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## Experiences of Dutch students growing up with a family member with a chronic illness: A qualitative study

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### Abstract

Students growing up with a family member with a chronic illness often delay or drop out of school when the combination of family care and their educational programme is too demanding. This study aims to describe the themes experienced by students growing up in this situation. A qualitative focus group design was used. The recruitment for this study was done through an online survey where students could indicate whether they also wanted to participate in a focus group. Twenty-five Dutch students (age 18–25 years) who grew up with a family member with a chronic illness participated in one of the total of seven focus groups. A qualitative inductive analysis was used to identify codes and main themes. Students growing up with a family member with a chronic illness experience responsibility issues, loyalty conflicts, peer alienation, role reversal, negative influence on personal development, daily worries and confronting situations. They reported substantial impact in terms of their general well-being, their family relationships and in their choices for their future. Students articulated that growing up in this situation has a serious and substantial impact on their lives. Further research is required in order to gain comprehensive insights into the requests of these students regarding personal and family support.

**What is known about this topic**

- Students, growing up with a family member with a chronic illness, often experience delay or drop out of their education when the combination of caregiving and studying becomes overly demanding.
- There is a gap of service provision between support for adult caregivers and young adult caregivers.

**What this paper adds**

- Students growing up with a family member with a chronic illness experience responsibility, loyalty conflicts, peer alienation, role reversal and influence on personal development, daily worries and confronting situations.
- The sense of responsibility seems to be a major issue for these students.
- The conceptual framework provides insight into impact and experiences of students who are growing up with a family member with a chronic illness.

## 1 Introduction

Students growing up with a family member with a chronic illness are a vulnerable group. These students are challenged to simultaneously organise their studies and invest time, psychological energy and financial resources for family caregiving responsibilities (Yeandle & Buckner, 2007). From studies analysing delay in or withdrawal from education, it is known that students whose caregiving tasks become overly demanding are overrepresented in this group (Baus, Dysart- Gale, & Haven, 2005; Becker & Becker, 2008; Cass et al., 2011; Sempik & Becker, 2013; Yeandle & Buckner, 2007).

Part of their vulnerability is inherent for their age bracket, which is commonly 18–25 years. This period of emerging adulthood is characterised by change and exploration whereby brain development of young adults continues. This is characterised by developing their own identity and receiving education in preparation for a long-term adult occupation (Arnett, 2000). These young adults are exposed to various emotional challenges with regard to, for example finance, sexuality, relationships with friends and their choice of profession. Psychological problems, such as anxiety and depressive symptoms, have been reported by students (Ibrahim, Kelly, Adams, & Glazebrook, 2013).

All these challenges are, to varying degrees, likely to influence students' passage into adulthood. Studies among young children (age 6–12 years) show that growing up with a family member with a chronic illness can negatively impact their development. Specifically, mental health problems (Reupert et al., 2013), stress, problems in the parent–child relationship, developmental problems and diminished school results (Sieh, Visser-Meily, Oort, & Meijer, 2012; Siskowski, 2006) have been described. Similar results have been shown for adolescents up to 18. They experience lower life satisfaction and increased internal behavioural symptoms such as feeling depressed, being withdrawn and anxiety (Sharpe & Rossiter, 2002; Sieh, Meijer, Oort, Visser-Meily, & Leij, 2010). Leu and Becker (2016) found that up to 8% of all children and adolescents in advanced industrialised societies are growing up in this situation. Despite the known disadvantages they might experience, there is limited follow-up of this group after reaching the age of 18.

A quantitative study by Greene, Cohen, Siskowski, and Toyinbo (2017) described the consequences of caregiving for a family member among students. They examined the relationship of family caregiving responsibilities and the mental health and well-being of 353 students age 18–24 years. The study reports significantly higher levels of depression and anxiety for caregivers than for non-caregivers. Because understanding the underlying mechanisms might provide treatment or support options, the researchers explicitly call for the need of additional in-depth analysis into the experiences of caregiving students. Specifically, they suggest gain more in-depth insight in how

students deal with personal and family life, academic tasks, work and social life. Levine et al. (2005) analysed data of two national surveys on adult caregivers and ascertained that 12%–18% of them were of the ages between 18–25 years old. Furthermore, they concluded that there is a lack of knowledge about this age group, for which they specifically advised additional qualitative studies. As part of a larger project on young adult caregivers in the United Kingdom, Becker and Becker (2008) studied young adults growing up with a family member with a chronic illness by performing in-depth interviews with 25 participants (mean age 19), of which seven were active students. The authors indicated that caregiving made these young adults experience a loss of personal free time, restricted social life and community-based activities and difficulties leaving their parental home. Furthermore, they found a gap of service provision between support for adult caregivers and young adult caregivers; the available support mainly focused on older caregivers which made it more challenging to engage with these young adults. As a follow-up study by Sempik and Becker (2013), in their survey among young adults and students (aged 14–25; mean age 15.5, n = 61) 38% of students reported mental health problems. Also, 42% of the participants reported not being recognised by support services as a student growing up with family member with a chronic illness and not receiving any support from school professionals.

Universities or education institutes in general are not only responsible for education and study results of students; they also hold responsibility regarding their students' health and well-being. The Hanze University of Applied Sciences initiated the current study in order to gain insight that is more in-depth into the experienced impact of growing up in a care situation as expressed by students. The results of this study may enable universities or education institutes to recognise these students and the challenges that they encounter and may subsequently provide directions in organising support for these students. We therefore specifically focus on students aged between 18 and 25 following secondary vocational or bachelor education at a university of applied sciences.

Research question:

How can experiences of students (18–25 years) growing up with a family member with a chronic illness be described?

## 2 Methods

### 2.1 Design

A qualitative descriptive design using focus group discussions was used.

### 2.2 Participants

Full time students between the age of 18 and 25 years old studying at a university of applied sciences or one of the schools for secondary vocational education in the northern part of the Netherlands were approached and asked to participate. Schools for secondary vocational education have a practical learning approach that is similar to the International Standard Classification of Education level 4, whereas the universities of applied sciences offer a bachelor degree similar to the International Standard Classification of Education level 6 (Schneider, 2013).

### 2.3 Recruitment

After approval by the Dutch Association for Medical Education (NVMO)-Ethical Review Board, the recruitment for this study was done through an online survey, sent out to all students (N = 5,997) registered at the four educational institutions in the north of the Netherlands. We chose to approach students following either healthcare-related studies (Nursing and Social Work) or nonhealthcare-related studies (Law and Communication, Media and ICT) in order to create a heterogeneous sample of students from different study programmes. The institutions sent out the survey in September 2017 via e-mail to which students could respond anonymously. Students were asked if they were

willing to participate in a focus group. Those who agreed were prompted to share their email address. All respondents were then approached by the principal investigator within two weeks to schedule an appointment. This yielded 40 students of which 25 actually participated in the focus group sessions in November 2017 until November 2018. Reasons for non-participation after showing initial interest were related to practical or logistical issues (e.g. prohibitive schedules of internships or work). Descriptive characteristics of the participants are summarised in Table 1.

## [Table 1]

### 2.4 Focus groups

We organised focus groups to create an interactive discussion and to gain a broad range of views on students' experiences of growing up with a family member with a chronic illness. Using focus groups, it was expected that the group element within them would be beneficial for identifying a range of different issues (Hennink, Hutter, & Bailey, 2011). Besides, a focus group might also generate more information compared to in-depth individual interviews because memories and reflections suddenly surface for participants through the comments from others (Morrison & Morrison, 1998).

A total of 25 participants, dispersed among seven focus groups, were included. The standard of 6–8 adult participants per focus group is recommended to create a lively discussion (Hennink et al., 2011). Horner (2000) and Kennedy, Kools, and Krueger (2001) argue for smaller focus groups of approximately four to a maximum of eight participants for children/adolescents and young adults. The reason for a smaller group is that young participants may feel inhibited in a larger group resulting in little input into discussions (Horner, 2000; Kennedy et al., 2001; Roose & John, 2003). Due to the sensitive topic and the age of the participants in this study, small focus groups with a maximum of five participants were planned.

Focus group discussions were organised using a semi-structured topic list that was conducted based on literature (Becker & Becker, 2008; Lloyd, 2013; Sieh et al., 2010). Prior to the focus groups, a draft topic list was discussed with 10 experts in the area of youth-care nurses ( $n = 8$ ) and psychologists ( $n = 2$ ) in order to judge the topics on relevancy and to evaluate the possible emotional impact on the participant. After their feedback, the draft topic list was pilot tested for comprehensibility and feasibility among six students growing up with a family member with a chronic illness. The content was discussed and adjusted in response to their feedback.

The topic list opened with broad questions such as Can you introduce yourself and tell us why you decided to participate in this focus group? and moved to questions that were more specific such as Can you tell us your experiences related to growing up with a family member with a chronic illness? This approach provided participants with time to become comfortable to contribute to the discussion. The focus groups took place in a separate and quiet room at the university or school where students were receiving their education. Each focus group lasted between 90 and 120 min. Two of the authors of this paper (GE and HMW) who are experienced in leading dynamic group discussions with students led the focus groups.

### 2.5 Ethical considerations

The study was approved by the Dutch Association for Medical Education (NVMO)-Ethical Review Board (#940). All the participants received written and verbal information prior to participation on the aim and procedures of the focus groups. Informed written consent was obtained before the start of the focus group session. Participation in this study was voluntary, and students could refrain from further participation or choose not to answer certain questions without giving a reason. As participation in a focus group could evoke unprocessed emotions, re-experiences and stress, an oral evaluation with each student after each focus group was provided. A referral for further support could be provided if necessary and with consent of the student.

## 2.6 Data analysis

The focus group discussions were audio recorded, transcribed verbatim and anonymised prior to analysis. Issues that arose from one focus group were also further explored in following focus group sessions. A pragmatic stepwise data analysis, following the steps described by Hennink et al. (2011) was used. During the first step of the data analysis, after transcribing the data, sections of texts addressing experiences of growing up with a family member with a chronic illness were identified and described into codes by HMW and MLAL. Data saturation was achieved and discussed with WP, MLAL and HMW. In the second step of analysis, codes were individually and critically examined, and overlapping codes were further refined and grouped together by the aforementioned researchers, supported by the use of the software program ATLAS.ti 8 (8.3.16). After this step of inductive coding, in the third step, subcodes with similar characteristics were sorted into meaningful categories. These categories were compared and discussed within the research team for accurate naming, resulting in seven themes. These themes were considered as reflecting the perceived impact on the lives of students growing up with a family member with a chronic illness and visualised by the research team into a conceptual framework (see Figure 1).

[Figure 1]

## 3 Results

### 3.1 General findings

Most of the 25 participant students were female nursing students with family members suffering from disorders such as cancer, cardio vascular diseases, depression, addiction or a combination of physical and mental disorders. All the participants articulated that growing up with a family member with a chronic illness had a substantial and serious impact on their lives in terms of their general well-being and family relationships as well as in terms of choices for their future. All of them, no matter what type of illness or which family member was ill, experienced complexity in organising their role as a caregiver and everyday life. They explained this complexity as surviving between the roles of being a caregiver, on the one hand, and being a student on the other hand.

The thorough analysis of the transcripts of the focus group sessions revealed a collection of seven themes that reflect the impact of growing up with a family member with a chronic illness on the lives of students. Figure 1 was made to visualise these seven themes in a conceptual framework. Responsibility seems to be the overarching theme, raising other issues as reflected in the related themes. The names of the participants have been replaced by participants numbers.

#### 3.1.1 Responsibility

All the participants mentioned feeling responsible, especially for taking care of their ill family member, as being an important factor that substantially influences their lives. In addition, they also felt responsible for other family members such as their siblings and parents as reported in focus group 2 by participant 6; *When my mother fell ill, I had no choice but to keep going. I felt responsible for keeping the family together and running the household.*

All the participants indicated that they wanted to fulfil tasks to support their family member with a chronic illness and reduce the burden of the other family members. However, the majority also described that the responsibility was sometimes too demanding as reported by participant 15 in focus group 4; *Bearing that responsibility is a very, very difficult thing. You kind of accepted it without realising what it meant and, uh, now you kind of want to hand it off, to share the burden, because you don't want the added responsibility of shouldering the role you took on in the first place. And it's a role everyone more or less assumes you're going to take on. Plus, if you hand it off to someone else,*



*they might do things quite differently. Then, uh, you feel guilty once again if it doesn't turn out the way we had expected. And I think that's what makes it such a burden, really.*

### 3.1.2 Loyalty conflict

The participants are loyal in supporting their family members. They articulate two types of loyalty conflicts. The first loyalty conflict is described by participants when they are confronted with relational problems between their parents or between other members of their family. They mention that they have the feeling that they need to choose between family members. The participants indicate that they try to counsel within their families and to remain loyal to both family members as stated by participant 8 in focus group 3 with her father suffering from depression; *So my father has a lot of fears about my mother—about infidelity, for instance, or that she'll leave him. And my mother has told me there's no cause for that, so I try to make that clear to him as well. But uh, about my mother, that's something I find really difficult. Because lately, seeing as things have gotten so much worse, she's constantly asking herself whether staying with him is really the best thing. Or, uh, she has these doubts—I also think my mother would be much happier if she were away from my father. That's the impression I get. That she would be better off [without him], but I hate to say that, you know.*

The second type of loyalty conflict is between their family members and themselves. Participants point out the conflict between feeling responsible and the wish to make personal choices without feeling the responsibility to take care of the family member with a chronic illness or other family member. Many students indicate that they feel guilty when they cannot fulfil their caregiving tasks as stated by participant 24 in focus group 7; *It's something you're always taking into account, so you're putting yourself second when it comes down to it. Yes. I guess that affects me, the fact that it's not about taking me or my needs into account... it's all about my mother.*

This conflict also arises when students make study choices. For example when the participants want to travel abroad for an internship, most of them choose to do an internship near their parental home. Being at a distance from there (e.g. when they live in another city) is experienced as being difficult because they are not able to support their family as mentioned by participant 17 in focus group 4; *Uh, yeah, especially that bit about still feeling responsible even when you're not living at home any-more. That you still feel a sense of responsibility and involvement. And worry about how your folks are doing. Like what I said about making sure it's not gone off the rails. The idea that she might kill herself, that's something that terrifies me. Sometimes, I feel like I'm just waiting for it to happen. That much is true. So that's very difficult to cope with because, if I'm not there, what happens then?*

### 3.1.3 Role reversal

Most of the participants (24) describe experiences that can be defined as role reversal; being a young adult who needs to take care of a parent or having to fulfil parental duties. They not only fulfil parental tasks such as caring for siblings and their parent(s) but also offer emotional or financial support to (one of) their parents. They mention that they did not choose to fulfil this role, and most of the participants expressed that they did not want the responsibility of offering emotional or financial support to (one of) their parents. Participant 12 in focus group 3 described role reversal in the following quote; *And I also have a little brother, so I had to take care of him. And uh, well, that was on top of being a mother to my own mother. Which I still am. That I, well, my mother comes to me with her problems, you see. It's as if the roles are reversed. I've taken on the mother role, and my mother plays the part of the child.*

One participant (participant 1) indicates that she was able to grow up without role reversal and taking care of parental duties. She grew up with two parents both with a physically chronic illness and stated in focus group 1; *My parents didn't want it to affect us, so they called on their network and my grandma and grandpa for help.*

#### 3.1.4 Alienation of peers

With the exception of one participant, all the other students mention that they have missed a part of their childhood and felt different from their peers. They described two mechanisms. First, they felt more mature compared to their peers due to adult bearing responsibility and performing duties for their family as mentioned by participant 16 in focus group 4; *When I was young, I was much more mature from quite an early age; I helped out a lot around the house and felt like I had much more responsibility than my classmates did.*

The second explanation is the experienced loss of personal free time, restricted opportunities for leisure, and a restricted social life in which there was less time to connect with peers because of their daily duties. This feeling is described as being alienated from their peers as stated by participant 9 in focus group 3; *It's fairly intense for me to hear that from you now and then I think, yeah – it really is very intense to have to do those things. And that's not what you should be doing when you're a kid, or even when you're 24, because you should be spending time with your friends. And I'm not picking up on that here at all. You are all just completely and utterly ignoring that aspect. You're so oblivious to what other people go through!*

The feeling of being alienated from peers makes it difficult to connect with those who are not living in the same situation and do not feel the same responsibility. This was experienced as a loss, and some of the participants felt lonely as mentioned by participant 25 in focus group 7; *Then you feel a sense of loss and worry about what you're going through. So, yes, that makes you feel lonely even if you have plenty of support from other people around you. That's definitely been my experience.*

#### 3.1.5 Influence on personal development

All the participants stated that growing up with a family member with a chronic illness had the influence on their personal development of gaining more empathy for others. They mention that they can better empathise within other situations and condemn less because they understand different situations as described by participant 2 in focus group 1; *Uh, well, perhaps I've become more caring, you know. Perhaps more understanding in certain situations. Like when people are going through the same thing, they understand what's the matter.*

In addition, they describe themselves as having become more caring and feeling responsible towards others.

Two participants also mentioned that talking about the disease within the family also caused enrichment in that the family bond has become much closer and open communication is a consequence of the disease within the family.

#### 3.1.6 Daily worries

All the participants describe the burden of the daily worries they experience expressed by not being able to sleep and experiencing stress. They daily worries include concerns about their family member with a chronic illness and also other relatives as stated by participant 12 in focus group 3; *'hose are the things that, like, give me the hardest time. It really sort of affects you in terms of, uh, you know. That you might think, yeah, is it all right to leave my mother home alone. Or, um, that you wake up in the morning and think, I hope nothing will happen today, she'll be able to make it to the toilet, or uh, and nothing bad will happen.*

Other daily worries vary from worries about finances to their own future. Participants mention that they have difficulty concentrating and that this has consequences for their studies. They are worried about whether they can meet deadlines and complete their study.

#### 3.1.7 Confrontation.

The theme confrontation was stated by all the participants and can be divided in two types. The first type of confrontation is looking into the future. All the participants indicate that they find it difficult

to look into the future of their family member with a chronic illness. They often see their family member deteriorate to what they refer to as confrontational and grieving. Participant 12 described in focus group 3 this confrontation with; *And then you see things getting worse. As in, you can tell that your mother isn't your mother anymore, not really. And slowly but surely, you see that she's simply gone. I mean, she's there, but she's not there. That kind of thing is tough.*

The students describe that they avoid confrontation because it makes them vulnerable. They avoid this vulnerable role in order to stay in their 'survival mode'. Confrontation with the future makes them anxious of losing this survival mode because they are not able to control the future as mentioned by participant 10 in focus group 3; *Because that's how it was, that was the reality in my home. And I had to go into survival mode because if I spent too much time thinking about how wrong it was, I wouldn't be doing nearly as well today. I wouldn't be sitting here right now.*

The second type of confrontation is described as the confrontation of intimacy. Fulfilling intimate care tasks is called confrontational because the reversal of roles and deterioration is even more apparent as stated by participant 18 in focus group 5; *It's a fact of life, you know. But yeah, uh, going along when they do the shopping is one thing, but it's a totally different matter when your grandma's had an accident and you have to bathe her. That's really confrontational.*

## 4 Discussion

The results of this study indicate that growing up with a family member with a chronic illness substantially impacts the lives of students between 18 and 25 years old. Experiences of students could be described in seven themes, represented in a conceptual framework (Figure 1). Responsibility seemed to be the overarching theme, raising other issues as reflected in the other themes.

The majority of participants mentioned that their family takes a central role in their life which contrasts with the normal process of emerging adulthood whereby young adults focus on becoming autonomous and developing their own identity (Arnett, 2000). Remarkably problems specifically related to students did not show up as prominent. The only theme that might be related to this specific student population is 'influence on personal development'. Participants mentioned specific differences between them and their peers and could easily reflect on their personal development. They mentioned that they were more able to empathise within other situations and described themselves as having become more caring and feeling responsible towards others. An awareness of the influence on one's personal development may therefore be specifically related to students since they are in the phase of developing their identity and are comparing themselves to their peers and others in their close environment (Arnett, 2000; Furstenberg, Rumbaut, & Settersten, 2008).

Other themes were more focused on dilemmas that arose when participants tried to maintain balance between their own development and the worries about their family. All the participants mentioned feeling responsible as one of the most important themes in their life. This finding is also found in studies among adolescents and adults who care for their family member with a chronic illness (Ali, Ahlström, Krevers, & Skärsäter, 2012; Becker & Becker, 2008; Hastrup, Berg, & Gyrd-Hansen, 2011). The strong experiences of responsibility seem to be related to the basic and existential principles of the system theory of Bertalanffy (1968); belonging and binding, role and position and the balance between give and take. The results of this study indicate that, in the situation in which a student is growing up with a family member with a chronic illness, all three principles seem to be under pressure or violated. Students mentioned their efforts to keep the family together, the change (reversal) of roles and positions within their family, and the imbalance between give and take in their caregiving role. The risk of imbalance as a result of feeling responsible for family members was also mentioned in the studies of Jönsson, Skärsäter, Wijk, & Danielson, 2011 and Hastrup et al.(2011). They also describe the feeling of being unable to let go the constant worry



and the uncertainty about the future. These findings seem comparable with the themes established in our study as 'daily worries' and 'confronting situations'.

The finding that students growing up with family member with a chronic illness experience loyalty conflicts, peer alienation and role reversal seems to be in accordance with the finding of the study of Becker and Becker (2008). Loyalty conflicts, peer alienation and role reversal are known as significant threats in the critical developmental stage of young adults. Young adults often need support from their family and peers and draw heavily on the resources of their families to make the transition to adulthood (Furstenberg et al., 2008). Particularly in this developmental stage the presence of well-functioning parents and peers, is important (Arnett, 2000; Kraaij et al., 2003). However, especially families with a family member with a chronic illness may be unable to offer the support that is needed in the transition towards adulthood.

From research among children and adolescents who are confronted with the divorce of their parents, it is known that especially loyalty conflicts and role reversal are associated with the development of mental health problems such as depression or an anxiety disorder (Baker & Brassard, 2013; Wozencraft, Tauzin, & Romero, 2019). It is also known that role reversal can provide mental health problems in a later stage as found in a study among young adults growing up with their mothers who were diagnosed with a mental illness (Abraham & Stein, 2013). The findings of these studies are worrisome in the context of societies and healthcare systems that place increasing emphasis on the importance of self-management and caregiving with the risk of causing serious health problems within this specific age group of young adults in their later life.

Despite the abovementioned difficulties, participants also mention positive consequences of growing up with a family member with a chronic illness. Participants described these positive consequences as having gained more empathy for others. They mention that they are better able to empathise in other situations and are less inclined to condemn because they better understand different situations. In addition, they describe that having become more caring towards others was experienced as a positive consequence. This finding has also been established in the studies of Dearden and Becker (2000) and Heyman and Heyman (2013) who ascertained that young informal caregivers generally become more mature and had learned to take more responsibility compared to peers who did not grow up with a family member with a chronic illness.

Other themes described in earlier studies among young adults, such as sexuality and choice of profession (Ibrahim et al., 2013), did not arise as prominent themes in this study. This is notable considering their age and the high number of participants enrolled in a healthcare-related study. Discussing sexuality might be too intimate to discuss in a focus group and, therefore, was not discussed. The high number of participants enrolled in a healthcare-related study could be explained by the findings of Becker and Becker (2008) who found that adolescents who grow up with a chronically ill family member are more likely to be drawn towards care-related careers. The choice of their study could be so self-evident that no other options are considered.

#### **4.1 Clinical and scientific implications**

This study is one of the first in-depth studies investigating the experiences of students growing up with a family member with a chronic illness. The conceptual framework that arose shows a need for attention for this specific target group in the development of both healthcare and educational policies. Since students in this study indicated that growing up in this situation has substantial impact on their lives, it appears to be important that healthcare professionals not only pay attention to their patient but also to the family situation. The concept of family health conversations (Benzein, Johansson, Årestedt, & Saveman, 2008; Broekema, Luttik, Steggerda, Paans, & Roodbol, 2018), discussing the family care situation, and the experiences of and consequences for each family member might be an intervention to consider within this context.

Also, education professionals need to be aware of students that grow up in a care situation; they need to recognize particular behaviour such as, for example peer alienation in order to identify those who are growing up in this situation and eventually refer them for support if needed. We would recommend the development of specific guidelines for lecturers on how to recognize young adults growing up with a chronically ill family member. Furthermore, easily accessible information about, for example psychological or financial help should be available for these lecturers in order to be able to support these students. However, we also emphasize that more research is needed to gain in-depth insight in the specific nature of the problems that these students experience and subsequently to develop and test effective types of support or interventions.

Additional research, both qualitative and quantitative, is required to validate the conceptual framework (see Figure 1) that was derived from this study. Furthermore, longitudinal research is needed to investigate the long-term consequences for young adults that experience the substantial consequences of growing up with a family member with a chronic illness. Finally, we would recommend research investigating the specific needs and wishes that these students have regarding support and, subsequently, the availability of this support within the current healthcare and educational systems.

## 4.2 Strength and limitations

The decision of using focus group sessions to gain insight in the experiences of students turned out to be a successful method that provided the study with rich data. Participants in this study showed a remarkable openness during the sessions. Many personal and emotional stories were exchanged and, sometimes, stories were told that were never told before as mentioned by the participants themselves. Evaluating the focus group session, they all stated that, at first, they were afraid to expose their family situation and talk about the difficult aspects of their lives. However, in the end, sharing experiences, listening to each other's stories and giving and receiving advice were experienced as being very valuable and supportive.

The fact that many students did not recognize themselves as a young adult growing up with a family member with a chronic illness created challenges in the recruitment of students for this study. We received reactions from students who described serious care situations who still wondered whether they satisfied the inclusion criteria of the study. They assumed that the illness of their family member with a chronic illness was not severe, or they considered their situation as 'normal'. As a result, we may only have spoken to students who recognized themselves in the inclusion criteria and were also more aware of their family situation.

The study population consisted of students from the northern part of the Netherlands who mostly (n = 22) have a native West European background. Further research is necessary to investigate whether these results remain valid for students with a different cultural background. The fact that only students were approached could be mentioned as a limitation of this study; these results may not be applicable to young working adults who are no longer in education but also growing up with a family member with a chronic illness. It would be interesting to investigate whether these results also apply to all young adults growing up with a family member with a chronic illness. Furthermore, the majority of students in our focus group sessions were female participants and mainly involved in a care-related study, which also limits the generalisability of the results. It would be interesting to investigate whether female students are more inclined to identify themselves as being a young caregiver or whether they feel more able, for example to discuss their chronically ill family member. This also applies for the high number of participants enrolled in a healthcare-related study. More research is needed towards this so called 'care identity' (Becker and Becker, 2008) to find out if the choice for a healthcare-related career is highly related to being a young caregiver or that it is truly considered as a choice for the profession.

## 5 Conclusion

All the participants articulate that growing up with a family member with a chronic illness has a serious and substantial impact on their lives. The sense of responsibility appears to be a major issue for these students. This study also indicated that they experience loyalty conflicts, peer alienation, role reversal, influence on personal development, daily worries and confronting situations. These experiences can have negative consequences on the mental health and well-being of these students. Further research is needed to validate the conceptual framework and to gain insight that is more in-depth to the specific needs that they have regarding support.

### Conflict of interest

HMW, WP, GE ALF, PFR and MLAL declare no competing interests.

### Authors' contributions

HMW, WP, GE, ALF, PFR and MLAL contributed to the conception and design of the study; authors HMW, MLAL and WP contributed to the analysis and interpretation of data; authors HMW, WP, GE, ALF, PFR and MLAL contributed to drafting the article or revising it critically for important intellectual content. All the authors read and approved the final manuscript and agreed to be accountable for all aspects of the work.

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## Tables and figures

*Table 1 Demographic data of the participants who attended a focus group*

Variables	Mean (standard deviation)
Age (years)	21.4 (1.7)
	N
Gender	
Female	24
Male	1
Level of education	
University of applied sciences	14
Secondary vocational education	11
Study	
Non-healthcare-related studies (Law and Communication, Media and ICT)	5
Healthcare-related studies (Nursing and Social Work)	20
Type of family member being ill	
Mother	5
Father	5
Sibling	4
Other <sup>a</sup>	4
Multiple	7
Type of illness	
Physical disorder	8
Mentally disorder <sup>b</sup>	8
Multiple health issues	

<sup>a</sup>Grandparents and uncle.

<sup>b</sup>Mental disorders and addiction-related problems.

*Figure 1 Conceptual framework of the themes reflecting the impact of growing up with a chronically ill family member on the lives of students*

