

Well-being and Need for Support of Adolescents with a Chronically Ill Family Member

Simone A. De Roos ¹ · Alice H. De Boer¹ · Sander M. Bot²

Published online: 4 October 2016
© Springer Science+Business Media New York 2016

Abstract This study investigates whether there are differences in the well-being, need for help and use of support services between adolescents with and without a chronically ill or disabled family member. It also examines the role played by the type of illness, the relationship to the family member and the nature and intensity of the help provided by the adolescent. A Dutch sample of 1581 adolescents (average age 14.6 years) completed a questionnaire in 2010 about mental health problems, pro-social behavior, need for and use of support and the illness of family members and any care tasks performed by the respondent. Young people with a sick family member had more mental health problems than their counterparts without a chronically ill family member. They also reported a greater need for and use of help and support. Performing domestic tasks was found to be a predictor for overall mental health problems. The intensity of the help given was related to the need for help by the adolescent. It is concluded that growing up with a chronically ill family member and spending a lot time performing (domestic) tasks are risk factors for adolescent mental health problems and adolescents' need for help. Special attention is warranted for those who need support but who do not translate that need into reality by seeking help.

Keywords Well-being · Need for help · Adolescents with a chronically ill family member · Care tasks

Many adolescents grow up in a family with a chronically ill or disabled parent, sibling or other family member in the household. Estimates of the number of adolescents affected in the Netherlands vary, but figures of between 11 and 37 % have been suggested (De Boer et al. 2012; De Veer and Francke 2008; Van den Einde-Bus et al. 2010). Most of them are children who have a parent with a chronic medical problem (Sieh et al. 2013). Other European countries, such as the UK, also find it difficult to estimate the number of young carers, but the numbers are indisputably high (cf. Becker 1995). It is estimated that between 5 and 15 % of children and adolescents in Western countries live with a seriously ill parent (Barkmann et al. 2007). There are no recent figures on the number of young carers in the European Union.

Public attention for these young people is increasing because there are growing indications that they may face difficulties and be at increased risk of developmental problems (De Veer and Francke 2008; Pakenham et al. 2006; Sieh et al. 2010). Sieh et al. (2013) reported the following based on an overview of research on children of chronically ill parents:

Children with a chronically ill parent seem to have more adverse outcomes in behavioral, psychosocial, and academic adjustment than other children. Although effects are small across studies it should not be neglected that adjustment difficulties may pose a threat to a healthy development of these children. (p. 210)

Although scientific research is devoting increasing attention to young people with sick family members, relatively little is yet known about the mental health consequences for those performing care tasks at home. The available studies were mainly focused on the negative effects (Lackey and Gates 2001; McMahon and Luthar 2007; Sharpe and Rossiter 2002; Sieh et al. 2010;

✉ Simone A. De Roos
s.de.roos@scp.nl

¹ The Netherlands Institute for Social Research (SCP), Research sector Care, Emancipation and Time Use, Postbus 16164, The Hague 2500, The Netherlands

² Social Affairs and Employment (SZW) Inspectorate, The Hague, The Netherlands

Visser-Meily et al. 2006). Those effects mainly manifested themselves in lower life satisfaction and internalised problem behavior such as feeling depressed, being withdrawn, and anxiety. Externalised problem behavior such as disobedience and aggression, lying and stealing appeared to be less associated with growing up with a sick family member. It is only recently that more studies have focused explicitly on positive effects. East (2010) and Siskowski (2009), for example, showed that living with and making allowance for a sick family member on a daily basis can help young people learn to be more understanding and tolerant of (feelings of) others. Looking at the positive as well as the negative aspects is important for an understanding of what it means for adolescents to have a chronically ill relative at home and to develop interventions to improve the support for them.

Earlier studies on the effects of living with a chronically ill family member on the well-being of adolescents were often small-scale and descriptive (Aldridge and Becker 1994; Dearden and Becker 2000; Lackey and Gates 2001; Shifren and Kachorek 2003). Most researchers targeted a select group, for example focusing on family members with a specific physical or mental illness, such as cancer, Parkinson's disease or depression (Champion et al. 2009; Huizinga et al. 2011; Meijer et al. 2008). In this way only effects of living together with single illnesses in families could be estimated. A 'mixed illness sample' based on a community sample of youngsters, including youth with various illness types in the family (physical, mental or a combination of both) and a control group of youth with healthy families, is rarely used, with some notable exceptions (i.e., Pakenham and Cox 2014; Pakenham et al. 2006; Van den Einde-Bus et al. 2010). It is therefore unclear how children who grow up with (different types of) illness in the household differ from their counterparts who do not. There are indications of a possible differential impact of type of illness in the household on mental health problems; for example, adolescents reported more problems when living with a mentally ill relative than a physically ill relative (Pakenham and Cox 2014; Van den Einde-Bus et al. 2010).

A further limitation of this body of research is that only few studies have examined the effects of the family relationship to the sick person (parent, sibling, or other) and the extent and nature of informal care tasks on adolescents' well-being. Many studies concentrated on specific informal care tasks or a specific family relationship (a sick parent or sibling) (Becker 2007; Di Biasi et al. 2016; Rossiter and Sharpe 2001; Warren 2007). Living with a chronically ill parent may be a heavier burden for young people than a sick brother or sister (Pakenham and Cox 2014; Van den Einde-Bus et al. 2010). Concerning effects of caregiving tasks, it is known that (the amount of) informal caregiving can contribute to the development of problem behavior (East 2010; Meijer et al. 2008). The nature of the care tasks also seem to

matter: adolescents who provide parents with emotional support or personal care reported more mental health problems than those who perform other tasks (Lackey and Gates 2001; McMahon and Luthar 2007). Based on current literature, it is however unclear whether these illness and informal care-related factors influence positive adjustment outcomes.

There is one study of Pakenham and Cox (2014) which met most of the above deficiencies. They found for the situation in Australia that—irrespective of increased caregiving responsibilities—the presence of any family member with an illness is associated with a greater risk of mental health difficulties for youth relative to peers from healthy families. However, in this study the role of different types of caregiving tasks was neglected. Furthermore, what remained unclear is whether these youngsters need or want more support than others. This is an important question given the concerns that growing up with a chronically ill relative adversely affects adolescents' development. If adolescents with a chronically ill family member experience more problems than their peers without a sick family member they will probably need more support (cf. Sieh et al. 2011). Among young people with physically chronically ill parents it was found that a third of them need support (Sieh et al. 2011), but whether this also applies for adolescents caring for family members other than their parents, such as siblings, and for family members having mental illnesses, is unknown. There were also indications that adolescents with a sick family member tend not to talk about their concerns and receive either too little help or too late (De Veer and Francke 2008; Drost et al. 2016; Sharpe and Rossiter 2002; Sieh et al. 2010). This may be especially the case for children of parents suffering from mental illness (Drost and Schippers 2015).

The present study addresses the aforementioned limitations of prior research into effects of growing up with illness on the well-being of youngsters, including not only mental health problems and the need for and use of help, but also a positive outcome, i.e., pro-social behavior (cf. Diener and Suh 1997). This group of youngsters is compared to a control group of adolescents who do not grow up with an ill family member expecting the former group to report more mental health problems, more pro-social behavior, and greater need for and use of support than the latter. Hereby we control for a wide array of background characteristics of adolescents and their families which are known from the literature to be potential determinants of well-being and/or need for and use of support, such as age, ethnicity, school level, family affluence, family structure, religion, degree of urbanisation of the residential setting, and stressful life events (cf. Ebstyn King and Furrow 2004; Ormel et al. 2001; Stevens et al. 2009; Thomson and McLanahan 2012; Vollebergh et al. 2006). We explore also the potential differences in adjustment and need for and use of support of

Table 1 Background characteristics of the total study population and adolescents with and without a chronically ill family member (in percentages, $n = 1581$)

	Total group ($n = 1581$)	Adolescents without sick family member ($n = 1439$)	Adolescents with sick family member ($n = 142$)
Age (in years)	14.6	14.6	15.0****
Sex (boys)	44.5	44.9	41.0
School level (averages)	2.73	2.74	2.70
Ethnicity (Dutch native)	89.5	89.7	88.1
Religious upbringing (yes)	46.6	47.1	41.5
Family affluence (averages)	73.7	73.9	71.6
Household form (complete family)	80.4	81.4	71.5**
Degree of urbanisation of residential setting (urban)	47.7	46.9	55.2*
Stressful life events	16.5	15.1	30.6****

* $p < .05$, ** $p < .01$, **** $p < .001$

those who grow up with an ill family member depending on varying types of illness, nature of the relationship (target member), and varying provision of caregiving.

Method

Participants

A total of 1581 adolescents aged 13–17 years took part in the survey, of whom 877 were girls and 704 boys. They were part of a follow-up study of the Dutch HBSC survey (Health Behaviour in School-aged Children, Roberts et al. 2009; Van Dorsselaer et al. 2010), an international study which is carried out every four years to measure the health, well-being and risk-behavior of schoolchildren aged between 11 and 16 years. Some of the secondary school students in the Dutch sample from 2009 (Van Dorsselaer et al. 2010) were presented with a new questionnaire a year later. The average age of the respondents was 14.6 years (see also Table 1). The design of the follow-up study means that the sample is not representative of all adolescents in the Netherlands; boys are slightly underrepresented, as are migrants and adolescents from less affluence families. Students in the higher school tracks are overrepresented. It is therefore impossible to draw conclusions about prevalence of adolescents with sick family members and adolescent informal caregivers in the Netherlands. The data does however provide information on the characteristics that are associated with well-being and the need for and use of help and support services.

Procedure

The data for this study was collected in the autumn of 2010. The adolescents were recruited via reply forms on the back

of the questionnaire that they had completed in 2009. 2958 of the 5719 respondents in 2009 indicated on the forms that they were willing to participate in a follow-up survey, and 2131 of them supplied a valid email address and/or telephone number. These adolescents were invited by email to complete an online follow-up questionnaire. If they did not respond within a few days, they were sent a reminder, first by email, followed if necessary by a telephone call. If they still did not respond, they were called and if possible completed the questionnaire by telephone. The response rate was 28 % of the original group of secondary school students and 74 % of those with a valid contact address.

The respondents were asked to complete the questionnaire (online) alone at home, without anyone else present. They received a gift voucher for eight euros for their participation.

Measures

Well-being, Need for and use of Support

Concerning well-being a distinction was made between mental health problems and pro-social behavior, using the Dutch version of the Strengths and Difficulties Questionnaire (SDQ). A low level of mental health problems ('difficulties') and a high level of pro-social behavior ('strengths') are indicative of a high level of well-being (Goodman 2001). The SDQ is a validated instrument (Goodman 2001; Muris et al. 2003; Van Widenfelt et al. 2003). Respondents were asked to score 25 statements about their behavior and feelings in the past six months; the response options were 'not true' (score 0), 'partly true' (score 1), or 'definitely true' (score 2). For this study we used the subscales 'emotional problems' (scores for five items aggregated, range between 0 and 10), 'total problems' (20 items comprising the scales 'behavioral problems',

‘hyperactivity attention deficit disorder’, ‘problems connecting with peers’ and ‘emotional problems’, range from 0 to 40) and pro-social behavior (five items, range from 0 to 10). The first two scales are reasonably reliable, with Cronbach’s alphas of 0.70 and 0.74, respectively. An example of an item indicating emotional problems is: ‘I spend a lot of time worrying’. The subscale pro-social behavior demonstrated somewhat low internal reliability (0.65). Earlier population studies on psychometric evaluations of the child version of the SDQ reported comparable reliabilities (Goodman 2001; Muris et al. 2003; Van Widenfelt et al. 2003). Also, in recent research on the well-being of youngsters with(out) an ill family member similar reliabilities were found (Pakenham and Cox 2014). An example of pro-social behavior is: ‘I try to be nice to other people. I care about their feelings’.

To measure adolescents’ need for and use of support respondents were asked whether they had experienced so many problems in the year preceding the survey that they would have liked to receive (more) help/support. They were also asked whether they had been in contact with one or more persons or agencies in the past year in connection with those difficulties: GP, school doctor/nurse, educational worker or (school) social worker, guardian, Youth and Family Centre, youth welfare services, a psychologist/psychiatrist/someone youth mental health worker, juvenile crime prevention agency (Bureau Halt in the Netherlands) or youth probation service, or another person/agency. In the latter case, an open question was used to elicit which person or agency this was (members of the respondent’s network with a certain function were usually mentioned here, such as mentors, sports leaders or members of the church).

Illness and Care Characteristics, Life Events, and Background Variables

To assess whether adolescents grow up with a chronically ill family member, respondents were asked to indicate whether someone in their family was chronically ill (physically or mentally) or disabled and therefore needed help. The response options were: ‘no’, ‘myself’, ‘my father/mother’, ‘my brother/sister’ and/or someone else. Respondents were also asked to state whether the health problems were mental and/or physical. Those with a sick family member also reported whether they regularly provided help to that person (or persons) and if so, for how many hours per week. They were also asked what kind of help they give (several answers possible): domestic help (cleaning, doing the washing, doing shopping), administrative and practical help (applying for and organising provisions for the sick person, supervising homework), personal care (help with washing, dressing, going to the toilet), nursing care (preparing/administering medicines and wound care) and

providing company (accompanying on visits to the doctor, family visits, providing comfort and distraction). The tasks were divided into domestic and administrative help (first two tasks, not directly related to illness; ‘yes/no’ answers possible) and care, nursing and company (last three tasks; directly related to illness; ‘yes/no’ answers possible).

To measure stressful life events in the family respondents were asked whether anything had changed in their home situation in the past year, and if so, what. We included the following stressful events: parents separated/divorced (yes/no), one (or both) parents unemployed in the past year, and whether the family had moved house in the past year. The death of a parent, brother or sister was also included as a stressful life event. At least one of these life events was included in the multivariate and bivariate analyses.

Eight background characteristics were measured, i.e., age, gender, household form, school level, religious upbringing, ethnicity, degree of urbanisation of residential setting, and family affluence. Respondents entered their date of birth, gender and whether or not (in 2009) they were living in a complete family (both biological or adoptive parents present). They also stated what school type they were in (ranging from 1 = pre-vocational secondary education (vocational pathway) (low) to 4 = pre-university education (high)) and in which school year they were. They also stated whether they were being brought up in a certain faith. The options were Roman Catholic, Protestant (Reformed/Orthodox), Islamic, other, or non-religious upbringing. The different religions were aggregated in the analyses to ‘religious upbringing’. Ethnic background was determined on the basis of the country of birth of the respondent, his/her father and mother. A respondent was counted as belonging to ethnic group other than Dutch if he or she or one of his/her parents was born outside the Netherlands. The degree of urbanisation of the respondent’s residential setting was determined by the postcode (Knol 1998). The affluence of the respondent’s household was determined using the Family Affluence Scale (FAS). This measures material possessions (e.g. the number of cars, computers and having one’s own bedroom) and the number of times the family has been on holiday in the past year. The sum score for these questions lies between zero and 100 (Van Dorsselaer et al. 2010).

Data Analyses

Bivariate and multivariate analyses were performed. First, *t*-tests were used to measure differences between groups (e.g. adolescents with and without a sick family member) (Tables 1 and 2). Multivariate (logistic) regression analyses were then used to see whether differences remained after controlling for relevant background characteristics (Tables 3–6) and illness and informal care factors (Tables 5

and 6). We also tested for multicollinearity in these analyses. The indices for collinearity (the highest mean variance inflation factor (VIF)=2.72 and the highest maximum VIF=3.80) showed that the common rules of thumb (the mean VIF is below 6 and the maximum VIF is below 10) are met. This indicates no multicollinearity. The information in Tables 5 and 6 relates to adolescents with a sick family member: 133 and 135 respondents, respectively (missing values for the independent variables mean the numbers are slightly below the 142 adolescents with a sick family member in Tables 1 and 2). In these latter analyses, the stepwise backward method was used to arrive at the simplest model.

Results

Of the total of 1581 adolescents surveyed, 1439 lived in a household without a sick family member and 142 (9 %) with a sick relative. Table 1 shows the distribution by background characteristics. The gender distribution, school level, ethnic origin, religious upbringing and family affluence were comparable for the two groups. Adolescents growing up with a sick family member were five months older on average than those without a sick family member. They also more often lived in incomplete families and in an urbanised setting than adolescents without a sick family member. They have also more often experienced stressful life events in the year prior to the survey. Supplementary analyses showed that only a very small number of adolescents with a sick family member had lost a parent through death (two parents). None of the respondents in this sample had a brother or sister who had died. This outcome shows that, in this sample, stressful life events are not related to the death of a loved one, but to separation or unemployment of the parents or the family moving home.

59 % of adolescents with a chronically ill family member had a sick parent, 30 % a sick brother or sister and 11 % another sick family member (e.g. a grandparent living in the home) (not shown in tables). 53 % of sick family members had a physical illness, 30 % a mental illness and 17 % a

combination of the two. 65 % of these adolescents provided help to their sick family member, for an average of 5.7 h per week (range from 1 to 24 h; standard deviation 5 h). 24 % of these young carers provided only domestic and/or administrative help; 43 % provided only care and/or company and 33 % provided both types of help.

Adolescents with a sick family member reported more emotional problems than those without a sick family member. They also scored higher on total problems. By contrast, they showed more pro-social behavior (see Table 2).

Adolescents living with a sick family member felt a greater need for support; they reported that they would like (more) help more than twice as often as adolescents without a sick family member (27 vs. 12 %). They also made more use of (professional) support services (33 vs. 19 %). Further analysis showed that adolescents with a sick family member had more often had contact with an educational/(school) social worker/guardian (11 vs. 3 %, $t=2.99, p < 0.005$), youth welfare services (6 vs. 2 %, $t=2.01, p < 0.05$) or psychologist/psychiatrist/youth mental health services (16 vs. 3 %, $t=4.13, p < 0.005$) than adolescents without a sick family member (not shown in table).

Regression Analyses

As well as (not) growing up with a sick family member, virtually all background characteristics, with the exception of ethnicity, degree of urbanisation of the residential setting and stressful life events, were related to a greater or lesser extent to a number of aspects of well-being and need for and use of support (see Tables 3 and 4). Religious upbringing and family affluence were only associated with adolescents’ well-being, not with their need for and use of help. Adolescents with a religious upbringing scored lower on the total problems scale than those without a religious upbringing. The more affluent the family in which an adolescent grows up, the fewer problems they had in general, the fewer emotional problems in particular and the more often they displayed pro-social behavior.

Table 2 Well-being (SDQ), need for and use of support of the total group and adolescents with and without a sick family member (in averages and percentages)

	Total group (<i>n</i> = 1581)	Adolescents without sick family member (<i>n</i> = 1439)	Adolescents with sick family member (<i>n</i> = 142)
SDQ			
Total problems	8.97	8.74	11.10***
Emotional problems	2.32	2.21	3.35***
Pro-social behavior	8.39	8.36	8.65*
Need for (more) support	13.9 %	12.4 %	27.1 %***
Use of help	20.4 %	19.1 %	33.3 %**

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 3 Regression of growing up with a sick family member on well-being of adolescents after controlling for background characteristics (standardised coefficients, $n = 1539$)

	Total problems	Emotional problems	Pro-social behavior
Age (in years)	0.06*	0.10***	-0.04
Sex (boys = ref.)	0.01	0.27***	0.29***
School level	-0.15***	-0.02	0.10***
Ethnicity (Dutch native = ref. vs. migrant)	0.01	-0.05	0.03
Religious upbringing (non-religious = ref.)	-0.06*	-0.05	-0.01
Family affluence (FAS)	-0.08**	-0.07**	0.09**
Household type (incomplete family = ref.)	-0.08**	-0.05	-0.04
Degree of urbanisation of residential setting	-0.02	-0.03	0.01
Stressful life events (none = ref.)	0.04	0.01	0.02
Presence of sick family member (none = ref.)	0.11***	0.11***	0.00
Explained variance (R^2)	7.6 %	12.0 %	10.3 %
<i>F</i> -test	$F(10, 1529) = 12.55***$	$F(10, 1530) = 20.90***$	$F(10, 1532) = 17.61***$

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 4 Logistic regression of growing up with a sick family member on the need for and use of support by adolescents after controlling for background characteristics (standardised coefficients, $n = 1544$)

	Need for (more) support	Use of support
Age (in years)	-0.08*	0.07*
Sex (boys = ref.)	0.15***	0.10**
School level	-0.14**	-0.10**
Ethnicity (Dutch native = ref. vs. migrant)	0.00	-0.02
Religious upbringing (non-religious = ref.)	-0.00	-0.04
Family affluence (FAS)	0.04	0.06
Household type (incomplete family = ref.)	-0.14***	-0.16***
Degree of urbanisation of residential setting	-0.01	-0.04
Stressful life events (none = ref.)	0.03	0.06
Presence of sick family member (none = ref.)	0.14***	0.09**
Explained variance (pseudo R^2)	5.1 %	4.7 %
Chi ² -test	LR Chi ² (10) = 64.25***	LR Chi ² (10) = 73.92***

* $p < .05$, ** $p < .01$, *** $p < .001$

Age, gender, school level and household form were associated with several indicators of both mental well-being and need for and use of support. Older adolescents had more problems in general and more emotional problems in particular. They also used more help, but had less need for (extra) support than younger adolescents. Girls had more emotional problems and a greater need for help and also made more use of it than boys. On the other hand, they displayed more pro-social behavior than boys. Adolescents in higher educational tracks presented a more positive picture as regards (general) problems and pro-social behavior. They also had less need for help and made less use of it. Finally, adolescents from an incomplete family scored higher on the total problems scale than adolescents growing up with both parents. They also needed more help and more often used it.

Role of Type of Illness, Family Relationship and Informal Care

After controlling for background characteristics, the type of illness of the family member was not significantly associated with the well-being and need for/use of help of adolescents growing up with a sick family member (see Tables 5 and 6). The family relationship also showed no correlation with the different outcome measures. Informal caregiving did show a partial association with well-being and need for help. The nature of the informal care tasks was a predictor for emotional symptoms (Table 5). Adolescents with a sick family member who perform household and/or administrative tasks displayed more emotional problems than their peers who do not perform these tasks. The intensity of the caregiving predicted the

Table 5 Regression (stepwise backward method) of informal care, family relationship, and type of illness on the well-being of adolescents with a sick family member after controlling for background characteristics (standardised coefficients, $n = 133$)

	Total problems	Emotional problems	Pro-social behavior
Background characteristics			
Age (in years)			
Sex (ref. = boy)		0.28**	0.22**
School level	-0.22**		0.20*
Ethnicity (Dutch native = ref. vs. migrant)			
Religious upbringing (ref. = non-religious)			
Family affluence (FAS)	-0.25**		
Household form (incomplete family = ref.)		-0.21*	
Degree of urbanisation of residential setting			
Stressful life events			0.17*
Informal care			
Number of hours care per week			
Care of and company for sick person			
Household and/or administrative tasks	0.19*		
Family relationship			
Sick parent (= ref.)			
Sick brother/sister			
Other sick family member			
Type of illness			
Mental (=ref.)			
Physical			
Physical and mental			
Explained variance (R^2)	16.8 %	11.8 %	11.7 %
<i>F</i> -test	$F(3, 129) = 8.66^{***}$	$F(2, 130) = 8.67^{***}$	$F(3, 129) = 5.69^{**}$

* $p < .05$, ** $p < .01$, *** $p < .001$

need for support: the more hours of informal care provided, the greater the need for support (Table 6).

Going through stressful events in the family was positively associated with pro-social behavior by adolescents growing up with a sick family member. Among the other background characteristics, gender, school level, family affluence and household form were important predictors of the well-being and need for/use of help by adolescents with a sick family member.

Discussion

Our study shows that adolescents growing up with a sick family member are more pessimistic about their well-being in terms of mental health problems than their peers without a chronically ill family member. This matches our hypothesis and findings from earlier research (Pakenham et al. 2006; Pakenham and Cox 2014; Sieh et al. 2010). The more sombre picture regarding mental health problems for adolescents with a sick family member remains after controlling

for several background characteristics, such as growing up in an incomplete family or in a family where stressful events have occurred. It can therefore be concluded that the presence of a chronically ill family member is a risk factor for mental health problems in adolescents. Adolescents with a sick family member have more problems across a broad front, including emotional problems such as feeling gloomy and anxious as well as angry, overactive and rebellious behavior, and difficulty connecting with peers. This finding is in line with earlier research showing that living with a chronically ill family member can impose psychological pressures on adolescents, for example due to anxiety and uncertainty regarding (the course of) the illness or due to anger and sadness about the limitations and pain suffered by the sick family member (Sieh et al. 2011). It is therefore important that those providing support, for example at school or in the sports club, are alert to these problems as soon as they become aware that adolescents have a sick relative at home.

Our results also show that adolescents with a sick family member make more allowance for other people’s feelings

Table 6 Logistic regression (stepwise backward method) of informal care, family relationship, and type of illness on the need for and use of support by adolescents with a sick family member after controlling for background characteristics (standardised coefficients, $n = 135$)

	Need for (more) support	Use of support
Background characteristics		
Age (in years)		
Sex (ref. = boy)	0.22*	0.22*
School level	-0.27*	
Ethnicity (Dutch native = ref. vs. migrant)		-0.29*
Religious upbringing (ref. = non-religious)		
Family affluence (FAS)		
Household form (incomplete family = ref.)	-0.24*	-0.25*
Degree of urbanisation of residential setting		
Stressfull life events		
Informal care		
Number of hours care per week	0.20*	
Care of and company for sick person		
Household and/or administrative tasks		
Family relationship		
Sick parent (= ref.)		
Sick brother/sister		
Other sick family member		
Type of illness		
Mental (= ref.)		
Physical		
Physical and mental		
Explained variance (pseudo R^2)	13.5 %	9.4 %
Chi ² test	LR Chi ² (4) = 20.23***	LR Chi ² (3) = 15.98***

* $p < .05$, ** $p < .01$, $p < .001$

and are more willing to offer help and share with others than adolescents without a sick family member. However, this difference is no longer significant when controlling for a number of sociodemographic characteristics and for experiencing stressful events in the family. These stressful events, such as divorce or unemployment in the family, may partly explain the difference in pro-social behavior between adolescents who do and do not grow up with a sick family member. Compared with ‘average’ adolescents, those with a sick family member more often encounter stressful events, and those events are related to pro-social behavior. The combination of having a sick family member and experiencing stressful events in the family may reinforce their empathic abilities.

Adolescents with sick relatives who display pro-social behavior should be reinforced in their skills in dealing with the illness (cf. Drost et al. 2016). These youngsters might also serve as an example for others, possibly boosting their self-confidence and encouraging positive experiences. There are indications that health workers can be helpful in this respect, by discussing their caring role and assisting them in finding ways to further improve their resiliency and coping skills they have already developed (Bilsborough

2004; Drost et al. 2016). One caveat is that these youngsters have to look after their own needs and wishes as well; too much pro-social behavior could undermine their assertiveness and healthy identity development (cf. Drost and Schippers 2015; Hay and Pawlby 2003). They might need for example time and/or space for friends and acquaintances (cf. Thomas et al. 2003). Our finding that adolescents with a sick family member have more problems in general, including in connecting with peers, also illustrates the need for such a nuanced interpretation of pro-social behavior.

The results also show that over a quarter of adolescents with a sick family member needed (more) support in the year preceding the survey and that a third had accessed professional help. These figures are substantially higher than for adolescents not confronted with illness and care in the family. The need for support is in line with earlier findings (Sieh et al. 2011). How we can explain the unfulfilled need for support is not clear. It may be linked to unfamiliarity with available services, the expectation that no adequate help will be forthcoming, feelings of shame, or that an adolescent with a sick family member does not want any extra help, for example due to the adolescent’s increasing desire for autonomy (Drost et al. 2010).

Furthermore, the existing programs and services may not be optimally adapted to the needs and preferences of the target group youngsters and their family situation. Earlier research recommended interventions that focus on peer support, illness related information, and resources such as coping skills (Sieh et al. 2011). Also, the internet may provide a new opportunity for professionals to offer easy access to information and support and to create a way to exchange experiences anonymously. Most adolescents in Western societies use internet as a means of social interaction, and therefore, support via internet is assumed to be a promising option for reaching, supporting and empowering adolescents with ill family members (Drost et al. 2010).

The nature of the illness and the family relationship was not found to have an effect on adolescents with a chronically ill family member. Earlier Dutch research showed that adolescents with a physically ill family member were better off on several fronts than adolescents living with a mentally ill relative (Van den Einde-Bus et al. 2010). That could not be confirmed in our study. It may be that the study by Van den Einde-Bus et al. (2010) found more effects because their sample was larger, with far more adolescents from the target group, thus creating more scope for significant effects to occur. It may also be that our question formulation—asking about a family member who is chronically (mentally and/or physically) ill and therefore needs help—was not subtle enough to serve as an indicator for the severity of the illness. It may be that our question formulation mainly reveals adolescents with a seriously (mentally and/or physically) ill relative, and there may be some under-reporting. Only 9 % of the adolescents in our study reported having a sick family member, whereas this percentage is likely to be slightly higher in the population (Van den Einde-Bus et al. 2010; De Boer et al. 2012). This may be partly due to the selective sample of school students (see ‘Participants’). One recommendation for follow-up research would be not only to ask respondents about the duration, severity and prognosis of the family member’s illness (cf. Korneluk and Lee 1998), but also to use a larger and more representative sample.

What did become clear is that the well-being and need for help of adolescents with a sick family member depends partly on the nature and intensity of the care they provide. Adolescents who perform domestic and/or administrative tasks suffer more from anger, sadness, over activity and lack of concentration and problems in connecting with peers than adolescents who do not perform these tasks. Evidently, performing these tasks can impose such a burden on adolescents that it creates a higher risk of mental health problems. We also found a greater need for support by adolescents providing more intensive help (cf. Lackey and Gates 2001; McMahon and Luthar 2007; Meijer et al. 2008). For household members providing care is less likely

to be a choice and there may be a lack of alternative caregivers as well. Our results do suggest that helping youngsters who grow up with a sick family member to ask for assistance and reducing the number of care hours and tasks could be a good intervention in preventing the development of problems in them. That would meet the greater need for support by them, and especially those who spend a lot of time providing informal care.

In conclusion, our study sheds light on the consequences of adolescents growing up with a chronically ill family member. Using a large national sample it was shown that living with an ill family member is a crucial factor for the well-being of youngsters. It confirms that they experience more mental health problems and a greater need of support as well. The care load is one of the predictors here. For them sharing responsibilities may reduce not only the objective burden, but also the use of professional support, as well as the emotional distress that results from dealing with the situation at home. More research is needed on contextual effects, preferably using information on youngsters with and without ill family members in different countries having different organisational service models for young people and young carers. Such information will increase insight in how care situations work out differently for adolescents living in specific conditions and may shed more light on the needs and preferences of young carers and their families, and on adequate support to compensate for (unmet) needs and to prevent or reduce burden.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

Ethical Approval All procedures performed involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants in the study.

References

- Aldridge, J., & Becker, S. (1994). *My child, my carer: The parents' perspective*. Loughborough: Loughborough University. Young carers research group
- Barkmann, C., Romer, G., Watson, M., & Schulte-Markwort, M. (2007). Parental physical illness as a risk for psychosocial maladjustment in children and adolescents: Epidemiological findings from a national survey in Germany. *Psychosomatics*, 48(6), 476–481.
- Becker, S. (1995). *Young carers in Europe; an exploratory cross-national study in Britain, France, Sweden and Germany*. Loughborough: Loughborough University. Young carers research group

- Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family. Research and policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy*, 7, 23–50.
- Bilsborough, S. (2004). What we want from adult psychiatrists and their colleagues: "Telling it like it is". In M. Goepfert, J. Webster, M. V. Seeman (Eds.), *Parental Psychiatric Disorder: Distressed Parents and their Families* (pp. 3–7). Cambridge, UK: Cambridge University Press.
- Champion, J. E., Jaser, S. S., Reeslund, K. L., Simmons, L., Potts, E., Shears, A. R., & Compas, B. E. (2009). Caretaking behaviours by adolescent children of mothers with and without a history of depression. *Journal of Family Psychology*, 23, 156–166.
- Dearden, C., & Becker, S. (2000). *Growing up caring: Vulnerability and transition to adulthood—Young carers' experiences*. Leicester: Youth Work Press.
- De Boer, A., Oudijk, D., & Tielen, L. (2012). Kinderen en jongeren met een langdurig ziek gezinslid in Nederland [Children and adolescents with a chronically ill family member in the Netherlands]. *TSG – Tijdschrift voor gezondheidswetenschappen*, 90(3), 167–170.
- De Veer, A. J. E., & Francke, A. L. (2008). Opgroeien met zorg. Quick scan naar de aard en omvang van de zorg, belasting en ondersteuningsmogelijkheden voor jonge mantelzorgers [Growing up with care. Quick scan into the nature and extent of informal care, burden, and opportunities for support for young carers]. Utrecht: Nivel.
- Di Biasi, S., Trimarco, B., D'Ardua, C., Melogno, S., Meledrandri, G., & Levi, G. (2016). Psychological adjustment, social responsiveness and parent distress in an Italian Sample of siblings of children with high-functioning autism spectrum disorder. *Journal of Child and Family Studies*, 25(3), 883–890.
- Diener, E., & Suh, E. (1997). Measuring quality of life: Economic, social, and subjective indicators. *Social Indicators Research*, 40, 189–216.
- Drost, L. M., Cuijpers, P., & Schippers, G. M. (2010). Developing an interactive website for adolescents with a mentally ill family member. *Clinical Child Psychology and Psychiatry*, 16(3), 351–364.
- Drost, L. M., & Schippers, G. M. (2015). Online support for children of parents suffering from mental illness: A case study. *Clinical Child Psychology and Psychiatry*, 20(1), 53–67.
- Drost, L. M., Van der Krieke, L., Sytema, S., & Schippers, G. M. (2016). Self-expressed strengths and resources of children of parents with a mental illness: A systematic review. *International Journal of Mental Health Nursing*, 25, 102–115.
- East, P. L. (2010). Children's provision of family caregiving: Benefit or burden? *Child Development Perspectives*, 4, 55–61.
- Ebstein King, P., & Furrow, J. L. (2004). Religion as a resource for positive youth development: Religion, social capital, and moral outcomes. *Developmental Psychology*, 49, 703–713.
- Goodman, R. (2001). Psychometric properties of the Strength and Difficulties Questionnaire. *Journal of American Child and Adolescent Psychiatry*, 40, 1337–1345.
- Hay, D. F., & Pawlby, S. (2003). Prosocial development in relation to children's and mothers' psychological problems. *Child Development*, 74, 1314–1327.
- Huizinga, G. A., Visser, A., Van der Graaf, W. T. A., Hoekstra, H. J., Stewart, R. E., & Hoekstra-Weebers, J. E. H. M. (2011). Family-oriented multilevel study on the psychological functioning of adolescent children having a mother with cancer. *Psycho-Oncology*, 20, 730–737.
- Knol, F. A. (1998). *Van hoog naar laag, van laag naar hoog. De sociaal-ruimtelijke ontwikkeling van wijken tussen 1971 en 1995 [From high to low, from low to high. The social-spatial development of neighborhoods between 1971 and 1995]*. Rijswijk: Sociaal en Cultureel Planbureau.
- Korneluk, Y. G., & Lee, C. M. (1998). Children's adjustment to parental physical illness. *Clinical Child and Family Psychology Review*, 1, 179–193.
- Lackey, N. R., & Gates, M. F. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing*, 34, 320–328.
- McMahon, T. J., & Luthar, S. S. (2007). Defining characteristics and potential consequences of caretaking burden among children living in urban poverty. *American Journal of Orthopsychiatry*, 2, 267–281.
- Meijer, A. M., Oostveen, S. J. E., & Stams, G. J. J. M. (2008). Zorgen voor een zieke ouder. De relatie tussen mantelzorg, ziekte van de ouder en gedragsproblemen bij kinderen [Care for a sick parent. The relationship between informal care, illness of the parent, and behavioral problems in children]. *Kind en Adolescent*, 29, 208–220.
- Muris, P., Meesters, C., & Van den Berg, F. (2003). The strengths and difficulties questionnaire (SDQ): Further evidence for its reliability and validity in a community sample of Dutch children and adolescents. *European Child and Adolescent Psychiatry*, 12, 1–8.
- Ormel, J., Neeleman, J., & Wiersma, D. (2001). Determinanten van psychische ongezondheid: Implicaties voor onderzoek en beleid [Determinants of mental health problems: Implications for research and policy]. *Tijdschrift voor Psychiatrie*, 43, 245–257.
- Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between caregivers and noncaregivers. *Rehabilitation Psychology*, 51, 113–126.
- Pakenham, K., & Cox, S. (2014). The effect of parental illness and other ill family members on the adjustment of children. *Annals of Behavioral Medicine*, 48, 424–437.
- Roberts, C., Freeman, J., Samdal, O., Schnor, C. W., De Looze, M. E., Nic Gabhainn, S., & Rasmussen, M. (2009). The health behaviour in school-aged children (HBSC) study: Methodological developments and current tensions. *International Journal of Public Health*, 54, 140–150.
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, 10, 65–84.
- Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, 27, 699–710.
- Shifren, K., & Kachorek, L. V. (2003). Does early caregiving matter? The effects on young caregivers' adult mental health. *International Journal of Behavioral Development*, 27, 338–345.
- Sieh, D. S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M. A., & Van der Leij, D. A. V. (2010). Problem behavior in children of chronically ill parents: A meta-analysis. *Clinical Child and Family Psychology Review*, 13, 384–397.
- Sieh, D. S., Visser-Meily, J. M. A., & Meijer, A. M. (2011). Jongeren met chronisch zieke ouders: Jonge mantelzorgers hebben behoefte aan aandacht [Adolescents with chronically ill parents: Young carer needs attention]. *Jeugd en Co Kennis*, 5, 18–26.
- Sieh, D. S., Visser-Meily, J. M. A., & Meijer, A. M. (2013). Differential outcomes of adolescents with chronically ill and healthy parents. *Journal of Child and Family Studies*, 22, 209–218.
- Siskowski, C. (2009). Adolescent caregivers. In K. Shifren (Ed.), *How caregiving affects development: Psychological implications for child, adolescent, and adult caregivers* (pp. 65–91). Washington, DC: American Psychological Association.
- Stevens, J., Pommer, E., Van Kempen, H., Zeijl, E., Woittiez, I., Sadiraj, K., Gilsing, R., & Keuzenkamp, S. (2009). *De jeugd een zorg. Ramings- en verdeelmodel jeugdzorg 2007. [Concern for youth. An estimate and distribution model of youth welfare work]*. Den Haag: Sociaal en Cultureel Planbureau.

- Thomas, N., Stainton, T., Jackson, S., Cheung, W. Y., Doubtfire, S., & Webb, A. (2003). 'Your friends don't understand': Invisibility and unmet needs in the lives of 'young carers'. *Child and Family Social Work*, 8, 35–46.
- Thomson, E., & McLanahan, S. S. (2012). Reflections on "Family structure and child well-being: Economic resources vs parental socialization". *Social Forces*, 91, 45–53.
- Van den Einde-Bus, A. E. M., Goldschmeding, J. E. J., Tielen, L. M., De Waart, F. G., & Van de Looij-Jansen, P. M. (2010). Jongeren die opgroeien met een langdurig ziek, gehandicapt of verslaafd familielid: Reden tot zorg [Adolescents who grow up with a chronically ill, disabled or addicted family member: Subject of concern]. *TSG – Tijdschrift voor gezondheidswetenschappen*, 88, 79–88.
- Van Dorsselaer, S., Vermeulen, E., De Looze, M., De Roos, S., Verdurmen, J., Ter Bogt, T., Vollebergh, W. (Eds.) (2010). *HBSC 2009: Gezondheid, welzijn en opvoeding van jongeren in Nederland [HBSC 2009. Health, well-being, and child rearing of adolescents in the Netherlands]*. Utrecht: Trimbos-instituut.
- Van Widenfelt, B. M., Goedhart, A. W., Treffers, P. D. A., & Goodman, R. (2003). Dutch version of the strengths and difficulties questionnaire (SDQ). *European Child and Adolescent Psychiatry*, 12, 281–289.
- Visser-Meily, J. M. A., Post, M. W., & Meijer, A. M. (2006). Mantelzorg bij CVA-patiënten, de gevolgen van een beroerte voor partners en kinderen [Informal caregiving with CVA-patients, the effects of a stroke for partners and children]. *Bijblijven*, 22, 37–42.
- Vollebergh, W., Van Dorsselaer, S., Monshouwer, K., Verdurmen, J., Van der Ende, J., & Ter Bogt, T. (2006). Mental health problems in early adolescents in the Netherlands: Differences between school and household surveys. *Social Psychiatry and Psychiatric Epidemiology*, 41, 156–163.
- Warren, J. (2007). Young carers: Conventional or exaggerated levels of involvement in domestic and caring tasks. *Children and Society*, 21, 136–146.