

# Master Thesis

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## *Exploring the psychosocial needs of adolescents whose parent is suffering from breast cancer*

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## **Abstract**

**Background:** Cancer has a major effect on the individual patient and their family, especially their children. Adolescents who face parental cancer exhibit high scores in mental health problems as anxiety, stress and depression. Literature has focused on the impact of parental cancer in the well-being of children and young adults. However, little is known about the needs of adolescents whose parent is specifically suffering from breast cancer. Insights in the psychosocial needs are important in order to develop appropriate guidance and support for these adolescents.

**Aim:** To explore psychosocial needs of adolescents whose parent is suffering from breast cancer to improve the support for these adolescents.

**Method:** This is a prospective, exploratory, qualitative study, performed in the Erasmus MC Cancer Institute. In-depth interviews were conducted with adolescents whose parent suffers from breast cancer. An interview guide was designed with the following topics: experiences, needs and support. The participants were selected purposively and approached via the parent(s) after the regular consultation. Interviews were audio-taped, transcribed and thematically analysed using NVivo.

**Results:** A wide variety of psychosocial needs were discussed and five themes were defined: distraction, support, being able to talk about it, information and, to continue the normal life. No differences in needs were found between adolescents with a parent in the curative and palliative phase.

**Conclusion:** Adolescents whose parent suffers from breast cancer need the best possible preservation of their normal lives. It is important for them to be able to share their story and find support from someone close to them.

**Recommendations:** Healthcare professionals need to pay attention to the well-being of adolescents whose parent suffers from breast cancer and invite these adolescents to regular consultations so they are able to ask their questions to the professional.

**Keywords:** nursing, breast cancer, parental cancer, psychosocial needs, adolescents

## Samenvatting

**Achtergrond:** Kanker heeft een grote invloed op de individuele patiënt en het gezin, vooral op de kinderen. Adolescenten die met ouderlijke kanker worden geconfronteerd, scoren hoog op psychische problemen zoals angst, stress en depressie. Onderzoek heeft zich tot op heden gericht op de impact van ouderlijke kanker op het welzijn van kinderen en jongvolwassenen. Er is echter weinig bekend over de behoeften van adolescenten van wie de ouder specifiek aan borstkanker lijdt. Inzicht in de psychosociale behoeften is belangrijk om passende begeleiding en ondersteuning te ontwikkelen voor adolescenten.

**Doel:** Het exploreren van de psychosociale behoeften van adolescenten waarvan de ouder lijdt aan borstkanker met als doel de ondersteuning voor deze adolescenten te verbeteren.

**Methode:** Dit is een prospectieve, explorerende, kwalitatieve studie, uitgevoerd in het Erasmus MC Kanker Instituut. Diepte-interviews werden uitgevoerd met adolescenten waarvan de ouder lijdt aan borstkanker. Er is een interview guide ontworpen met de onderwerpen: ervaringen, behoeften en ondersteuning. De deelnemers werden doelgericht geselecteerd en na het reguliere consult via de ouder(s) benaderd. Interviews werden opgenomen, getranscribeerd en thematisch geanalyseerd met behulp van het softwareprogramma NVivo.

**Resultaten:** Uit de analyse van de interviews zijn vijf thema's van psychosociale behoeften geïdentificeerd: afleiding, ondersteuning, erover kunnen praten, informatie en het normale leven voortzetten. Geen verschillen zijn gevonden in behoeften tussen adolescenten met een moeder in de curatieve en palliatieve fase.

**Conclusie:** Adolescenten met een ouder met borstkanker hebben het best mogelijke behoud van hun normale leven nodig. Het is belangrijk dat zij hun verhaal kunnen delen en steun kunnen vinden bij iemand die dichtbij hen staat.

**Aanbevelingen:** Zorgprofessionals moeten aandacht hebben voor het welbevinden van adolescenten met een ouder met borstkanker. Nodig deze adolescenten uit op de reguliere consulten zodat zij hun vragen kunnen stellen aan de zorgprofessional.

**Trefwoorden:** Verpleegkunde, borstkanker, ouderlijke kanker, psychosociale behoeften, adolescenten

## Introduction and Rationale

Breast cancer is the most common cancer in women and the second most common cancer all over the world(1). In the Netherlands, one in seven women develop this life-threatening disease and in 2020 the incidence of breast cancer accumulated to 15,077 cases(2). Thanks to medical developments in breast cancer care, the chances of survival are increasing. Nevertheless, approximately 3000 people die of breast cancer in the Netherlands every year(3). The presence of cancer has a major effect on the individual patient and their family, especially their children(4,5). In particular children in the phase of adolescence (10-19 years), since this is an important stage of development(6,7). During this stage, various developments take place on a physical, mental and emotional level. An emotional shift is taking place away from their parents towards friends and peers(8). Although it is difficult to indicate a specific number of adolescents who have to deal with parental cancer, recent research shows that these numbers are likely to be substantial(5). In the United States of America the percentage of diagnosed cancer survivors who live in a household with a minor child is fourteen percent(4). Parents with cancer differ in various aspects from adult cancer patients without children, such as in their willingness to receive more aggressive treatments in an effort to secure more time with their children(4,9).

The illness and loss of a parent for adolescents and young adults can result in physical, cognitive, emotional and behaviour problems(10). Adolescents and young adults with a parent with cancer are considerably psychosocial vulnerable(11). In addition adolescents who face parental cancer exhibit high scores in mental health problems such as anxiety, stress and depression(10,12). Despite the important developments and vulnerabilities in the stage of adolescence, in the past ten years research has mainly focused on the impact of parental cancer on the well-being of young people in general (10-24 year)(6,7,11,13). For example, the studies of Patterson et al. provide a reasonable understanding of the needs of young people whose parent suffers from cancer(13,14). Patterson et al. developed a measurement tool to assess the psychosocial unmet needs of young people who have a parent with cancer, also known as the Offspring Cancer Needs Instrument (OCNI). The concept of psychosocial needs can be defined as a desire or requirement for help or support for a person's emotional and psychosocial wellbeing(14). Focus groups, telephone interviews and a staff survey were used for the design of the measurement tool(11,13) However, this measurement tool only provides superficial information about the psychosocial needs of young people. In addition, the instrument is difficult to interpret by younger adolescents because of the textual design. Deeper perception of the experiences and needs can only be explored through in-depth interviews.

Despite the exploration of the psychosocial needs of adolescents and young adults with a parent with cancer in general, recently only few studies have investigated the impact of parental breast cancer on adolescents(15,16). Whereas earlier research shows that this particular group faces different challenges. For example, the adolescents often feel burdened by additional responsibilities as a result of parental breast cancer(17). The coping of adolescents whose parent suffers from breast cancer differs between sons and daughters. In particular daughters may fear to be at risk of inheriting this life-threatening disease. Given the genetic component, there is the possibility daughters will develop resentment towards the mother due to the contribution to the genetic vulnerability to breast cancer(18). Not all adolescents dealing with parental cancer need psychosocial interventions(8). However, assessing the self-expressed psychosocial needs helps the healthcare professional providing proper support for those in dire need(11,13,14). At this moment, there are no tools or programs for healthcare professionals to provide proper support. The professional practice recognizes the lack of scientific evidence regarding the psychosocial needs of adolescents whose parent suffers from breast cancer and endorses the importance of research into this subject. In daily practice they regularly find no social safety net for these adolescents, for example due to family problems. Professionals are therefore concerned about the psychosocial well-being of the adolescents and its possible consequences. Nowadays the insight into the psychosocial needs of adolescents whose parent suffers from breast cancer is incomplete. Therefore, the aim of the study is to explore the psychosocial needs of adolescents whose parent is suffering from breast cancer in order to improve the support for these adolescents.

## **Methods**

### **Design**

A prospective, exploratory, qualitative study was performed in the period from February to July 2021 at the Erasmus MC Cancer Institute in Rotterdam, the Netherlands. The study was performed by a female, practicing registered nurse with support of the supervisor W.H. Oldenmenger PhD. Methodologically driven by thematic analysis, the data was systematically analysed using the constant comparison method(19,20). The analysis was performed using the NVivo software program(19). In order to achieve explicit and comprehensive reporting of the findings the 'consolidated criteria for reporting qualitative research' (COREQ) guideline was used(22,23).

## **Population & Domain**

The population of this study is defined as: adolescents whose parent is suffering from breast cancer in the Netherlands. In order to recruit the adolescents the purposeful sampling strategy has been used(18,22). Adolescents were eligible for inclusion in the study if they were between ten and nineteen years of age and were able to speak and read the Dutch language. The adolescent's parent had to be diagnosed with breast cancer in either the curative or palliative phase of the disease. Adolescents were not eligible for inclusion in the study if they have been diagnosed with, or have been treated for a mental disorder. They were also not eligible for inclusion in the study if their parent was in the terminal phase of breast cancer.

## **Data collection**

Semi-structured, in-depth interviews were conducted by the researcher (LH) with adolescents whose parent was treated in the Erasmus MC Cancer Institute. In order to establish a good connection with the younger adolescents during the interviews, the researcher has undergone personal training to gain experience in and learn about interviewing young people. The personal training consisted of a short training course by a child psychologist, a pedagogical counselor and a primary school teacher about interviewing children and adolescents. The interviews took place through the Microsoft Teams program where audio was recorded with a separate device. The adolescent was able to choose a place where he or she would feel comfortable and not be bothered during the interview. In all cases, only the adolescent and the researcher were present during the interview. An interview guide has been designed which has been pilot tested. Based on the literature and the experiences of the healthcare professionals, the following main topics have been formulated: experiences, impact on family, needs and support. A few sample questions have been adjusted as a result of the interviews. Field notes were made during the interview including notes about the adolescent's behaviour, technical details and methodological notes(24). Summaries of the interviews were sent to the adolescents with the purpose of member checking. This in order to assess the accuracy with which the researcher has represented the adolescent's subjectivity(25). In this study, the goal was to achieve data saturation. Data saturation is the point where the collection of new data does not shed any further light on the issue under investigation(26). In this study, this was the point where no new insights about the psychosocial need of adolescents whose parent suffers from breast cancer emerged from the data. When data saturation appeared to have been reached, three additional interviews were conducted to confirm this finding, after which the targeted sampling was stopped(20).

## **Data analysis**

During the analysis, the data was coded by the researcher (LH) from open coding, to axial coding and eventually selective coding(19,20). As a result of this process, a number of major themes were identified. The codes and major themes were peer reviewed by the supervisor (WHO).

## **Procedures**

At the start of the study, the doctors and nurse practitioners who are part of the breast cancer care in the Erasmus MC Cancer institute were informed about the study by the researcher and they were asked to discuss the study during consultations. During the regular consultation, the patients were asked for permission to approach the adolescent by phone. During the telephone call between the adolescent and the researcher, the adolescent received further information about the study. If the adolescent decided to participate, a date for the interview was scheduled. A fully introduction took place between the adolescent and the researcher during the first meeting along with a short illustration of the researcher's background. Both the parents and the adolescents received the information letter and informed consent form via email and both were asked to sign this form.

## **Results**

A total of fourteen adolescents were interviewed. The duration of the interviews varied between 35 and 60 minutes. All adolescents who were approached for the study subsequently participated in the study. Baseline characteristics are presented in Table 1. The ages of the adolescents ranged between twelve and nineteen years of age (median = 16 years). In all cases the adolescent's mother was diagnosed with breast cancer. The time between the diagnosis of breast cancer and the moment of the interview varied between six months and six years. Of the fourteen adolescents, nine had a mother in the curative phase and five a mother in the palliative phase of breast cancer. The member check procedure has not resulted in any feedback on the findings. The thematic analysis method has resulted in five main themes, namely (1) distraction, (2) support, (3) being able to talk about it, (4) information and (5) to continue the normal life. The themes with associated codes are presented in the code tree in Figure 1.

### **1. Distraction**

All adolescents indicated that distraction is an important element in coping with their mother's breast cancer. Distraction means that they do not have to think about the illness of their

mother and its possible consequences for a while. This gave the adolescents energy to be able to continue with their daily life.

*“As long as I am very focused on something else, I do not have to think about my mother for a moment.” (R5)*

Distraction was defined in several ways. Common elements were distraction from hobbies, school, friends, work or volunteer work. Not talking about the breast cancer now and then was indicated as pleasant.

*“Distraction is what I need the most. I mainly get this through my friends and hobbies. Then I can just get away from my worries for a while.” (R10)*

## 2. Support

Support was an important aspect for the adolescents to be able to continue their lives. Three elements of support have been mentioned, namely support from family, from friends and from their mentor at school.

*“My friends are there to support me. They are there to comfort me when my mother is not feeling well.” (R10)*

This support was especially important at times when the adolescent or the mother was not doing well. It was reassuring to know that someone is there for you to listen or help if needed.

*“Things weren't going well at school for a while. My mentor was very observant and regularly asked how things were going. I found that very pleasant. When I look back on the situation, my mentor helped me a lot.” (R4)*

The adolescents indicated that they have experienced sufficient support from people close to them at the time of the mother's illness. There was no need for support from a healthcare professional. However, the adolescents could imagine that in the absence of a social network, there may be a need for such professional support.

*“I have a lot of people around me who want to listen to me, so I don't really need support from a doctor, for example. I can imagine that if you don't have such a safety*

*net, it's nice to be able to talk about it with someone who has knowledge about breast cancer.” (R7)*

### 3. Being able to talk about it

It was important for almost all adolescents to be able to talk about their mother's breast cancer. This helped in understanding the effects of breast cancer and its possible consequences. The majority of the adolescents preferred to speak with a familiar and well-known person about the mother's illness rather than to strangers. Talking about the disease was a part of coping with their feelings about their mother having breast cancer.

*“It helps me a lot if I can talk about it.” (R4)*

In general, it was experienced as pleasant that family and friends showed interest and compassion. But talking about the breast cancer to someone close to them who has been through a similar situation and getting recognition gave them the feeling of being really understood.

*“There are some girls with whom I can talk about it, because they have experienced the same situation.” (R2)*

### 4. Information

Some adolescents indicated the importance of getting information about the breast cancer, treatments and potential consequences.

*“I find it pleasant to get information, because then you know what is really going on.” (R10)*

*“I actually find it very interesting to know how it all works.” (R1)*

There is a need for information to be able to understand the situation properly and to assess the risks for their mother, the family and themselves.

*“The day my mother told me she had breast cancer, she immediately told me how everything would go. It was nice that I knew things right away.” (R14)*

Some of the adolescents would like to ask their questions to the healthcare professional themselves in order to obtain factual information about breast cancer and the treatments.

*“You should not give a brochure, because it will be thrown away anyway. I would like to be able to ask questions myself once in a while to get an explanation about the disease in understandable language.” (R12)*

5. To continue the normal life

To continue the normal life was a theme that was mentioned by many adolescents. This helps them to keep a grip on life.

*“Going on with my normal life is one of the things that helped me.” (R4)*

The adolescents indicated the importance to continue normal activities, both inside and outside the family. There should also be room for funny and precious moments. This balance helped in dealing with their emotions.

*“You should not always be confronted with the disease, then it is no longer livable. It is also important to have a nice day with friends every now and then, to get away from it all.” (R12)*

The adolescents whose mother is in the palliative phase of breast cancer are generally more aware of the consequences of breast cancer for their mother's future and for their own future. They think diligently about life choices, such as the choice for study, work and where to live.

*“There are certain choices you have to make, and sometimes you adjust them. Because my mother is going to die and you don't want to live too far away.” (R12)*

## **Discussion**

According to this qualitative study, the needs of adolescents whose mother suffers from breast cancer are mainly aspects based on the relationship and contact with the parents. Both parents play a clear role in meeting these needs. In addition, there should be room for distractions and activities outside the family, so that the adolescents can withdraw and take time for themselves. No differences were found between the needs of adolescents with a mother in the curative phase and in the palliative phase of breast cancer. However, it is clear that adolescents whose mother was in the palliative phase of breast cancer think more consciously about the future and their life choices.

Earlier research on the needs of adolescents whose parent suffers from breast cancer is limited(15,16,18). The results of the studies that examined the needs of adolescents and young adults with a parent with cancer in general are quite in line with the results of this study(10,12). However, there are some differences.

First of all, previous studies focus on a different population in terms of age. For example, most studies have examined the needs of young people between the ages of 10 and 24. This is a combination of adolescents (10-19 years) and young people (15-24 years) as defined by the WHO(10,12,13). This study only focused on the needs of adolescent, given the various developments that take place on a physical, mental and emotional level(8). In addition, adolescents who face parental cancer exhibit high scores in mental health problems such as anxiety, stress and depression.

According to Patterson et al., the psychosocial needs of young people with a parent with cancer can be divided into eight domains(13). Two of the eight domains were not identified in the results of this study, namely the need for access to support services and support for caregivers. This difference may be related to the difference in study populations.

Another difference between this study and the previous studies is that most studies have examined the needs of young people through questionnaires(8,11,13). By using in-depth interviews and a well-founded analysis method, this study has been able to provide a more detailed description of the needs(19,20).

One of the strengths of this study is the constructive peer review by the supervisor. In addition, the structured analysis through the NVivo program made a contribution to the quality of the research. Another strong point of this study is that data saturation was achieved during the 11th interview. This finding was confirmed by conducting three additional interviews, because no new findings emerged from the data. Using the COREQ guideline contributed to the quality of the research report of this qualitative study(22,23).

The study also has a number of limitations. For example, the interviews with the young adolescents (12-14 years) were difficult and it was not clear whether they fully understood the questions and were able to answer the questions. It was difficult for the researcher to avoid a pattern of questions requiring a one-word response when the younger adolescents could not engage in the in-depth conversation. These experiences are in line with scientific knowledge about interviewing adolescents(27). Despite the difficult conversations with the younger adolescents, the researcher managed to retrieve the core findings during the interviews due to the personal training. However, the underlying stories and experiences underneath the core findings were not retrieved.

Conducting the interview through MS Teams may have been a limiting factor. Studies on online interviewing in qualitative research indicate that this method may be a good alternative

to live face-to-face interviews, but may result in missed opportunities for the researcher in observing and responding to body language and emotional cues(28,29). However, the online interviews allowed the adolescents to participate in the interview from their own safe environment.

This study was a single centre study. At the Erasmus MC Cancer Institute, a specific group of women is being treated for breast cancer. This concerns a predominantly young and relatively small group of women who suffer from a very aggressive or genetically determined form of breast cancer. Since the average age of women with breast cancer treated in an academic hospital is generally low, their children are also predominantly young. Because of the focus of the study on the needs of adolescents, the setting and patient population were appropriate for this study. Nevertheless, the results of this study are generalizable to adolescents who are in a similar situation, whether they are being treated in an academic hospital or a non-academic hospital.

In conclusion, adolescents need the best possible preservation of their normal lives. It is important for them to be able to share their story and find support from someone close to them.

The recommendation to the healthcare professionals is to pay attention to the well-being and needs of the adolescents during the consultations with the parents. In addition, it may be important to invite the adolescent to the regular consultation so they are able to ask their questions to the healthcare professional.

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## Appendix

Table 1. Baseline Characteristics of the Adolescents and Mothers.

Characteristics	Numbers	
	n=14	Percentages
Age adolescents		
11-13 year	3	21%
14-16 year	5	36%
17-19 year	6	43%
Gender adolescents		
Male	7	50%
Female	7	50%
Education level adolescents		
Primary school	1	7%
High school	6	43%
College	7	50%
Occupation adolescents		
None	7	50%
Side job/Student job	5	36%
Voluntary work	2	14%
Home situation adolescents		
Living at home	13	93%
Living on their own	1	7%
Phase of breast cancer mother		
Curative	9	64%
Palliative	5	36%
Marital status parents		
Married	9	64%
Divorced	5	36%

\* Rounding errors can lead to percentages slightly above 100%.

Figure 1. Code tree

