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# Making life work for both themselves and their parents alone-how children aged 11–16 view themselves in relation to their chronically ill parents in a primary health care setting

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## ABSTRACT

This study explores the main concern and life strategies of children whose parents are chronically ill in a Primary Health Care (PHC) center in Stockholm, Sweden. Data was collected through semi-structured individual interviews, and qualitative inductive constant comparative analysis resulted in a conceptual model. The two main strategies the children used were to understand the situation and to adopt a parental role. Children saw themselves as main contributors into the functioning of their families. Results show that these children also viewed their situation as difficult. It is an important mental health task for professionals in PHC to reach out and inform both ill parents and their children that children are very interested and involved in their parents' health. These children need respect for both their capacity and their vulnerability as they struggle to make life stable and functional for themselves and their parents. Further research and development of appropriate interventions are needed in this ethically challenging area.

## ARTICLE HISTORY

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## KEYWORDS

Children of impaired parents; primary health care; parent-child relations; medical ethics; qualitative research; health promotion

## Introduction

In order to highlight the rationale for this study, we will provide an overview of intergenerational transmission of illness, efforts to intervene in this transmission, laws and policies designed to protect the health of the child, and the setting of the study (i.e. a Primary Health Care clinic).

## Intergenerational transmission of illness

Children of seriously chronically ill parents run, in a very broad sense, a higher risk of falling ill compared with children of healthy parents. This association can be found for many illnesses but is most studied in the case of depression. A systematic review (Mendes et al., 2012) found an association between depression in mothers and depression in their school-aged children. The presence of governmental economic compensation support to sick parents is also associated with elevated risk of health-related inability to work for their children when the children become young adults (Pape et al., 2013). This intergenerational transmission is very

complex. One helpful model divides transmission of risk into the following types of mechanisms: 1) heritability of depression, 2) innate dysfunctional neuro-regulatory mechanisms, 3) exposure to mothers' negative and/or maladaptive cognitions, behaviours and affect, and 4) exposure to a stressful environment (Beardslee, Gladstone, & O'Connor, 2011). Intergenerational transmission of health beliefs such as bodily preoccupation and disease phobia have also been shown to be present between children and parents with somatoform disorders (Marshall, Jones, Ramchandani, Stein, & Bass, 2007). In this study we will not discuss heritability or dysfunctional neuro-regulatory mechanisms but rather focus on points 3 and 4: exposure to negative or maladaptive cognitions, behaviours and affect, and exposure to a stressful environment.

### ***Efforts to intervene in the intergenerational transmission***

Discovering and intervening in childhood anxiety and depression are essential for the future health of the child (Griffiths & Fazel, 2016). Expression of positive emotions by the sick parent, co-parent support, high-quality social relationships, self-efficacy, and frequent exercise have been shown to be associated with sustained mental health for the child (Collishaw et al., 2016).

In psychiatric services for adults, it has been shown that the increased risk of childhood depression in the patient's offspring can be partly influenced by pedagogical interventions which increase knowledge and openness in the family about the parent's illness (Loechner et al., 2017; Siegenthaler, Munder, & Egger, 2012). Among patients with mood disorder in Finland two different pedagogical interventions were shown to be effective in reducing their children's emotional symptoms and improving the children's pro-social behaviour (Solantaus, Paavonen, Toikka, & Punamaki, 2010). In Sweden, research has reported that parents both long to and fear to speak with their children about their illnesses (Pihkala & Johansson, 2008). Furthermore, the parents' confidence and security in the professionals and in the method(s) used for communication were prerequisites for initiating conversations with their children about the parents' mental illnesses (Pihkala, Sandlund, & Cederstrom, 2012).

In PHC in Norway, research has shown that parents with mental illness, substance abuse or severe somatic illnesses want to be regarded as competent parents in ordinary families. At the same time, these parents are aware that their illnesses affect their parenting, and they wish to receive advice about how to inform the children of their illnesses (Gullbra, Smith-Sivertsen, Rortveit, Anderssen, & Hafting, 2016). Doctors in the Norwegian PHC (GP's) considered themselves to be in a good position to help children and made a great effort to support many of them. Still, support of these children by GP's often seems to depend, not on careful consideration of what is best for the patient and the child in the long run, but more on short-term solutions and convenience (Gullbra, Smith-Sivertsen, Rortveit, Anderssen, & Hafting, 2014).

### ***Law and policy to protect the health of the child***

The *Global Goals* of the UN's 2030 *Agenda for Sustainable Development* challenge us all in goal number three to 'Ensure healthy lives and promote well-being for all at all ages' (United Nations, 2015). Also, The United Nations Convention on the Rights of the Child (United Nations General Assembly, 20 November 1989) states that the child should enjoy rights which include the right to be listened to, and at the same time be given special protection, opportunities and facilities. In Sweden health care personnel are required by law ("*Hälso- och sjukvårdslag* (SFS 2017:13) ") to give information, advice and support to underage children whose parents are seriously psychologically or physically ill, have an addictive disorder (including gambling), or have died. Still, there is a lack of research on how this information and support can be delivered effectively in PHC. Barriers to and supports of the implementation of primary prevention and health promotion activities in PHC have previously in a meta-analysis (Rubio-Valera et al., 2014) been described to include the professionals'

beliefs about primary prevention and health promotion, professional experiences, skills/knowledge, and self-concept.

### ***The primary health care setting***

Patients with specific and severe diagnoses, such as cancer, multiple sclerosis (MS) and psychosis are often initially seen in PHC but quickly referred to a relevant sub-specialist who will henceforth serve their continued health care needs. The need to inform the children about the parent's illness in these cases falls on the relevant specialty clinic. Patients without specific severe diagnoses, however, may also continue to have severely reduced functionality in daily as well as professional life. They continue to visit the PHC clinic for their symptoms as well as their need for sick-leave authorization. These patients often have a combination of depression and anxiety, which is also often combined with chronic pain. PHC personnel are often the only professionals who are aware of the parent's on-going illness and therefore the child's potentially adverse situation.

### ***The rationale for this study***

There was a research need for an explorative study from the perspective of children in order to thereafter construct and test a method of best practice for this target group in PHC.

The aim was therefore to explore children's experiences when a parent is ill and on long-term sick-leave through contact with PHC.

## **Methods**

### ***Study design***

As mentioned above, the characteristics of seriously ill patients in PHC are diverse and multiple, often including a combination of psychiatric and somatic symptoms as well as social and economic risk factors. The severity of the illness is usually not defined by the diagnosis or mortality, but rather by a lack of everyday function over an extended period of time. Sick leave, rather than diagnosis, was therefore chosen as the inclusion criterion of the study.

Patients on sick leave, defined as certified medical inability to work for more than 90 consecutive days, were identified in the medical database. The children of these patients were identified via the Swedish Tax Agency. The patients were invited, orally and in writing, to participate in the study via their GP's at the clinic and, if the patients consented, they were invited to ask their children whether they also wished to participate in the study. A nurse assistant at the clinic met the interested patients and children and informed them about the study orally and in writing. In the spring of 2015, consenting children were interviewed.

### ***Study population and sample***

The study was conducted in a suburb of southern Stockholm with a population of about 14 000. Forty percent of the population in this suburb was born abroad or had two parents born abroad, compared to 31% in the greater Stockholm region and 22% nationally. Fifteen percent of the neighbourhood population had no more than the compulsory nine years of basic schooling, compared to 12% nationally. The average annual number of days on verified sick-leave with economic support was, both locally and nationally, 27 days per adult (Statistics Sweden, 2015).

The sample in this explorative study was six children whose mothers were on sick leave. The total transcribed time was 3 hours 53 minutes. On average, the interviews took 39 minutes (SD = 13) (Range 21–58 minutes). No child ended the interview prematurely. The participants were between 11 and 16 years old: two were 11, two were 13, one was 15 and one was 16. Four

were girls and two were boys. Four lived with both their parents, and two lived with one parent. The data in this sample size was sufficient for a conceptual model of the children's main concern and strategies, fulfilling the broad aim of this study.

### ***Collection of narrative data and analyses***

The interviews were carried out face-to-face and audiotaped by two graduate students in psychology from Karolinska Institutet (Holmsved & Sahin, 2015) in an examination room at the PHC Centre, under the direct supervision of the first and last authors. In order to protect privacy, the interviews were numbered and the background data is presented on a group level. The technique of 'open-ended conversations' (Glaser & Strauss, 1967), using an interview guide, was used (See Appendix 1). To get the conversation started, a short story was read to the child about a sick mother seeking and receiving help at the clinic for several months (See Appendix 2.) The data was first transcribed and analyzed using content analysis, then published in Swedish as a Master's thesis (Holmsved & Sahin, 2015).

The transcribed interviews were then imported into the software program, *NVivo11* (QSR International), which was used as a coding tool. The first author used open inductive coding, using in-vivo codes, until the core and related categories had emerged. The last author (PI), as well as a GP/PhD student of cultural medicine, also read the interviews and in-vivo coded. The emerging categories were discussed among the three researchers. After that, selective coding was conducted. Incidents, codes and categories were constantly compared (Glaser, 1978, 1998; Glaser & Strauss, 1967). Multiple interchangeable, reoccurring incidents were required for each category (Glaser, 1978). Theoretical codes were explored so as to integrate categories. Throughout, memos were written. The interview language was Swedish, and the analysis was therefore conducted in Swedish. The categories were named in both Swedish and English. When the conceptual model had emerged, a seminar was conducted by the first-author with the co-authors in order to verify the model. These experienced clinicians and postdocs first read 70 pages of dense interview material. Thereafter, each one individually wrote down their own understanding of the child's main concern and strategies. A clear and common understanding emerged in the group. The categories are presented in the results below and illustrated with unidentified anonymous quotations from the interview participants.

### ***Role of the researcher***

In a qualitative approach one strives to minimize the distance between the researcher and the participant in order to attain collaborative knowledge construction (Creswell, 2014). The two students performed the interviews under the supervision of the first and the last authors. The first author listened to the taped interviews and read the transcribed text several times in order to get familiar with the content. Thus, the distance between the first author and the participants was reduced. The first author is an experienced GP at the PHC center. The last author had prior knowledge and experience in the field and was the main supervisor of the students who performed the interviews, providing theoretical sensitivity in the analysis phase.

### ***Ethical considerations***

Studying parents and their children in PHC is ethically challenging.

Benefits include generating new and critically needed knowledge; it would therefore be ethically unsound to avoid doing the research. When and if this knowledge is implemented, it has the potential to help many children who are burdened by parental ill health. The new knowledge might also help PHC professionals to better understand the complexity of their work and provide critical assistance in their efforts to both understand and help patients and their children. If the project is done well it might, furthermore, increase both the participating and future parents' and

their children's trust level, as well as their feelings of being perceived, heard and cared for as whole people by the PHC and Research community.

Ethical risks include putting negative stress or stigma on already vulnerable patients and their children (Flewitt, 2005). To single out ill parents is possibly hurtful for the parent and the child. Ill parents and their children might risk thinking or feeling that health care professionals doubt their intent or capacity to be the best parents possible for their children. This risk can be reduced if the professionals speaking to the parents and children approach them as persons of capacity whose help the professionals wish to enlist in their research effort. Despite this, however, an unequal power relationship between children and researchers is inherent in the research situation (Einarsdattir, 2007). After considering the ethical dimensions, this study was deemed important enough to conduct. It was approved by the Regional Ethical Review Board of Stockholm (2013/62–31/5, 2014/1454–32/5 and PUL KI 2–3750/2014).

To lessen the risk of negative ethical consequences for the children, the interviews took place at the PHC clinic known to these children. The interviewer also took time to acquaint each child with the room, the interviewer and the purpose of the interview. The children were informed that they could end the interview whenever they wished without giving any reason. They were also encouraged to ask any questions they wished, and they did, in fact, ask many different questions about the study, the interviewer and health care in general, indicating that they were quite comfortable. The fact that the interviewer was a student made the inequality of age, role and social status less pronounced. After the interview, the participants received two cinema tickets as a token of our appreciation.

## Results

### *Making life work for both themselves and their parents alone*

The main concern of children of chronically ill patients in PHC setting is the question of how to, without the sick parent's help or leadership, make life stable and functional for both themselves and their parent. The child is both emotionally attached to the parent and spends a lot of time with the parent. Because the parent, as a rule, indicates to the child that conversation about the illness and the loss of parent's parenting capacity is taboo, the child is left to struggle on their own to help the parent get better while at the same time helping themselves to grow up. A relevant citation by one of the children is:

Well, you get worried for your parent... because, well, it is your parent... even if you know, it still becomes like this, you wish your parent the best... that is ... normal (B3).

A core category, two main categories and six sub-categories emerged in the analysis and describe the strategies children adopt when trying to handle parental weakness. The two main categories – 1) understanding the situation and 2) adopting the parental role – were used to 'alone make life work for both of us' (Figure 1)

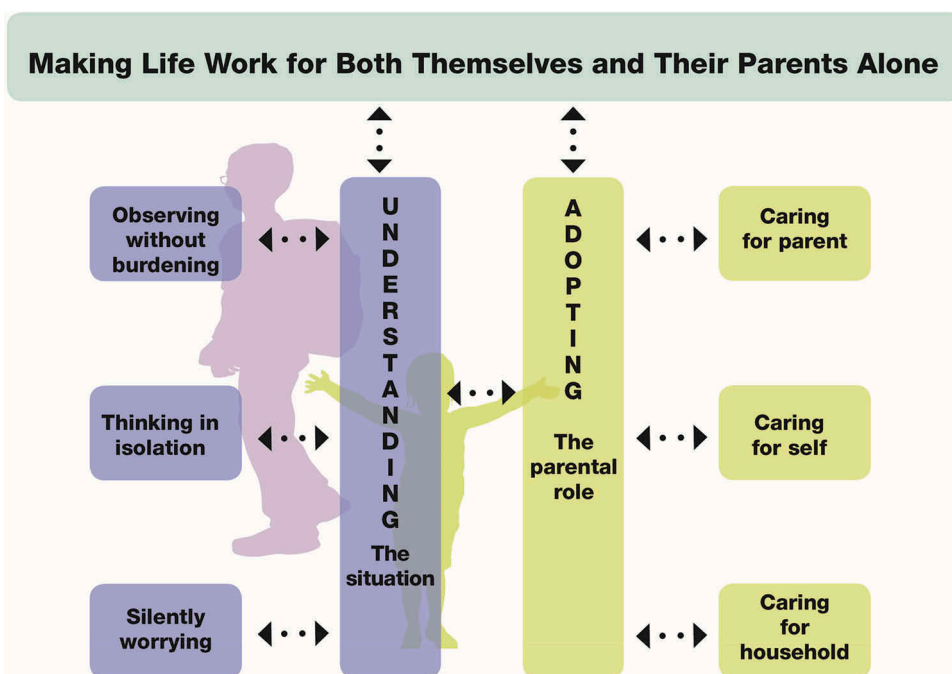
### *Understanding the situation*

The child's understanding of reality, including the parent's situation, grew gradually over several years. The child compared observations of his/her parent over time with their observations of other adults and thought deeply about how things were connected. The child also observed his/her own emotions, reactions, and the results of the child's actions. In a gradual process, these children tried to understand the situation, their parents and themselves, as shown in this dialogue:

I just want to know the name of the illness.

Interviewer: Have you asked your mother?

No...she might get sad... that's it. (B1).



**Figure 1.** Conceptual model, of the core category, two main categories and six sub-categories, describing the strategies children adopted when trying to handle parental chronic illness by making life work for both themselves and their parents alone. Design: Daphne Macris.

### *Observing without burdening*

The child observed the mother's symptoms, such as hip or back pain, paleness, sensitivity to light, noise and smell, and spending time in bed. The child noted that the mother was not engaged in household activities, as she had been before, and that the parent wanted practical help from the child. The parent did not smile or sing as before, sometimes wishing for company and sometimes not. The child noted the fact that the parent wished the child to succeed in school but did not provide help and support with schoolwork or after-school activities. The parent did not have the energy to participate in socializing. The child was also aware that the family's money was scarcer, compared to before the parent was sick. Thus, the child's observations, gained without burdening the parent with uncomfortable questions, became an important part of understanding the parent's illness.

So, you know that your mother is keeping a great deal from you, ermm ., I can see that in her. (B3).

### *Thinking in isolation*

The child was in a continuous process of thinking about what had caused the situation and what the solution could be. If the parent did not answer questions, the child had to accept that. Insights generally appeared gradually. The sick parent could either assist in the process of understanding or make it more difficult by not answering questions.

Why does she never open up to us? There are explosive questions in my head (B3).

In the end I gave in...well, if she does not want to talk, I cannot force it out of her.

Interviewer: So, you have asked her but do not get any answers.

B3: Yes (Silence) (B3)

Interviewer: How is it when your mother is very ill?

Then you are sad. I am in my room thinking (B1).



### ***Silently worrying***

The child was in a constant state of worry about what would happen today and in the future. The child took responsibility for preventing bad things from happening and for resolving the situations that did occur. The child was in continual longing for nearness and normality, and was sometimes in active grief over the loss of positive interaction with the parent.

The day is really influenced...I get worried...well, today she seems to feel bad so maybe we will have to call the ambulance or the health advice line or something (B5).

The first thing you want when you get home from school is to see your mother smile... when she doesn't you see that she is not well... you get sad ...you blame yourself that you can't do anything about it ... why can't I help her? (B3).

### ***Adopting the parental role***

The child took it for granted that children have the duty of helping their parents. Help consisted mainly of nursing tasks, taking care of oneself and thereby relieving the parent of parenting, and taking responsibility for the household. The child also performed parental tasks for their sibling(s), such as attending a parent-teacher conference at school, or accompanying their sibling to the dentist or doctor. One of the older children interviewed stated, 'The most important thing is that Mom maintains her leadership' and thereby showed an understanding of the burden of responsibility that otherwise fell on the child.

### ***Caring for the parent***

The child kept an eye on the mobile phone in expectation of contact from the parent, ready to run home to assist if needed. The child guided the mother to rest, protected her from light, sound and smell, fetched medicine, asked the neighbour for help, called for medical advice and the ambulance, calmed the mother and the rest of the family down, and kept the mother company.

Mom rings me and needs help to carry food home from the shop... I would quite seriously be able to get the tube to go faster to be able to go and help her. Many times I have run home from school because I do not want her to carry anything because of her back (B3).

### ***Caring for self***

The child learned from experience to not expect parenting and tried alone to do things that normally would be done together with a parent or with a parent's assistance, such as transporting oneself, going alone to meetings at school, healthcare appointments and the dentist, and taking care of schoolwork alone. Also, the child had to do without social activities together with the parent, such as visiting family and friends together, or going shopping, swimming or to the movies together. The child had to participate in, for instance, sports without a parent's presence and had independently learned skills, such as baking, without a parent's help.

It feels like we are sliding apart...it feels like we are missing out...there are certain things parents do with their children and...we miss out on that... and it gets sad... (B3).

I cannot make her healthy, but I can take care of my studies better... so she sees that I am involved in things and that I can help her psychologically at least, not physically... (B6).

### ***Caring for the household***

The interviewed children tidied up, shopped, carried groceries, cooked, washed dishes, cleaned, washed clothes or walked the dog, knowing that this would relieve the parent of stress and, therefore, help the parent keep their composure.

I usually wipe the counter and wash the dishes and put things away... she does not like when it is messy...she gets stressed and panicky and easily gets angry ... so I help, so she will not get stressed, as that takes her energy and makes her more exhausted (B5).



## Discussion

### Main findings

The results showed that the children viewed themselves as key contributors to the functioning of their families. The main concern which emerged was the question of how to make life stable and functional for both themselves and their parent, without the parent's help. The children also saw themselves as a main contributor to the effort of rehabilitating the parent; they tried to understand and help day and night, did not give up, and became very competent. However, they also felt very isolated, suffered, and were unaware that there were other adults who could assist them in understanding and helping the parent. It is as if the child said, 'Mother, by understanding and helping you I will make life work for both of us'. Based on this recurring concept of role in relation to the parent's illness, we conclude that children of chronically ill parents in this PHC setting view their parents and their own situation as problematic and serious, indicating a risk for intergenerational transmission of illness.

The fact that children take on such an important position and role in the family might appear surprising, but is understandable when keeping in mind that the child is emotionally attached to the parent. That attachment might be of differing quality, such as safe, unsafe or chaotic, but in any case, the relationship matters and has a great influence on the child. Bowlby describes emotional attachment as a lasting psychological connectedness between human beings (Bowlby, 1981). Attachment is first created between the infant and its primary caregiver. If the primary caregiver is physically and psychologically available and responsive to an infant's needs, the child is allowed to develop a sense of security. The infant first understands itself through the feelings and reactions of the caregiver. Gradually, the child discovers its individuality and place in the family and community. The interviewed children were adolescents with a current developmental challenge of separating themselves from their parents. Among children whose parents have Multiple Sclerosis (MS) it was found that children with a MS-affected parent displayed higher levels of depression and anxiety than children from the control group as well as a greater degree of separation anxiety, compared to the control group (Yahav, Vosburgh, & Miller, 2007). Professionals need to keep in mind that the children of ill patients are attached to their parents and that parental symptoms will influence the parent's relationship to the child and thereby the child. The natural separation in adolescence might be made more complicated because of the parent's illness.

Trying to understand one's situation is a key coping mechanism in any person's life. For a child, it has added dimensions. The child gradually becomes aware of him- or herself, the family and society with increasing age and capacity and need to integrate different aspects into one complete but multifaceted whole. Antonovsky defines the sense of coherence as: 'The extent to which one has a pervasive, enduring though dynamic, feeling of confidence that one's environment is predictable and those things will work out as well as can reasonably be expected' (Antonovsky, 1979). This coherence has three components: comprehensibility, manageability, and meaningfulness. The component *comprehensibility* is similar to our category, *understanding the situation*. The component *manageability* is similar to our category, *taking on the parental role/helping the parent*. The component *meaningfulness* is possibly the motivating factor behind the child's effort: by making life work for oneself and the people in the household, the child strives for what is most meaningful: a family. Sense of coherence is naturally developed in interaction with important persons in a child's life. The adult silence described by the children interviewed might to an unnecessary degree make it more difficult for the growing child to evolve a sound understanding of the situation and a sense of coherence. Conversely, by helping the child to make the situation of the parent comprehensible, manageable and meaningful, health care professionals might contribute to the future health of the child.

Helping the parent is a strategy also found in previous research about young carers (Becker, 2007) and children who interpret for their parents (S. Cohen, Moran Ellis, & Smaje, 1999). This research has shed light on the fact that, even in highly developed Western countries, children often carry the heavy

burden of caring for their parents. Furthermore, the pressure to help might be higher in societies where households are small and there simply is no one else present to help. Care includes both tasks and responsibility. If the amount, frequency, complexity, time demand, intimacy and duration of care is too heavy, the child's development will suffer (D. Cohen, Greene, Toyinbo, & Siskowski, 2012).

### ***Revisiting qualitative research on children of ill parents in other health care settings***

Our findings are similar to findings in other health care settings. A meta-synthesis (Dam & Hall, 2016) found that children of parents with mental illness are 'navigating in an unpredictable everyday life.' These children are responsible, loving and worried children who want to do everything to help and support their families. Children feel shame when the parent behaves differently due to illness, and they conceal their family life out of fear of stigmatisation and bullying. The children cope through information, knowledge, frank communication and trustful relationships. Another systematic literature review (Drost, van der Krieke, Sytema, & Schippers, 2016) of twenty-six studies of self-expressed strengths and resources for children of parents with a mental illness found that the children described themselves as more mature, independent, and empathic than their peers who did not have a parent with a mental illness, and as having acquired several abilities. The statements about resources indicated that the children regarded social support, information, and particularly the support of mental healthcare professionals as helpful when living with a parent with a mental illness. The main concern of adolescent children of patients with multiple sclerosis (MS) was found to be preserving control in an uncertain everyday life. This concern was resolved by 'balancing needs', implying the pattern of (1) reflecting, (2) adjusting, (3) taking responsibility and (4) seeking respite (Mauseth & Hjalhmult, 2016). In a study of adolescent daughters of mothers with breast cancer, a similar pattern appeared, but with the added threat and impact of death. The following eight major themes were found: 1) A World Turned Upside Down, 2) Stop the Intrusion – Need to Get Away – Reluctant to Leave, 3) Mom Can't Die, 4) A Hole Where Mom Used to Be, 5) Filling in the Hole Where Mom Used to Be, 6) Being There for Mom – Managing Mom, 7) Managing My Reactions – Being Selfish or Difficult, and 8) Guarded Relief (Stiffler, Barada, Hosei, & Haase, 2008).

### ***Practical implications of study findings***

PHC treats patients who are so affected by illness that their children describe the situation as 'serious', and these children express a need for help in their efforts to understand their parent's illness. Health Care Professionals are particularly well placed to give information to the child directly, or via the parent, about the parent's illness: the name of the illness, its symptoms, its treatment and its prognosis. Thereby the child is substantially helped in the process of understanding. This hopefully assists the adolescent to remain healthy and continue in the process of individuation. In a study of facilitators of group interventions for children of mentally ill parents, the facilitators found that educating the children about mental health was important because they believed that knowledge equates to power, and can be cathartic (Reupert & Maybery, 2010).

Reaching out to children of chronically ill patients is an important task in PHC. PHC personnel need to inform parents and children that children are usually very interested in their parents' health, and that the children view themselves as contributors to the family, who naturally strive to understand and help. Professionals need to welcome the children's observations and feelings, acknowledge their contributions, and invite their questions, while at the same time keeping in mind that the child's main task is to grow and develop and gradually separate from the parent. This can best be done by honoring the child's bond to their parent. PHC professionals may ask chronically ill patients, 'What does your child see and understand of your illness?' This question may open up a conversation which leads to the invitation, 'Would you like to bring your child along to our next visit, so we can all talk together about your illness?' Further research on the parents'

main concern and strategies will bring greater clarity to the question of how to initiate a conversation about the parent's illness between patients and their children.

Sometimes these conversations with patients and their children might reveal such difficult and harmful social situations that the Health Care Professional becomes worried about the welfare of a particular child. In that case, support must be sought through the social services under the Child Protection Laws.

This area of study explores a specific aspect of the general rights and needs of children, as expressed internationally at the UN in the *Rights of the Child* and, more recently, in the 17 Global Goals for 2030. This particular study has given voice to the concerns, feelings and strategies of the child facing an ill parent in a non-specialized health care setting. Efforts to support child participation in decision-making have been discussed (J. Hart, Paludan, Steffen, & O'Donoghue, 2011) and developed elsewhere, in models such as *The Ladder of Participation* (R. Hart, 1994) and *A Model for Involving Children* (Shier, 2001), and these global goals, conventions, and models can be helpful in future efforts to design necessary interventions suited to the PHC setting.

### **Strengths and limitations**

A major strength of this study is that the data and the resulting model were solidly collected and analysed at the PHC level. That the PHC centre was known to the children might have made it possible for somewhat younger children to participate. It is more difficult to obtain data from younger children (Malterud, 2014), but it is also vital, as support for the younger children is of paramount importance.

In qualitative research, the results need to be trustworthy (i.e. credible), dependable and transferable (Malterud, 2014). Specifically, in *Grounded Theory* the questions of validity and reliability are answered by the following four questions: Does the theory fit the data collected? Is the theory relevant to the area of study? Does the theory work to explain what is going on? Is the theory flexible enough to be able to integrate new data? (Glaser, 1998). The cooperation of the co-authors ensured that the theory fitted the data. The last three questions were favourably answered when the theory was presented to 35 doctors in training to become specialized in PHC, as well as six specialists of Family Medicine. All of them confirmed that the conceptual model is very relevant to their clinical work; that it, in an engaging way, explains what goes on from the child's perspective; and that they will be able to apply and use it in future encounters with patients and their children.

A particular limitation of this study is that only children who cooperated with their parents could be reached. As the invitation to the study reached the children via their parents, it is likely that the children included are those individuals who to some reasonable extent cooperate with their parents. There might be other children who are not on such good terms with the parent and who could not be included in this type of study. Children with severely dysfunctional relationships with their parents might rather be found in settings of institutionalized care and, to our knowledge, there is as of yet no research on this theme in that setting. This study reached individuals who wished and were able to cooperate with both their parents and the PHC Clinic.

### **Conclusion**

Children of chronically ill parents in a PHC in Sweden view themselves as main contributors to the functioning of their families. They strive to make life stable and functional for both themselves and their parent by trying to understand and help. They naturally have a bond with their parent, and are affected when the parent is chronically ill. When striving to give these children information about their parent's illness, PHC professionals need to keep in mind these children's position and understanding of their role in relation to the situation and meet them where they are, with respect for both their capacity and their vulnerability.

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No potential conflict of interest was reported by the authors.

## Notes on contributors

CLO, AN, JM, TE and SE were involved in the conception and design of the study, the interpretation of the data, and the drafting and revision of the manuscript. All authors read and approved the final manuscript.

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## Appendix 1.

### An Example/The Situation

Many people who feel sick come to this local clinic for help with many different things. Some kinds of sicknesses last a long time. One parent, we'll call her Maria, feels pain in her body for a long time. As time goes on, Maria becomes tired, irritated and sad. She can't work and has to stay home from work for a long time. This affects her everyday life a lot, and even her economy. The pain and tiredness she experiences makes her life difficult. She doesn't have the energy, for example, to spend time with her friends. Maria worries a lot about the future. Her sickness affects her child, too. Her child doesn't get as much help from her as before. Also, her child worries about Maria's health.

## Appendix 2.

### Interview guide: Questions for the Child

What are your thoughts about Maria and her children's situation?  
 What do you think of your and your sick parent's situation?  
 How do you feel when you think about your parent being sick?  
 How are things going in your family?  
 Who are the members of your family?  
 Does your family ever talk together about your parent's illness? Give examples.  
 Is there anything you would like to ask your parent about her illness, which you haven't asked?  
 Why is it that you haven't asked about that?  
 Would you say it's generally calm or stressful in your family and home? Give examples.  
 How do your parents get along? What's their relationship like?  
 Has their relationship changed in any way since one of them got sick?  
 How are you affected by the fact that your parent is sick? (Try to get both practical and emotional examples)  
 Is there anything your parent can't do anymore?  
 Is there anything which has gotten better since your parent got sick?  
 What do you do when you are home?  
 In which ways do you help out at home?  
 Is this different from when your parent wasn't sick?  
 Do you have anywhere to go (place or activity) where you don't need to think about your parent's illness?  
 How are things for you at school?  
 How's it going with your studies?/How are your grades?  
 Is this different from before, when your parents wasn't sick?  
 Do your teachers know about your situation at home?  
 If not, would you like it if someone contacted your teacher(s) and explained?  
 How can the doctor (or others who work at the local clinic) support Maria and her child?  
 How is it for you – what do you want the local clinic to do for you and your mom/dad? Give examples.  
 What would you like to know about your parent's illness?  
 What would you like advice about?  
 What kind of support would you like?  
 Who would you prefer to receive the information, advice and support from?  
 What would you like to ask the local clinic about?  
 Do you feel like you've been helped by the local clinic?  
 Would you want to meet with other children who are in your situation and get advice and support from them?  
 If so, how would that happen on a practical level? (where, who leading it, etc.)  
 If someone from the local clinic would want to reach you and speak with you about your parent's illness, what would be the best way for them to contact you?  
 The interview is almost over. How was it to talk about all this?  
 Is there anything else you would like to talk about or ask about?