Aadland E, Resaland GK. Psychometric properties of the Norwegian version of the Kidscreen-27 questionnaire. *Health Qual Life Outcomes* 2016; 14: 58.
- 65 Schlarman JG, Metzging-Blau S, Schnepf W. The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature. *BMC Public Health* 2008; 8: 414.
- 66 Gresham FM, Elliott SN. *Social skills rating system: Manual.* 1990, American Guidance Service, Circle Pines, MN.
- 67 Ogden T. The validity of teacher ratings of adolescents' social skills. *Scand J Educ Res* 2003; 47: 63-76.
- 68 Sørli M, Hagen K, Ogden T. Social competence and antisocial behavior: Continuity and distinctiveness across early adolescence. *J Res Adolesc* 2008; 18: 121-44.
- 69 Joseph S, Becker S, Becker F, Regel S. 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 Development* 2009; 35: 510-20.
- 70 Joseph S, Becker F, Becker S. *Manual for measures of caring activities and outcomes for children and young people.* 2012, Carers Trust, London.
- 71 Nowicki S, Strickland BR. A locus of control scale for children. *J Consult Clin Psychol* 1973; 40: 148-54.
- 72 Ware JE, Kosinski M, Dewey JE, Gandek B. *How to score and interpret single-item health status measures: a manual for users of the SF-8 health survey.* 2001, QualityMetric Inc., Lincoln, RI.
- 73 Turner-Bowker DM, Bayliss MS, Ware JE, Kosinski M. Usefulness of the SF-8 Health Survey for comparing the impact of migraine and other conditions. *Qual Life Res* 2003; 12: 1003-12.
- 74 Strand BH, Dalgard OS, Tambs K, Rognerud M. Measuring the mental health status of the Norwegian population: a comparison of the instruments SCL-25, SCL-10, SCL-5 and MHI-5 (SF-36). *Nord J Psychiatry* 2003; 57: 113-8.
- 75 Olson DH, Portner J, Lavee Y. *FACES-III: family adaptability and cohesion evaluation scale.* 1985, Social Science, University of Minnesota, St. Paul (Minn.).
- 76 Olson DH. Circumplex model VII: validation studies and FACES III. *Fam Process* 1986; 25: 337-51.
- 77 Vandvik IH, Eckblad GF. FACES III and the Kvebaek Family Sculpture Technique as measures of cohesion and closeness. *Fam Process* 1993; 32: 221-33.
- 78 Crowley SL. A psychometric investigation of the FACES-III: confirmatory factor analysis with replication. *Early Educ Dev* 1998; 9: 161-78.
- 79 Haugland BSM. Recurrent disruptions of rituals and routines in families with paternal alcohol abuse. *Fam Relat* 2005; 54: 225-41.
- 80 Cleaver H, Unell I, Aldgate J. *Children's needs -parenting capacity: child abuse, parental mental illness, learning disability, substance misuse, and domestic violence* (2nd edition). 2011, The Stationery Office, London.
- 81 Cohen S, Hoberman HM. Positive events and social supports as buffers of life change stress. *J Appl Soc Psychol* 1983; 13: 99-125.
- 82 Altman DG. *Practical statistics for medical research.* 1990, Chapman & Hall/CRC Press, London.
- 83 Pollak E, Bullinger M, Jeske J, Wiegand-Grefe S. How do mentally ill parents evaluate their children's quality of life? Associations with the parent's illness and family functioning. *Prax Kinderpsychol Kinderpsychiatr* 2008; 57: 301-14.
- 84 Jeske J, Bullinger M, Wiegand-Grefe S. Do attachment patterns of parents with a mental illness have an impact upon how they view the quality of life of their children? *Vulnerable Child Youth Stud* 2011; 6: 39-50.
- 85 Bjorgvinsdottir K, Halldorsdottir S. Silent, invisible and unacknowledged: experiences of young caregivers of single parents diagnosed with multiple sclerosis. *Scand J Caring Sci* 2014; 28: 38-48.
- 86 Lackey NR, Gates MF. Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *J Adv Nurs* 2001; 34: 320-8.
- 87 East PL. Children's provision of family caregiving: benefit or burden? *Child Dev Perspect* 2010; 4: 55-61.
- 88 Jacobson S, Wood FG. Contributions of children to the care of adults with diabetes. *Diabetes Educ* 2004; 30: 820-6.
- 89 Nickels M, Siskowski C, Lebron CN, Belkowitz J. Medication administration by caregiving youth: An inside look at how adolescents manage medications for family members. *J Adolesc* 2018; 69: 33-43.
- 90 Armstrong-Carter E, Ivory S, Lin LC, Muscatell KA, Telzer EH. Role fulfillment mediates the association between daily family assistance and cortisol awakening response in adolescents. *Child Dev* 2019; 1-15.
- 91 Tsai KM, Gonzales NA, Fuligni AJ. Mexican American adolescents' emotional support to the family in

- response to parental stress. *J Res Adolesc* 2016; 26: 658–72.
- 92 Nordenfors M, Melander C. Young carers in Sweden - A short overview: Swedish Family Care Competence Centre (Nka); 2017; http://www.anhoriga.se/Global/BSA/Dokument/Rapporter_kunskaps%C3%B6versikter/YoungCarers_Sweden_2017.pdf.
- 93 Mauseth T, Hjalhmult E. Adolescents' experiences on coping with parental multiple sclerosis: a grounded theory study. *J Clin Nurs* 2016; 25: 856–65.
- 94 Pakenham KL, Chiu J, Bursnall S, Cannon T. Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *J Health Psychol* 2007; 12: 89–102.
- 95 Becker S. 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. *Glob Soc Policy* 2007; 7: 23–50.
- 96 Stamatopoulos V. The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child Youth Serv* 2018; 39: 180–205.
- 97 Nilsen ACE, Wærdahl R. Gender differences in Norwegian children's work at home. *Childhood* 2014; 22: 53–66.
- 98 Armstrong-Carter E, Olson E, Telzer E. A unifying approach for investigating and understanding youth's help and care for the family. *Child Dev Perspect* 2019; 13: 186–192.