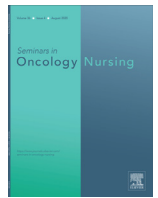




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## Exploring the Psychosocial Needs of Adolescents Whose Parent Is Diagnosed With Breast Cancer

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## ABSTRACT

*Purpose:* Cancer has a major impact on the individual patient and their family, especially children. However, little is known about the needs of adolescents (10–19 years) whose parent is diagnosed with cancer, especially breast cancer. Insights into psychosocial needs are important to develop appropriate guidance and support for these adolescents. The aim of this study is to explore the psychosocial needs of adolescents whose parent is diagnosed with breast cancer to improve the support for these adolescents.

*Data sources:* This is an exploratory, qualitative study. In-depth interviews were conducted, and an interview guide was designed with the following topics: experiences, needs, and support. Participants were selected purposively and approached via the parent(s) after consultation. Interviews were audiotaped, transcribed, and thematically analyzed by using the software program NVivo.

*Conclusion:* Fourteen adolescents (12–19 years) were interviewed, which resulted in five themes: distraction, support, being able to talk about it, information, and continuing a normal life. Adolescents whose parent is diagnosed with 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.

*Implication for Nursing Practice:* The route to the adolescent is always through the parent. Healthcare professionals can discuss the well-being of the adolescent during regular consultation with the parent. If there are concerns, healthcare professionals can advise the parent about the possible needs of the adolescent and could coach the parent in supporting the adolescent to discuss their needs.

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### 1 Introduction

2 Breast cancer is the most common cancer in women and the sec-  
3 ond most common cancer all over the world.<sup>1</sup> In the Netherlands,  
4 one in seven women develop this life-threatening disease, and in  
5 2022 the incidence of breast cancer was 18,000 cases.<sup>2</sup> Medical devel-  
6 opments in breast cancer care have improved survival. Nevertheless,  
7 approximately 3,000 people die of breast cancer in the Netherlands  
8 every year.<sup>3</sup>

9 The cancer diagnosis has a major impact on the individual patient  
10 and their family, especially their children.<sup>4,5</sup> In particular, children in  
11 the phase of adolescence (10–19 years) are affected, because this is

an important stage of development.<sup>6,7</sup> During this stage, various  
12 developments take place on physical, mental, and emotional levels.  
13 An emotional shift is taking place away from their parents toward  
14 friends and peers.<sup>8</sup> Although it is difficult to indicate a specific num-  
15 ber of adolescents who have to deal with parental cancer, recent  
16 research shows that these numbers are substantial.<sup>5</sup> In the United  
17 States, 14% of diagnosed cancer survivors live in a household with a  
18 minor child.<sup>4</sup>

19 For adolescents and young adults, the disease itself and the loss of  
20 a parent can result in psychosocial, emotional, and behavior prob-  
21 lems.<sup>9</sup> Adolescents and young adults with a parent with cancer are  
22 considerably psychosocially vulnerable.<sup>10</sup> In addition, adolescents  
23 who face parental cancer exhibit high levels of mental health prob-  
24 lems such as anxiety, stress, and depression.<sup>11</sup> Patterson et al  
25 described in general the needs of young people whose parent is diag-  
26 nosed with cancer; the authors using a screening tool to assess  
27

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psychosocial unmet needs of the young people.<sup>10,12</sup> However, this tool provides only superficial information about the psychosocial needs. To have a deeper perception of the needs of adolescents, a more extensive research approach is required.

Despite the important developments and vulnerabilities in the stage of adolescence, research has mainly focused on the impact of parental cancer on the well-being of young people in general in the past 10 years.<sup>5,8,10,12</sup> Earlier research shows that adolescents face different challenges and often feel burdened by additional responsibilities as a result of parental breast cancer.<sup>13</sup> In the past 20 years, only a few studies have investigated the impact of parental breast cancer on adolescents specifically.<sup>13,14</sup> Their findings show that coping of adolescents whose parent is diagnosed with breast cancer differs between sons and daughters. In particular, daughters may fear being at risk of inheriting this life-threatening disease. Given the genetic component, there is the possibility daughters will develop resentment toward the mother due to the contribution to the genetic vulnerability to breast cancer.<sup>15</sup> However, these studies had a relatively small number of respondents and did not use an extensive analysis method. A detailed and rich description of adolescents' psychosocial needs in the literature is lacking.

In this study, to improve the support of adolescents we aim to explore the psychosocial needs of adolescents whose parent is diagnosed with breast cancer through the use of in-depth interviews.

## Methods

A prospective, exploratory, qualitative study was performed from February to July 2021 at the Erasmus University Medical Center (Erasmus MC) Cancer Institute in Rotterdam, the Netherlands. Semistructured, in-depth interviews were conducted by the researcher (LH) with adolescents having a parent who was treated at the Erasmus MC Cancer Institute. To achieve explicit and comprehensive reporting of the findings, the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline was used.<sup>16,17</sup>

## Sample

After approval of the Erasmus MC Ethics Committee, adolescents were recruited using the purposeful sampling strategy.<sup>18</sup> Adolescents were eligible for inclusion if they were between 10 and 19 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 and needed to be treated at the Erasmus MC Cancer Institute between February and July 2021. Adolescents were not eligible for inclusion in the study if they have been diagnosed with a mental disorder.

## Procedure

To establish a good connection with the younger adolescents during the interviews, the researcher (LH) received 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. At the start of the study, the doctors and nurse practitioners who are part of the breast cancer care team 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 phone call, the adolescent received further information about the study. If the adolescent decided to participate, a date for the interview was scheduled. Both the parents and the adolescents received the information letter and informed consent form via e-mail, and both were asked to sign this

form. A full introduction took place between the adolescent and the researcher during the first meeting along with a short illustration of the researcher's personal and professional background. An interview guide was designed based on the literature and the experiences of the healthcare professionals. The interview guide contained the following topics: experiences, impact on family, needs, and support. Based on the results of the first three interviews, many questions were added to the interview guide.

The interviews took place through Microsoft Teams due to the pandemic. Audio recordings were made with a separate device. The adolescent chose the place where he or she would feel comfortable and not be bothered during the interview. Parents were aware that the interview took place so they could support the adolescent after the interview, whenever necessary. Every interview started with the question: "How are you doing?" Field notes were made during the interview including notes about the adolescent's behavior, technical details, and methodological notes.<sup>18</sup> Summaries of the interviews were sent to the adolescents for member checking.<sup>19</sup>

## Analysis

The data were analyzed systematically using the thematic analysis method in order to give a rich, detailed description of the data set and to interpret the various aspects of the research topics.<sup>20–22</sup> For a systematically analysis process, the verbatim transcriptions were entered into NVivo software (version 12, QRS International).<sup>23</sup> Thematic analysis is a method for identifying, analyzing, and reporting patterns within data, via a constant comparison method. In this study, the steps outlined by Braun and Clarke were followed.<sup>22</sup> These steps are (1) familiarizing with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. As a part of steps 2 and 3 of the analysis, the data were coded using an inductive approach by the researcher (LH) from open coding, to axial coding and eventually selective coding.<sup>20,21</sup> As a result of this process, several major themes were identified. In this study, a "theme" was defined as a pattern that contains important information from the data in relation to the research question. It represents a certain level of patterned response of meaning within the data set.<sup>22</sup> The codes and major themes were peer-reviewed by the supervisor (WO). After this analysis, a second researcher (MvR) from the breast cancer treatment team performed the thematic analysis again to check the results. The analysis and data collection took place in the same period. This enabled the researchers to identify the point of data saturation that implies the state of data analysis where no new codes, subthemes, and themes could be identified.<sup>21</sup> Some improvements were made in the interview guide, based on the data analysis of the first interviews.

## Results

A total of 14 adolescents were interviewed. All adolescents who were approached for the study participated in the study. The duration of the interviews varied between 35 and 60 minutes. The age of the adolescents ranged between 12 and 19 years (median: 16 years). All mothers were under treatment at the Erasmus MC Cancer Institute at the time of the study. The time between the diagnosis of breast cancer of the mother and the moment of the interview varied between 6 months and 6 years. Of the 14 adolescents, 9 had a mother in the curative phase, and 5 had a mother in the palliative phase of breast cancer (Table 1). When data saturation appeared to have been reached, three additional interviews were conducted to confirm no new insights about the psychosocial needs of adolescents whose parent is diagnosed with breast cancer emerged from the data. The

**TABLE 1**  
Baseline Characteristics of the Adolescents and Mothers.

Characteristic	n (N = 14)	%
Gender of parent with breast cancer		
Female	14	100
Age of adolescents, y		
10–13	3	21
14–16	5	36
17–19	6	43
Gender of adolescents		
Male	7	50
Female	7	50
Education level of adolescents		
Primary school	1	7
High school	6	43
College	7	50
Occupation of adolescents		
None	7	50
Side job/student job	5	36
Voluntary work	2	14
Home situation of adolescents		
Living at home	13	93
Living on their own	1	7
Phase of breast cancer		
Curative	9	64
Palliative	5	36
Marital status of parents		
Married	9	64
Divorced	5	36

148 member check procedure did not result in any feedback on the find-  
149 ings.

150 The study resulted in five main themes: (1) distraction, (2) sup-  
151 port, (3) being able to talk about it, (4) information, and (5) continu-  
152 ing the normal life (Fig 1).

### 153 *Distraction*

154 Distraction was an important element in adolescents' coping with  
155 their mother's breast cancer. Distraction meant that they did not  
156 have to think about the illness of their mother and its possible conse-  
157 quences for a while. This gave them energy to be able to continue  
158 with their daily life. Distraction was reported in several ways. Com-  
159 mon elements through which the adolescents experienced distrac-  
160 tion were practicing their hobbies, going to school, spending time or  
161 doing activities with friends, going to their side job, and, in some  
162 cases, conducting volunteer work. In this way, they were able to con-  
163 centrate on something different and did not have to talk about breast  
164 cancer, unless colleagues or friends specifically asked for it.

165 "Distraction is what I need the most. I mainly get this through my  
166 friends and hobbies. Then I can just get away from my worries for  
167 a while." (Boy, 13 years)

### 168 *Support*

169 Support was an important aspect for adolescents to be able to  
170 continue their lives. Four ways of support have been mentioned: sup-  
171 port from family, from friends, from their mentor at school, and, in  
172 some cases, from their supervisor at work. This support was espe-  
173 cially important at times when the adolescent or the mother was not  
174 doing well. It was reassuring to know that someone is there for them  
175 to listen to their stories or give help if needed. The way in which sup-  
176 port was provided differed among the adolescents. For some, there  
177 was a mentor who contributed ideas to an adapted school program  
178 in order to pass tests. For the other, there was an older family mem-  
179 ber who was close to the adolescent and gave personal advice on  
180 how to handle the situation.

"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." (Boy, 19 years)

The adolescents indicated that they have experienced sufficient  
support from people close to them at the time of the mother's illness.  
The adolescents did not mention that they also discussed their own  
well-being with their mothers. There was no need for support from a  
healthcare professional, such as support from a psychologist or from  
a general practitioner. This professional is proverbially "too far away"  
from them. In addition, the moment when support is actually needed  
does not always coincide with the scheduled appointment with the  
healthcare professional. The adolescents therefore did not see added  
value in this. However, they could imagine that in the absence of a  
social network, for some adolescents there might be a need for such  
professional support.

### *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 aided them in understanding the  
effects of breast cancer and its possible consequences. The majority  
of the adolescents preferred to speak with their parents and with a  
well-known person close to them about their 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.

In general, it was experienced as pleasant that family and friends  
showed interest and compassion. Talking about the illness of their  
mother to someone close to them who has been through a similar situa-  
tion and getting recognition gave them the feeling of being understood.

"There are some girls with whom I can talk about it because they  
have experienced the same situation. They understand what I am  
saying" (Boy, 14 years)

Many adolescents felt comfortable talking to their mother about  
the disease. They were curious about what the treatment meant to  
their mother, both physically and mentally. The mother often took  
the initiative to start the conversation. The motivation for a conversa-  
tion can be a consultation with the doctor or nurse practitioner or a  
test in the hospital.

### *Information*

Predominantly, the older adolescents mentioned the importance of  
getting information about breast cancer, treatments, and potential con-  
sequences of their mother's illness. They had a need for information  
about the disease, to be able to understand the situation properly and  
to assess the risks for their mother, the family, and for themselves.

"The day my mother told me she had breast cancer, she immedi-  
ately told me how everything would go. It was nice that I knew  
things right away." (Boy, 14 years)

Some adolescents would like to ask their questions to the health-  
care professional themselves to obtain factual information about  
breast cancer and the treatments. A reason for this, which was  
addressed by several adolescents, is that parents themselves were  
sometimes unable to answer the adolescents' substantive questions.  
Almost all respondents searched for information about the disease  
via the Internet if people close to them could not provide an answer.

"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." (Girl, 19 years)

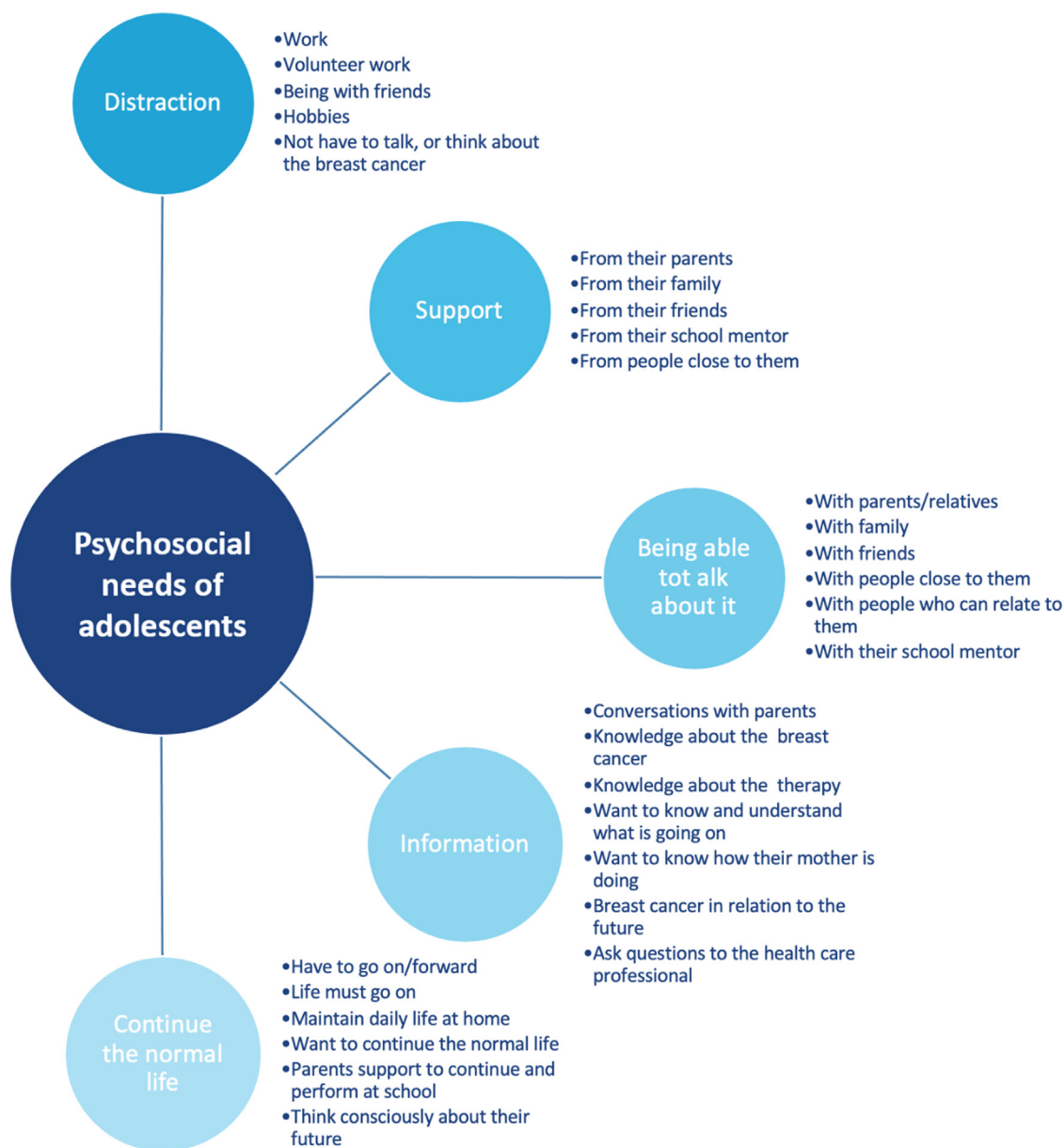


FIG 1. Code tree.

Especially when talking about this theme, it became clear that the younger adolescents (12–13 years) found it more difficult to specifically address their needs compared to the older adolescents. The younger adolescents expressed themselves initially in a few words, with no detailed description of their needs. Through subsequent questioning, the researcher was able to get a deeper description of the needs of the younger adolescents. The younger adolescents differed from the older adolescents in this theme because they did not need a very detailed explanation but considered a low-level explanation about the disease sufficient.

#### To Continue the Normal Life

To continue a normal life was most important for adolescents. This helped them to keep a grip on life. The adolescents indicated the importance to continue normal activities, both inside and outside the

family. It is important that the normal life continues at home. Continuing the normal life at home is described as helping with cooking and eating together, helping the parents in the household, and watching television with the whole family. They emphasized the need 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.” (Girl, 19 years)

The adolescents whose mother was in the palliative phase of breast cancer seemed to be more aware of the consequences of breast cancer for their mother’s future and their own future. They thought diligently about life choices, such as the choice for study, work, and where to live. Sons and daughters mentioned comparable needs in the interviews.

269 “There are certain choices you must make, and sometimes you  
270 adjust them. Because my mother is going to die and you don’t  
271 want to live too far away.” (Girl, 19 years)

## 272 Discussion

273 This study shows that the needs of adolescents whose mother is  
274 diagnosed with breast cancer are mainly based on the relationship  
275 and contact with people close to them. They liked to talk about their  
276 own well-being with people close to them but not their parents. In  
277 addition, there should be room for distractions and activities outside  
278 the family so that the adolescents can take some time for themselves.  
279 There were mostly similarities between the needs of adolescents  
280 with a mother in the curative phase and in the palliative phase of  
281 breast cancer. However, adolescents whose mother was in the pallia-  
282 tive phase of breast cancer thought more consciously about the  
283 future and their life choices. Some adolescents would like to ask their  
284 questions to the healthcare professional themselves to obtain factual  
285 information about breast cancer and the treatments.

286 Our results are somewhat different compared to previous studies.  
287 First, previous studies focused on a different population in terms of  
288 age. For example, most studies have examined the needs of young  
289 people between the ages of 10 and 24 years. This is a combination of  
290 adolescents (10–19 years) and young people (15–24 years) as  
291 defined by the World Health Organization.<sup>7</sup> Our study only focused  
292 on the needs of adolescents, given the various developments that  
293 take place on a physical, mental, and emotional level.<sup>8</sup> In addition,  
294 adolescents who face parental cancer exhibit high scores in mental  
295 health problems such as anxiety, stress, and depression.<sup>11</sup> According  
296 to Patterson et al, the psychosocial needs of young people with a par-  
297 ent with cancer can be divided into eight domains.<sup>12</sup> Two of the eight  
298 domains were not identified in the results of this study: the need for  
299 access to support services and support for family caregivers.

300 Another difference between this study and the previous studies is  
301 that most studies have examined the needs of young people through  
302 the use of questionnaires.<sup>8,10,12</sup> By using in-depth interviews and a  
303 well-founded analysis method, the current study has been able to  
304 provide a more detailed description of the needs.<sup>20,21</sup>

305 We found no differences in needs between sons and daughters.  
306 This is in contrast with Davey et al (2005), who reported a difference  
307 in coping between sons and daughters whose parent is diagnosed  
308 with breast cancer.<sup>15</sup> The difference in results may be due to the dif-  
309 ference in research method. The study by Davey et al used three focus  
310 groups with a total of 10 adolescents, and the data were analyzed by  
311 means of a systematic review of the transcripts, using content analy-  
312 sis techniques where the unit of analysis is a statement or group of  
313 statements. The difference in results may be explained by the differ-  
314 ence in data collection and analysis method. This study contains a  
315 larger number of respondents who were questioned individually and  
316 in a more in-depth manner. The analysis method in this study was  
317 also more far-reaching by means of the thematic analysis.

318 This study has several strengths. The chosen qualitative research  
319 method is the most suitable for this research question and is better  
320 than any other qualitative design. It provides insight into the breadth,  
321 depth, and nuance of the adolescents’ experience and their needs. In  
322 addition, the research team includes two experienced qualitative  
323 researchers. As Braun and Clarke point out, qualitative research is a  
324 comparatively easy to learn qualitative analytic approach, without  
325 deep theoretical commitments. Qualitative research fits well for  
326 research teams where researchers have different levels of expertise  
327 in the field of qualitative research.<sup>24</sup> Another strength of this study is  
328 the constructive peer review by the senior researcher with experi-  
329 ence in the qualitative research field. The researcher was also trained  
330 in conducting interviews with young respondents and in conducting  
331 qualitative research in general. In addition, the structured analysis

through the NVivo program contributed to the quality of the 332  
research. Furthermore, in this study data saturation was achieved 333  
during the 11th interview. This finding was confirmed by conducting 334  
three additional interviews because no new findings emerged from 335  
the data. Use of the COREQ guideline contributed to the quality of the 336  
research report of this qualitative study.<sup>16,17</sup> 337

338 The study also has a few limitations. First, the interviews with the 338  
young adolescents (12–14 years) were considered more challenging 339  
by the researcher compared to the interviews with the older adoles- 340  
cents, because the young adolescents mainly answered with short 341  
and superficial answers to open questions. They seemed to need a lit- 342  
tle bit more explanation about the question before they were able to 343  
answer the open questions properly. In some cases, it helped to 344  
phrase the question differently. These experiences are in line with 345  
scientific knowledge about interviewing adolescents.<sup>25</sup> Furthermore, 346  
the younger adolescents sometimes found it difficult to define their 347  
needs. Most of the younger adolescents could not describe directly 348  
what their needs were when they were asked at first. Children from 349  
the age of 11 years have conceptualizing abilities that enable them to 350  
reflect on their experiences; however, this skill is not yet properly 351  
developed, making it difficult to answer profound questions.<sup>26</sup> 352  
Through subsequent questioning and by paying attention to their 353  
behavior during the interview, the researcher managed to receive a 354  
deeper description of their needs. Finally, this study was a single- 355  
center study. At the Erasmus MC Cancer Institute, we are specialized in 356  
treating young women with breast cancer and women who is diag- 357  
nosed with a very aggressive or genetically determined form of 358  
breast cancer. Because the average age of women with breast cancer 359  
treated in an university medical center is generally lower compared 360  
to the general population of breast cancer patients in general hospi- 361  
tals, their children are also predominantly young. Because of the 362  
focus of the study on the needs of adolescents, the setting and homo- 363  
geneous patient population were appropriate for this study. Never- 364  
theless, the results of this study are generalizable to adolescents who 365  
are in a similar situation. 366

## 367 Conclusion and Implications for Nursing Practice

368 Adolescents whose parent is diagnosed with breast cancer need 368  
the best possible preservation of their normal lives. They need to be 369  
able to share their story and find support from someone close to 370  
them. Healthcare professionals are recommended to pay attention to 371  
the well-being of the adolescents during the consultation with the 372  
parent(s). The needs of these adolescents vary, which means that not 373  
a generic but rather a person-centered approach is necessary. We 374  
advise inviting the adolescent to regular consultation together with 375  
the parent(s) to allow the adolescent to ask their questions. The route 376  
to the adolescent is always through the parent. Healthcare profession- 377  
als can discuss the well-being of the adolescent during the regular 378  
consultation with the parent. When there are concerns regarding to 379  
the adolescent’s well-being, the healthcare professional could advise 380  
the parent in how to handle needs of the adolescent and could coach 381  
the parent in supporting the adolescent to discuss their needs with 382  
whom he or she prefers to do so. 383

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385 The authors declare that they have no known competing financial 385  
interests or personal relationships that could have appeared to influ- 386  
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