Young carers in Sweden—A pilot study of care activities, view of caring, and psychological well-being

Ulrika Järkestig-Berggren¹ | Ann-Sofie Bergman¹ | Maria Eriksson² | Gisela Priebe³

¹Department of Social Work, Linnaeus University, Sweden

²Department of Social Sciences, Ersta Sköndal Bräcke University College, Stockholm, Sweden

³Department of Psychology, Lund University, Lund, Sweden

Correspondence

Ulrika Järkestig-Berggren, Associate Professor, Department of Social Work, Linnaeus University, Kalmar, Sweden.

Email: ulrika.jarkestig-berggren@lnu.se

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Abstract

Children who have parents with any kind of illness may become young carers who take a responsibility not expected of children for household tasks, or personal or emotional care for parents and siblings. So far, little is known about children in Sweden who are at risk of becoming young carers. The aim of this article is therefore to explore the extent and impact of children's caring activities as reported in a pilot study by a sample of children in Sweden. A number of international questionnaires measuring the amount of caring activities, impact of caring, quality of life, and psychological well-being were translated and combined into a survey. The pilot survey was completed by 30 children 10–18 years of age. Also, when completing the survey, the children were interviewed concerning their experiences of caregiving. The participants report on a group level emotional symptoms such as fear and nervousness above the clinical cut-off value. They also rate a lower level of caring compared with findings from the United Kingdom, but they report a higher degree of negative impact of caring than young carers in the United Kingdom.

KEYWORDS

care activities, child protection, impact of caring, psychological wellbeing, young carers, youth

1 | INTRODUCTION

Children may take on responsibilities for household care and personal and emotional care for parents and siblings when there are unmet needs in the family due to various problems of the parents, such as mental health issues, drug addiction, and physical illness (Pakenham, Chiu, Bursnall, & Cannon, 2007). So far, little is known about the children in Sweden who are young carers, the caring tasks they do, how they perceive their caring, and the psychological well-being of the children. Young carers can be defined as:

young people under the age of 18 who provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but

can be a sibling, grandparent or any other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision. (Leu & Becker, 2017, p. 750)

When defining young carers, there are differences among countries concerning the age interval included: in the United States, up to the age of 18 years; the United Kingdom, up to the age of 17 years; and Australia, up to the age of 24 years of age (Cass, Smyth, Hill, Blaxland, & Hamilton, 2009; Cunningham, Shochet, Smith, & Wurfl, 2017). In Sweden, no formal definition of young carers exists, therefore we have adopted the definition above mentioned for our study. We refer to young carers as children up to the age of 18, adjusting to Swedish law that grant children and adults different kinds of support when being a caregiver. Adults from 18 years are granted support according to the Social Services Act as a caregiver, whereas children are not. An early

study (Becker et al., 1995) suggested that there has been an understanding among professionals and researchers in Sweden that the welfare state protects children from any kind of child labour, and also that general welfare services provide children and their parents with ample resources for a positive childhood upbringing such as child benefits for all families, nursery schools for children, and rights to parental leave. The idea of a comprehensive and protective welfare system may conceal the impact of deinstitutionalization and fragmentation of support systems, for example, that the family has been reintroduced as the main responsible entity to give support for adult persons with various kinds of needs (Bergman, 2016; Trondsen, 2013). The nuclear family as the major support provider, whether it is for children or adults, has not always been recognized by society, or by research in Sweden. In some other countries, however, prominently England and Australia (Leu & Becker, 2017; Pakenham & Cox, 2015), practice and research has found means to identify children who become young carers, and support for those children has been developed. Depending on measurement used, estimates from Australia, United Kingdom, and the United States indicate that 2–8% of the population of children under 18 years of age are young carers (Cass et al., 2009; Leu & Becker, 2017). A Swedish regional survey in the general population in the southwest of the country, aimed at children ages 15–16, found that 7% of the children in the study reported a high amount of caring activities (Nordenfors, Melander, & Daneback, 2014).

In Sweden, there are provisions for parents within the Social Services Act (law 2001:543) to provide help with domestic tasks and to promote the welfare for children and protect children from any kind of neglect. However, due to the lack of recognition in research, it still remains to be explored as to what extent children who take on caring activities are aided.

2 | AIM

The overarching aim of this study is to explore the extent and impact of children's caring activities as reported by a sample of children in Sweden. More specifically, the study sought answers to the following questions:

- a. What kind and amount of caring activities do children report?
- b. What level of psychological well-being do children report?
- c. Are there any differences in children's reports due to age and gender?
- d. How do children who report a high degree of caring activities perceive and describe the impact of their caregiving?

2.1 | Young carers in research

Children may become young carers due to unmet needs in the family and parent's problems (Cunningham et al., 2017; Pakenham & Cox, 2015). Low income occurs as a factor that both influence the process of becoming a young carer and the level of caregiving undertaken (Kallander et al., 2017; Smyth, Cass, & Hill, 2011). Children's caring

activities also seem to be related to the offered support of the welfare system, when parents do not get sufficient support from society (Cunningham et al., 2017; Kallander et al., 2017; Leu & Becker, 2017; Pakenham & Cox, 2015).

Children's amount of caring can be described as a continuum starting with a low level of caring at 1–19 hr per week up till a high level of caring at 50 hr per week or more (Becker, 2007). Joseph, Becker, Becker, and Regel (2009b), who constructed a questionnaire for identification of young carers in the United Kingdom, found that the caring tasks can be divided into six domains: personal care, sibling care, domestic chore, emotional care, household management, and financial/practical support. The variable amounts of caring and caring tasks may then form different situations for children; some children may provide care for many hours a day that involves household management and practical tasks, whereas others provide less care but may involve personal or emotional care that affects the child. The combination of these variables may then affect the child's psychological well-being (Cunningham et al., 2017).

Taking on caregiving tasks in the family may pose risks for children in their health and in their educational, social, and emotional development (Leu & Becker, 2017; Pakenham & Cox, 2015). The risk for adverse outcomes is also shown to increase when the child is responsible for intimate personal care or emotional care (Joseph, Becker, Becker, & Regel, 2009b) and when the situation with the parent is unpredictable (Pakenham et al., 2007). Despite these risks, caring can also have positive consequences, such as contributing to closeness with family members (Cassidy & Giles, 2013), a sense of maturity, and daily living skill independence, such as cooking and cleaning (Smyth et al., 2011). Also, not all young carers experience adverse outcomes. Research shows that young carers who find the caring manageable, have social support, and have developed coping strategies experience less distress and better adjustment than children who lack protective factors (Chikradze, Knecht, & Metzger, 2017; Pakenham et al., 2007).

3 | METHOD

The empirical data are derived from a pilot study aiming to construct and validate a questionnaire in Swedish, based on validated questionnaires in English that can be used by professionals and researchers to identify children who take on a high amount of caring tasks, and to assess their psychological well-being. The grant for the study was received from the Children's Welfare Foundation Sweden. The study presented here used a mixed methods design in keeping with the definition of Johnson, Onwuegbuzie, and Turner (2007), using both quantitative and qualitative data in order to gain a deeper understanding of the caring activities that children do and their views on their caring. A mixed methods approach is applicable to enhance description and understanding of a largely unknown research field with uncertain answers that rely on interpretations (Mertens, 2014), which is the case of this study with its explorative aim because the knowledge about young carers in Sweden is still scarce (Leu & Becker, 2017).

3.1 | Participants

The children were recruited through support groups, which is a common form of support in Sweden for children in adverse circumstances due to parental addiction, mental health problems, or violence against a parent (Forinder & Hagborg, 2008). All children in each group were invited to participate. Thirty children between 10 and 18 years of age took part in this pilot study; 23 girls and 7 boys registered. They were recruited from 5 support groups in various parts of southern Sweden. As participants in a support group, they represent a risk group of having experiences of being young carers, and we presumed they would be able to assist in testing the survey.

3.2 | Procedure

This study has been approved by the regional ethical review board in Linköping (ref. 2014/282-31). A central ethical issue in this research has been the balance between protecting vulnerable children from being exposed to additional stress while at the same time respecting the children's skills and allowing them to express themselves about their own lives and experiences in research. Children's own voices are important in the process of increasing knowledge about children's experiences as young carers and for developing appropriate forms of support for them (Eriksson, 2017).

Informed consent was obtained from the children themselves and from the children's guardians in cases where the children were under the age of 15. The survey and interviews took place during their support group meeting or at a meeting during a camp for adolescents.

The entire survey consisted of 32 questions, taking between 30 and 60 min to complete. One of the researchers was present, helping out if any question was difficult to read or understand.

3.3 | Interviews

Finally, when completing the survey, participants were interviewed lasting 15–30 min in small groups of 3–6 children. Using an interview guide, the children were asked about their experiences related to caring and also about questions asked in the questionnaire. The interviews were then transcribed. In the phase of analysis, the interviews were read and coded thematically into (a) issues children suggested being important and missing in the survey, (b) issues about difficult or wrongly asked questions, and (c) their experiences of caring. For this article, the theme of experiences of caring was further analysed together with survey data.

3.4 | Measures

For the original study, we constructed a survey that included several existing questionnaires: sociodemographic variables: *The Family Affluence Scale* (FAS; Boyce, Torsheim, Currie, & Zambon, 2006; Currie et al., 2004), assessment of caring variables: *Unpredictability of the parent's condition* (Pakenham et al., 2007). *Multidimensional Assessment of Caring Activities* (MACA-YC42), *Positive and Negative Outcomes of Caring Questionnaire* (PANOC-YC20; Joseph, Becker, Becker, & Regel, 2009b), *What I like and dislike about caring* (Joseph, Becker, & Becker, 2009a). In addition, questionnaires that measure health-related quality

of life and psychological well-being: *Kidscreen-27* (Ravens-Sieberger et al., 2007) and *Strengths and Difficulties Questionnaire* (SDQ; Goodman, 2001; Smedje, Broman, Hetta, & von Knorring, 1999; Svedin & Priebe, 2008). Those questionnaires not available in Swedish were translated from the original English using a forward-backward translation procedure (Group, 2004; The KIDSCREEN Group, 2004). We used the questionnaires presented below to answer the aim of this article.

3.5 | Sociodemographic measures

The children were asked about gender, age, whether they lived together with one parent, a parent and a step-parent, both parents in alternating residence after parental separation, in institutional or foster care, or other. Also, the child and the parents' country of origin was collected.

The FAS, developed in the World Health Organization (WHO) Health Behaviour in School-aged Children Study (Boyce et al., 2006), measures family wealth as described by the child. It comprises four items, for example, Do you have your own bedroom for yourself? (0 = No, 1 = Yes). The composite FAS score ranged between 0 and 7. Three categories indicating low affluence (score 0–3), middle affluence (score 4.5), and high affluence (score 6.7) have been calculated (Currie et al., 2004). The scale has been validated and found to be useful in analyses that focus on relationships between socioeconomic status and adolescent health (Boyce et al., 2006). Nevertheless, Cronbach's alpha was 0.080 in this study, which is very low.

3.6 | The context of caring activities

The children were asked, "whom they use to take care of?" with the response alternatives: Mom, Stepmom, Dad, Stepdad, Brother/Stepbrother, and Sister/Stepsister, and with the possibility to mark several alternatives.

Unpredictability of the parent's condition consists of four (Pakenham, Burnnall, Chiu, Cannon, & Okochi, 2006) or five items (personal communication with K. I. Pakenham). This study used the five-item version, and the items referred to a parent or sibling's condition, for example, "It is difficult to plan ahead because my parent's or sibling's condition is unpredictable." Respondents rated on a 5-point scale ranging from 0 (*Strongly disagree*) to 4 (*Strongly agree*). A total score ranging from 0 to 20 is calculated, with high values indicating high amount of unpredictability. Cronbach's alpha was 0.702 in this study.

3.7 | The amount and perception of caring activities

The MACA-YC (Joseph, Becker, Becker, & Regel, 2009b) measures the amount of caring activity undertaken by the young person over the last month. The MACA-YC18, with 18 items, has been developed from originally 42 items (MACA-YC42) using exploratory principal components analysis, and three response alternatives (0 = *Never*, 1 = *Some of the time*, 2 = *A lot of the time*) are provided. By summing up the responses, an index of the total amount of caring activity is calculated (range 0–36). A score of 18 and above is labelled as "Very high amount of caring activity" (Joseph, Becker, Becker, & Regel, 2009b). Six subscales are Personal care (e.g., "Help someone you live with to dress or undress"), Sibling care (e.g., "Taking brothers or sisters to school"),

Domestic tasks (e.g., "Wash up dishes or put dishes in a dishwasher"), Emotional care (e.g., "Keep an eye on someone you live with to make sure they are alright"), Household management (e.g., "Take responsibility for shopping for food"), and Financial/practical (e.g., "Work part time to bring money in"), with three items in each subscale (range 0–6). Cronbach's alpha in this study was 0.898 (Personal care), 0.756 (Sibling care), 0.597 (Domestic tasks), 0.702 (Emotional care), 0.651 (Household management), 0.593 (Financial/practical), and 0.780 (Total scale); which are somewhat low for most subscales and total scale, but in line with the original scale (Joseph, Becker, Becker, & Regel, 2009b).

The PANOC-YC20 for young carers (Joseph, Becker, & Becker, 2009a; Joseph, Becker, Becker, & Regel, 2009b) measures the subjective cognitive and emotional impact of caring in young people. The questionnaire consists of two 10-item subscales assessing positive (e.g., "Because of caring I feel closer to my family") and negative effects (e.g., "Because of caring I feel very lonely"), with three response alternatives (0 = *Never*, 1 = *Some of the time*, and 2 = *A lot of the time*). The responses are summed up for each subscale (range 0–20), with high values indicating a high amount of positive or negative effect of caring. Cronbach's alpha in this study was high, 0.906 (positive impact) and 0.918 (negative impact).

What I like and dislike about caring (Joseph, Becker, & Becker, 2009a) is a short questionnaire with the purpose of providing professionals with information about the nature and extent of caring undertaken, and the young carer's feelings about the caring tasks they do. Young carers are asked how many hours of caring they do on a typical day in a week or at weekends, at what age they first started to do caring jobs, and how many days during the last 2 weeks they have missed or were late for school, college, or university because of caring. Also, young carers are asked to describe, in their own words, what they like, dislike, and find upsetting about caring.

3.8 | Psychological well-being of the children

The SDQ (Goodman, 2001; Smedje et al., 1999; Svedin & Priebe, 2008) is a behavioural screening instrument. The questionnaire consists of five subscales with five items in each: Emotional symptoms (e.g., "I worry a lot"), Conduct problems (e.g., "I get very angry and often lose my temper"), Hyperactivity/inattention (e.g., "I am easily distracted; I find it difficult to concentrate"), Peer relationship problems (e.g., "Other children or young people pick on me or bully me"), and Prosocial behaviour (e.g., "I am kind to younger children"), with three response alternatives (0 = *Not true*, 1 = *Somewhat true*, 2 = *Certainly true*). Some of the items have to be reversed when calculating the score for each subscale (range 0–10). The total difficulties score (range 0–40) consists of scores from all subscales despite prosocial behaviour. High values in the prosocial scale indicate strength, while high values in the four other subscales and the total score indicate difficulties.

3.9 | Analysis

Percentages for the different categories of sociodemographic variables, such as gender, age, country of origin, and the child's living circumstances were calculated. Scores for total scales and subscales

in the MACA-YC, PANOC-YC20, Unpredictability of the parent's condition, and the SDQ, were calculated following the guidelines in manuals and other literature for each scale. Also, means (*M*) and standard deviations (*SD*) were calculated for each scale. Normality tests were conducted by calculation of *z*-values for skewness and kurtosis and visual inspection of histograms, normal Q-Q plots, and box plots for all scales and subscales, separated for gender and age group. The results of the normality tests are not shown in this paper but can be requested from one of the authors (G. P.). For comparisons between boys and girls or between age groups, the independent samples *t* test was used when the data were normally distributed, and the Mann-Whitney *U* test when they were not. For better comparison with previous studies, means and not median values are provided in the tables, even when the data are not normally distributed. Data analysis was conducted using IBM SPSS Statistics 24.

In order to gain insight into whether there might be any tentative pattern in children's views of caring related to how they score their amount of caring, we combined the qualitative data from the interviews and the questionnaire in a mixed-methods analysis. The data of the children with the three highest scores on MACA-42 and the three most negative scores of PANOC were selected. The analysis is therefore based on the scores and quotes from six children. We combined scores and open-ended answers of each child to search for any pattern that describes how children perceive their caring tasks. Children's views of caring are therefore empirically grounded. However, the conceptualization used of a positive, ambivalent, or negative view of caring are to be understood as analytical positions, highlighting the differences in an analysis of what might influence how children perceive their caring.

4 | RESULTS

4.1 | Participant sociodemographics

Majority of the young people in the study (76.7%) were girls, Table 1. The participants were between 10 and 18 years old with a mean age of 14.87 years (*SD* = 2.649). All participants were born in Sweden, and more than 90% had one or both parents born in Sweden. Low family affluence was reported by 16.7% of the youth, and the mean value in the FAS was 4.67 (*SD* = 1.269). More than half of the young people (53.3%) lived together with one parent or had alternating residence after parental separation, Table 1.

4.2 | The context of caring activities

Children in the study are most often helping their mother (*n* = 21); second most common, a sibling (*n* = 19); and third, their father (*n* = 15). Sixteen children explicitly stated that they help more than one person.

The mean value for unpredictability of the parent's or sibling's condition was 10.66 (*SD* = 5.00), Table 2. The range in the sample was 1–19. There were no significant differences between boys and girls or between age groups. There is no given cut-off value for this scale from previous studies that indicates a high amount of unpredictability. In our study, five out of 29 children (17%) who answered the questions had a total score of 16 or more.

TABLE 1 Sociodemographic dates ($n = 30$)

		<i>n</i> (%)
Gender	Girl	23 (76.7)
	Boy	7 (23.3)
Age	10–12	8 (26.7)
	13–15	7 (23.3)
	16–18	15 (50.0)
Country of origin, child	Sweden	30 (100)
Country of origin, parents	Both parents born in Sweden	23 (76.7)
	One parent born in Sweden, one in other country	5 (16.7)
	Both parents born in other country	1 (3.3)
	Unknown for child	1 (3.3)
Family Affluence Scale	Low affluence	5 (16.7)
	Middle affluence	16 (53.3)
	High affluence	9 (30.0)
Siblings	No sibling/s	2 (6.7)
	One sibling	3 (10)
	Two siblings	10 (33.3)
	Three or more siblings	15 (50%)
Child living together with	One parent	10 (33.3)
	Alternating residence after parental separation	6 (20.0)
	Both parents	5 (16.7)
	Parent and stepparent	4 (13.3)
	Institution or in foster care	4 (13.3)
	Other	1 (3.3)

4.3 | The amount and the perception of caring activities

On average, the children are helping 2.9 hr per weekday (range 0–12, $n = 22$) and 3.1 hr per day on weekends (range 0–15, $n = 20$). The mean age when they started caring was 8 years of age (range 3–14, $n = 22$). However, especially the younger children, found it difficult to estimate the amount of time they spent caring.

TABLE 2 Unpredictability of the parent's or sibling's condition ($n = 29$)

Participant	Range	Gender			Age	
		Total <i>M</i> (<i>SD</i>)	Girls <i>M</i> (<i>SD</i>)	Boys <i>M</i> (<i>SD</i>)	10–15 years <i>M</i> (<i>SD</i>)	16–18 years <i>M</i> (<i>SD</i>)
Unpredictability of the parent's or sibling's condition		$n = 29$	$n = 23$	$n = 6$	$n = 14$	$n = 15$
	0–19	10.66 (5.00)	10.70 (5.19)	10.50 (4.64)	9.50 (4.78)	11.73 (5.12)

Note. *M*: mean; *SD*: standard deviation. Independent-samples *t* test.

TABLE 3 The amount and the perception of caring activities ($n = 30$)

Participant		Range	Total <i>M</i> (<i>SD</i>) $n = 30$	Gender		Age	
				Girls <i>M</i> (<i>SD</i>) $n = 23$	Boys <i>M</i> (<i>SD</i>) $n = 7$	10–15 <i>M</i> (<i>SD</i>) $n = 15$	16–18 <i>M</i> (<i>SD</i>) $n = 15$
MACA-YC18	Personal care	0–3	0.13 (0.57)	0.13 (0.63)	0.14 (0.38)	0.07 (0.26)	0.20 (0.78)
	Sibling care	0–4	0.93 (1.46)	1.13 (1.58)	0.29 (0.76)	0.80 (1.21)	1.07 (1.71)
	Domestic tasks	1–6	3.53 (1.48)	3.61 (1.47)	3.29 (1.60)	3.40 (1.72)	3.67 (1.23)
	Emotional care	0–6	1.90 (1.71)	1.96 (1.85)	1.71 (1.25)	2.20 (1.90)	1.60 (1.50)
	Household management	0–6	1.93 (1.68)	1.78 (1.70)	2.43 (1.62)	2.20 (1.94)	1.67 (1.40)
	Financial/practical	0–5	0.60 (1.22)	0.65 (1.37)	0.43 (0.54)	0.60 (1.30)	0.60 (1.18)
	Total score	2–22	9.03 (4.99)	9.26 (5.63)	8.29 (1.89)	9.27 (4.96)	8.80 (5.19)
			$n = 30$	$n = 23$	$n = 7$	$n = 15$	$n = 15$
PANOC-YC20	Positive	0–20	10.67 (5.41)	10.72 (4.91)	10.43 (7.28)	11.47 (6.07)	9.87 (4.73)
	Negative	0–17	5.90 (4.80)	6.22 (5.02)		5.13 (4.66)	6.67 (4.97)

Note. *M*: mean; MACA-YC18: Multidimensional Assessment of Caring Activities Checklist for young carers; PANOC-YC20: Positive and Negative Outcomes of Caring; *SD*: standard deviation. Questionnaire for young carers. Independent samples *t* test or Mann–Whitney *U* test.

The amount of caring activities (MACA-YC18) for the entire sample, as well as separated for gender and age is shown in Table 3. In our sample, the mean total score was 9.03, ranging between 2 and 22. The participating children report most often that they are engaged in domestic tasks ($M = 3.53$) or household management ($M = 1.93$), while few report caring activities such as personal care ($M = 0.13$) or financial/practical tasks ($M = 0.60$). There were no significant differences between boys and girls or between the two age groups. Out of 30 youth participating in the study, two (6.7%) reported a total score of 18 or above which indicates a very high amount of caring activity according to Joseph, Becker, Becker, and Regel (2009b).

Table 3 also shows the perception of caring activities as measured by PANOC-YC20. The mean score for positive outcomes of caring was 10.67 (range in this sample was 0–20) and the mean score for negative outcomes of caring was 5.90 (range 0–17). We found no significant differences between boys and girls or between the two age groups.

4.4 | Psychological well-being of the children

The highest amount of symptoms reported in SDQ were found for emotional symptoms ($M = 5.30$) and hyperactivity ($M = 4.97$), Table 4. Girls reported significantly more prosocial strengths than boys, $t(28) = 2.823$, $P = 0.009$; and older youth reported significantly more emotional symptoms, $t(28) = 2.075$, $P = 0.044$; hyperactivity, $t(28) = 2.113$, $P = 0.044$; and prosocial strengths, $t(28) = 2.278$, $P = 0.031$.

4.5 | Children's views and descriptions of caring responsibilities

The open answers from the interviews and questionnaires of the six children, three scoring the highest amount of care on MACA-42 and

TABLE 4 Psychological well-being of the children ($N = 30$)

	Range	Total M (SD)	Gender		Age	
			Girls M (SD)	Boys M (SD)	10–15 M (SD)	16–18 M (SD)
SDQ		$n = 30$	$n = 23$	$n = 7$	$n = 15$	$n = 15$
Emotional symptoms	1–10	5.30 (2.51)	5.57 (2.63)	4.43 (1.99)	4.40 (1.96)	6.20 (2.73)*
Conduct problems	0–7	2.40 (1.87)	2.35 (1.72)	2.57 (2.44)	2.60 (2.26)	2.20 (1.42)
Hyperactivity	0–9	4.97 (2.83)	5.09 (2.98)	4.57 (2.44)	3.93 (2.74)	6.00 (2.62)*
Peer problems	0–7	3.10 (1.85)	2.87 (1.89)	3.86 (1.57)	3.07 (2.15)	3.13 (1.55)
Prosocial	3–10	8.37 (1.63)	8.78 (1.20)	7.00 (2.16)**	7.73 (1.87)	9.00 (1.07)*
Total difficulties score	5–27	15.77 (6.21)	15.87 (6.31)	15.43 (6.35)	14.00 (7.17)	17.53 (4.67)

Note. M: mean; SD: standard deviation; SDQ = Strengths & Difficulties Questionnaire; t test.

* $P < 0.05$, ** $P < 0.01$.

three children scoring most negatively on PANOC, point at children taking three differing positions towards caring; “positive towards my caring responsibility,” “negative towards my caring responsibility,” and “ambivalent towards my caring responsibility.” Children with the three highest scores on MACA-42 are taking on a high amount of care. The children, however, position themselves rather differently in viewing the impact of caring in their lives. The analysis of the highest negative scores on PANOC shows that the most negative score comes from a child who scores a medium-level of caring on MACA-42. The findings underline that children may not be caring for a large amount of time as measured by MACA-42, but they may still find the burden of caring to be quite heavy.

The children that take on a high amount of caring activities are either the eldest child or the only child staying with the parent(s). Also, they all live with a parent who misuses alcohol or experiences mental health problems, and they all understand their parent's condition to be unpredictable. All six children reported that they have gained knowledge from their support group about how to take care of themselves.

The differing qualities between the positions described above are related to what kind of tasks the child takes on, if the child feels that he or she receives recognition from the parent for the tasks that he or she is doing, the level of responsibility that the child has to take on, if

the child perceives that the caring improves his or her closeness with the family, and if the child can have some self-determination of how much, what, and when he or she will perform the caring tasks.

In Figure 1 below, the three positions towards caring are described, emphasizing the differences between the positions taken by the children.

All children undertake domestic chores, household management, and to some extent, financial/practical tasks. However, personal caregiving tasks for their parents are only experienced by children who express a negative view of caring. Also, emotional care is scored solely by children who express ambivalent or negative views. Some of the things children do not only have something to do with intimate personal care but also with supervising a parent that is not able to take care of herself or himself. A girl tells of the tasks that she dislikes the most:

Take care of my father. I had to shave my father's head when he sat in the bath tub, drunk. (Johanna, 17)

Another crucial aspect is the level of responsibility of caring undertaken by the child. This is not merely a question of the nature of the tasks or the amount of time spent in care, but how much of the responsibility of the caring weighs upon the child. Some children say that they are helping out and doing things together with their parent.

Aspects of the caring	Children's' positions towards caring		
	<i>Positive position</i>	<i>Ambivalent position</i>	<i>Negative position</i>
Tasks	Domestic chore, household management financial support/practical support	Emotional care	Personal care Emotional care
Level of responsibility	Helping, doing tasks together with parent	Helping out	High level of responsibility for caring tasks
Self-determination in caring	Some, can take a break	Some, can take a break	Little, cannot take a break
Parent's view of child's caring	Recognition Appreciation	Some recognition Some appreciation	Taken for granted
Experience of family closeness	Improved by caring	To some extent	Conflicts because of caring

FIGURE 1 Children's positions towards caring

We help each other in our family. I do things to be kind, and everybody does their part at home. (Lisa, 16)

Some children take on full responsibility for managing the tasks at home. The girl below explains her position in the family and the tasks she carries out as a parental responsibility:

Take care of my siblings, take care of my father ... feel like a parent and not like a sibling or their child (Hanna, 18)

The level of responsibility is also connected to how the children perceive if they can choose when they help, with what tasks, and if they can take a break when they feel like it. In the negative position, children experience that they have little possibility to choose what they do and when. Also, they express that they cannot take a break. Children expressing an ambivalent view, think they have some possibility to choose what to do and when, and also express that it is possible to take a break from caregiving.

The caring is undertaken by children interacting with parents, and it seems that the parent's recognition of the child's caregiving is crucial in order to understand how the child perceives doing the caring tasks. Some children experience that parents appreciate and recognize their helping:

I do the shopping, cook and clean. ... it makes my dad happy and proud of me, then I feel happy. (Tilda, 12)

Other children experience that their family relies on them for help and expresses appreciation at times, whereas some children feel that their work at home is taken for granted. In some research, caregiving is perceived as contributing to family-cohesion, and that the child experiences closeness to the family. In this study, the positive position in relation to caring highlights that some children experience that their caregiving makes them feel closer to their family. In contrast, some children taking on the negative position towards caring do not feel that the caring brings them closer to their family. On the contrary, there is quarrelling over the caregiving both with parents and siblings, causing conflicts within the family.

5 | DISCUSSION

5.1 | Sociodemographic, age, and gender differences

This pilot study among Swedish youth at risk reports no differences due to gender or age in the tasks that children perform. There are also few differences in the report concerning psychological well-being, nor were there any differences in the impact of the unpredictability of the parent's or sibling's condition correlating with age or gender. This might be a result of the small sample size and the uneven gender mix. However, the results can be discussed in relation to a broader context, for example, the results from the United Kingdom (Becker, 2007; Joseph, Becker, Becker, & Regel, 2009b) and Australia (Pakenham et al., 2006) offer insights into the situation of young carers in Sweden.

A comparison with the WHO Health Behaviour in School-Aged Children study from 2001/2002 shows that the reported family affluence was lower among participants in this pilot study. In the WHO

study, the mean value in the FAS was 5.8 for Swedish children at age 11, 13, or 15 (Boyce et al., 2006) and 9.2% of them reported low family affluence (Currie et al., 2004) as compared with a mean value of 4.7 and with low family affluence of 16.7% in our study. Parental problems such as mental health issues and alcohol or drug addiction have been shown to be related to economic problems (Hjern & Manhica, 2013) whereas low family affluence is associated with poorer health among young people (Currie et al., 2004). The small sample size in this pilot study did not allow for analyses involving the relative contributions of parental problems/need for care and family affluence in the psychological well-being of young persons. This could be an important issue for future research.

5.2 | Caring tasks and amount of care activities

The children in our study report a lower amount of caring activities for different types of caring activities in MACA-YC18 than youth in the Joseph et al. (2009b) study from the United Kingdom, with domestic tasks as the exception. The amount of emotional care as scored by the Swedish children is lower. In both studies, there were no significant differences between boys and girls with the exception of British girls reporting a higher amount of personal care.

5.3 | Psychological well-being

Malmberg, Rydell, and Smedje (2002) developed clinical cut-off values for the SDQ total difficulties score and the five subscales, based on parent reports on 5- to 15-year-old children from a community sample and a child psychiatric sample in Sweden. At the group level, the children in our study reported values above the clinical cut-off for the total difficulties score, emotional symptoms, hyperactivity, and peer problems. Also, when compared with a population-based sample of Swedish 17–19 year old youth (Svedin & Priebe, 2008), the 16–18 year old youth in our sample reported more emotional symptoms, hyperactivity, and peer problems, but also more prosocial behaviour. Although the samples are not completely comparable, there is some indication that the children in our study perceive more mental health symptoms, and thus a lower degree of psychological well-being.

5.4 | Children's descriptions of impact of caring

Although the reported amount of caring activities was lower in the Swedish sample as compared with the above-mentioned British study, Swedish youth reported less positive and more negative outcomes of caring for young carers in PANOC-YC20. We found no gender differences in the Swedish sample, although boys reported significantly more positive outcomes than girls in the British study.

Research has pointed out that personal care often involves the tasks with most negative impact on children (Becker, 2007; Cunningham et al., 2017). The finding of our study is congruent with this. The most negative scores on PANOC entail personal care of a parent. Furthermore, the most negative scores on PANOC also indicate that children supervise the parent and worry about the parent when not at home. The findings suggest that this emotional care is perceived to be a heavy and negative responsibility to take on for a child. Our findings of the three differing child positions of caring as negative,

ambivalent, and positive, further underline that the negative consequences are linked to emotional and personal care. Therefore, it is important to measure the emotional care and level of psychological worrying experienced by children.

5.5 | Circumstances of importance for children's views of their caring responsibilities

An important circumstance influencing children's views of caring is the unpredictability of the situation. Pakenham et al. (2006) report approximately the same mean value for unpredictability of the parent's condition ($M = 10.42$, $SD = 3.74$) that we found in our study ($M = 10.66$, $SD = 5.00$), although they used only four items as compared with five items in our study. This indicates that the children in our study perceived their parent's or sibling's condition as less unpredictable than the youth in the Australian study by Pakenham et al. The participants in the Pakenham et al. study were 100 young caregivers between 10 and 25 years old, with a variation in recruitment methods including support groups for children of parents with a mental illness or physical disability.

Another aspect of importance for how children view their caring is the level of responsibility that children experience. The level of responsibility does not merely have to do with hours of caring or the specific task. It has to do with the level of responsibility for caring such as managing the household and being responsible for their parent's psychological well-being and personal care. The ambivalent and positive views of caring indicate that the responsibility is shared with a parent, but in a negative view, the children perceive that they are alone in carrying the responsibility for that task.

5.6 | Study limitations

Due to the small number of participants in this pilot study and the specific sample from children at risk taking part in a support group, there is no claim of being representative for children's caring experiences overall, or even in Sweden. Children with a non-Swedish background are underrepresented in the study. Also, children placed in out-of-home care are overrepresented in the study. This is possibly reflected in low ratings on psychological well-being and adverse experiences of caring, although they are not doing any caring in their current situation. However, in combining the quantitative data with the interviews presenting the children's experiences of caring, this article presents some insights into the responsibilities of caring and the impact on children's lives.

5.7 | Conclusions and implications

Summing up the results of this study, the main finding is that the children in our study reported less psychological well-being and quality of life than children in the general population. Some children reported clinical values. The second main result is that the characteristics of the care reported by Swedish children differ from the care described by children who took part in studies in the United Kingdom. Swedish children provide a lower amount of care, but they report a higher degree of negative consequences and lower psychological well-being than young carers in other countries. How is this to be interpreted?

One explanation may be found in the societal view of children taking on responsibilities for caring which might differ among different welfare societies and cultures. In comparison, the United Kingdom has developed various forms of support and also carer allowance for young carers (Leu & Becker, 2017). The response of the Swedish welfare state on the contrary is that children are to be protected from caregiving responsibilities because it could be considered as child labour and goes beyond the responsibilities that should be entrusted on a child. The welfare policy is therefore all about protecting children and not to develop support for children who despite the intentions are caregivers. Therefore, children gain little recognition for what they do as carers, and they may even feel that they are doing tasks they should not be doing. The view of the protective welfare state paradoxically then conceals the experiences of children who do take on caring tasks. This pilot study is the first step of the development of a Swedish assessment tool for identifying young carers. A revised version of the survey could be useful, for example, in social services or healthcare in order to identify young carers and provide the support they may need.

The implication of this study is that further studies need to investigate not only the magnitude and the consequences of children taking on caring responsibilities, but also children's experiences of taking on caring responsibilities, in order to develop a social policy that recognizes and provides adequate support for these children.

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ORCID

Ulrika Järkestig-Berggren <http://orcid.org/0000-0002-1325-9965>

Ann-Sofie Bergman <http://orcid.org/0000-0001-5202-0722>

Maria Eriksson <http://orcid.org/0000-0002-7261-6643>

Gisela Priebe <http://orcid.org/0000-0001-8386-8881>

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