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Author(s)	Rodríguez, Leonor
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# An exploration of resilience in adolescents facing maternal cancer

Leonor Rodríguez  
UNESCO Child and Family Research Centre NUI Galway, Galway, Ireland

## Correspondence

Leonor Rodríguez, UNESCO Child and Family Research Centre NUI Galway, Galway, Ireland. Email: leonor.rodriguez@nuigalway.ie

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## Abstract

**Background:** Research findings on the impact of parental cancer on adolescents are inconsistent, some studies identifying negative psychosocial impact but others identifying positive impact; however, there is not enough understanding on the underlying factors that may lead to differences in outcomes. Research has found that resilience has a role in adolescents' adaptation to maternal cancer; however, the nature of this requires further exploration.

**Aims:** This analysis will help understand resilience in adolescents that experience maternal cancer by exploring the nature of resilience and the individual, family, and environmental risk and protective factors that determine resilience in adolescent lived experiences of maternal cancer that enable positive outcomes.

**Methods:** This study is part of a larger investigation focused on understanding adolescent adjustment to maternal cancer and the psychosocial factors that promote adjustment. Original adolescent interview transcripts (n = 15) were subject to a secondary thematic analysis.

**Results:** The analysis yielded four themes: the first theme, *The Journey of Maternal Cancer*, describes adolescent experiences of maternal cancer over time; the second theme is a detailed description of adolescent *Protective Factors* and how these supported the adolescents; the third theme describes the *Risk Factors* that adolescents faced; and the fourth theme summarizes the *Positive Outcomes* that adolescents self-identified.

**Conclusion:** This study found resilience as dynamic, as it changes over time. These changes are a result of the course of maternal illness and its treatment over time. Adolescents can adapt to change, but this capacity is shaped by protective factors and risk factors as well as challenges that are unique to having a mother diagnosed with cancer. Most adolescents managed to navigate successfully and identified positive outcomes from a difficult and life-changing experience. The study suggests the need to provide long-term supports for adolescents and carry out longitudinal research to further understand the trajectories of resilience in adolescents who experience maternal cancer.

## KEYWORDS

adolescence, maternal cancer, resilience

## 1. INTRODUCTION

Research findings on the impact of parental cancer on adolescents are inconsistent, some studies identifying

negative psychosocial impact but others identifying a positive impact and the capacity for post-traumatic growth.<sup>1</sup> Therefore, research is needed to understand the underlying factors that may lead to the determination of why some adolescents have positive experiences and others have difficulties<sup>2,3</sup> when they experience parental cancer.

Every year, around 0.3% of all families with children less than 18 years of age encounter parental cancer, and 3.1% of children and 8.4% of adolescents have a parent who has been diagnosed with cancer in Norway.<sup>4</sup> Some research studies have described that adolescents who are facing parental cancer can experience more psychosocial difficulties, internalizing problems, psychological issues, and posttraumatic stress compared with the general population.<sup>5</sup> Other studies also report anxiety, depression, and reduced self-esteem.<sup>5,6</sup> A systematic review on the somatic symptoms in adolescents who had a parent with cancer found that they can experience somatic complaints such as eating problems, pain, sleeping difficulties, and bedwetting. These complaints were associated with increased emotional distress.<sup>7</sup> Other studies; however, have found that most young people experiencing parental cancer cope successfully and only a minority have psychosocial problems.<sup>8</sup>

Research has described that adolescence is a particularly vulnerable developmental stage in which to experience maternal cancer because adolescents are facing conflicting demands. These include a developmental need for separation from the family,<sup>9</sup> while at the same time requiring limit setting, nurturing and security,<sup>10</sup> and a continuous connection with a parental figure such as their mother.<sup>11</sup> In the case of maternal cancer, mothers may not be available to meet these complex needs due to their illness and treatment side effects. Parental cancer can be a positive experience for adolescents by increasing their maturity and appreciation for other people in their lives.<sup>11</sup> Research has suggested that the differences between those adolescents who cope well and those that struggle are associated with individual differences in coping styles, family functioning, resilience, emotional management, social support, and gender.<sup>5,12-14</sup> Previous studies have shown that parental cancer is a challenging experience for adolescents, yet they also showed strength, resilience and hope when facing the challenges of the illness,<sup>10</sup> and some experienced positive outcomes related to posttraumatic growth and resilience.<sup>1,2</sup>

## **1.1 Resilience**

Resilience is a multi-layered concept that can be defined in different ways, and this is one of the challenges for research as the concept has also been operationalized and measured in different ways.<sup>15</sup> Ungar<sup>16</sup> defined resilience as “*the ability of young people, families and communities to navigate to the resources they need (which means those resources have to be available and accessible) and negotiate for these resources to be provided in meaningful ways*” (p.18). Resilience involves three processes which are recovery (return to same level of functioning it had before the problem), adaptation (change to accommodate disturbance to survive and thrive), and transformation (individuals or environments change to do well under stress).<sup>16</sup> Masten and Barnes<sup>17</sup> have suggested that resilience definitions are a variety between resilience as a capacity, process, or outcomes of positive adaptation to adversity. Resilience as a capacity is a person's ability to adapt to change and stressful events in a healthy way. Resilience as a process consisting of a reintegrating and returning to normal functioning because of the support of protective factors. Resilience as a result are the positive outcomes resulting from navigating a stressful event successfully.<sup>3</sup> Therefore, for the purposes of this research, resilience will be explored as a capacity, a process, and as an outcome.

Previous research on positive youth development in adolescents coping with parental cancer defined resilience as the “primary outcome” of the experience, specifically as a psychosocial developmental

experience where adolescents consciously decided to take the “positive route” of resilience in action (2, p.6). Resilience was described as an outcome of the experience of parental cancer, and it is a conscious choice made by adolescents which suggests a degree of adolescent autonomy over the outcomes of maternal cancer.

## 1.2 Protective and risks factors

According to Ashurst et al,<sup>2</sup> adolescence is an opportunity to bolster protective factors, and achieve positive outcomes and positive futures. Ashurst et al<sup>2</sup> explained that adolescents experiencing parental cancer that have enough protective factors in their lives can take a “resilient path.” Protective factors related to resilience included attachment and closeness of family members, increased communication, perceiving the ill-parent as helpful, support from others, re-establish routines, perseverance, self-reliance, peace of mind, faith, helping others, priority changes, opportunities to escape, and humour. Lee et al<sup>3</sup> carried out a conceptual review on resilience as a positive youth development construct and identified bonding, emotional competence, self-regulation, positive self-perceptions, valued talents, optimism, perceived control, self-efficacy, attractiveness to others, an organized home environment, and active coping as protective factors for psychological resilience in adolescents; however, these findings do not refer specifically to adolescents experiencing parental cancer. Openness to adult relationships, identification of personal strengths, and the establishment of mentor relationships are tools for building resilience.<sup>18</sup> Ungar (16, p.24) summarized the protective factors required for resilience to occur in persons in general: (a) close relationship with a caring adult; (b) self-esteem; (c) experience control in some aspect of life; (d) opportunities to use talents; and (e) access to supports to thrive (education, housing, and health care). Risk factors were identified as barriers to resilience including avoidance of family communication, addiction, cut-off relationships, secrets, emotional suppression, perceiving the non-ill parent as unhelpful, prior losses, ignorance of others, denial, pessimism, juggling multiple stresses, use of drugs or sex to escape, guilt, feeling helpless, suddenness, fears of self, concerns about future losses, and barriers to closure.<sup>2</sup> A summary of protective and risk factors identified in the literature is provided in Table 1.

Table 1: Summary of Protective and Risk Factors Identified in the Literature

	<b>Protective Factors</b>	<b>Risk Factors</b>
<b>Individual factors</b>	Emotional competence (3, 28) Self-regulation (19, 28) Self-efficacy (3) Positive self-perceptions/ Self-esteem (2,17, 19) Valued talents/ Identify personal strengths (3, 17) Humour (2, 3) Optimism (2, 3, 19) Perceived control/ control in some aspect of life (2, 3, 17) Active coping (2, 3, 17, 19) Attractiveness to others (3) Access to supports to thrive (17) Empathy (19)	Emotional suppression (2) Supress problems (17) Denial (2) Pessimism (2) Guilt (2) Feeling helpless (2) Fears (2, 19) Struggle to deal with multiple stresses (17, 19, 28) Prior losses, concerns of future losses (2) Barriers to closure (2) Addiction (2) Use of drugs/ sex to escape (2, 17)
<b>Family Factors</b>	Good communication (2, 28) Attachment/ bonding (2, 3, 17, 28) Closeness of family members (2, 28) Organised home environment (3)	Avoidance of family communication (2) Family secrets (2)
<b>Social Factors</b>	Openness to adult relationships/ close relationship with a caring adult (17, 19) Mentor relationships (17, 19)	Cut-off relationships (2)

	Support from others (2, 3) Bonding with cultural beliefs (3, 17)	
<b>Parental cancer related factors</b>	Perceive non- ill parent as helpful (2) Re-establish routines (2, 28) Opportunities to escape (2)	Perceive non-ill parents as unhelpful (2) Suddenness of diagnosis (2)

This secondary data analysis will contribute to the body of research to further understand resilience in adolescents that experience maternal cancer by exploring the nature of resilience in adolescents experiencing maternal cancer underpinned by Resilience Theory.<sup>3</sup> The analysis will also identify the individual, family and community risk, and protective factors that determine resilience in adolescent experiences of maternal cancer that enable positive outcomes for them.

## 2. METHODOLOGY

This study is part of a larger study focused on understanding adolescent adjustment to maternal cancer and the psychosocial factors that promote adjustment. The original study found that individual differences in perceived stress, coping skills, social support, attachment, and self-efficacy have an impact on adolescent adjustment; however, resilience was not explored in the original analysis.<sup>20</sup>

For this study, participants were recruited using different strategies. Adolescents were allowed to take part in the study if they were between 12 and 24 years of age.<sup>21</sup> Oncology nurses in breast cancer centres and staff in cancer support centres in Ireland provided female patient details. These patients who had a nonterminal cancer diagnosis in the previous 24 months were asked to invite their adolescents to take part. Adolescents were also directly recruited through media (newspapers and radio), and official University emails were sent to all registered students. All potential participants received online information or a postal information package including information sheets and consent forms. These information packages were tailored to be age appropriate, and ethical approval for the study was obtained from the NUI Galway Research Ethics Committee.

Adolescents who provided consent were asked to take part in a semi structured interview to explore their experience of maternal cancer (Table 2). Interviews were carried out at a time and venue of participants choosing and varied in style from face-to-face, telephone, or Skype. Interviews were recorded, transcribed, and analysed. For the purposes of this study, a secondary thematic analysis was carried out with interview transcripts.

Table 2 Adolescent Interview Script

<ul style="list-style-type: none"> <li>• What are you currently concerned about?</li> <li>• Do you have enough people in your life with whom you can talk to about these concerns?</li> <li>• What are your roles/responsibilities in your house? Have you noticed changes in these roles or responsibilities recently?</li> <li>• Have you noticed changes in your usual activities since your mothers' diagnosis and treatment (Sports, school, family time, friends time, others)</li> <li>• What activities have you done recently to relax and/or have fun?</li> <li>• Did you get all the support you expected from family, school, community, friends others? Did you get support when you asked for it? What strategies do you use when you need to ask for help?</li> <li>• What kind of support did you feel you needed the most?</li> <li>• Tangible/ Concrete (visible, practical, like loaning a book to a friend)</li> <li>• Emotional (feelings, relationships, like talking to a friend)</li> <li>• Esteem (positive characteristics people recognise in you)</li> <li>• Advice (help with a decision or provide information)</li> <li>• Who informed you about your mothers' cancer diagnosis (father, mother, sibling, another family member,</li> </ul>
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teacher, friend, health staff)?

- How did you cope/deal with your mothers' diagnosis?  
Is there anything in particular that has helped you through this time?  
What do you think could help you even more?  
Do you have a person (s) to talk to about the cancer experience?
- Where did you look for information about cancer and/or treatment (father, mother, sister, brother, another family member, teacher, friend, health staff, books or didn't look for information)?
- Have you noticed changes in the relationship with your mother since diagnosis?
- Has the experience of maternal cancer made you realise who you can really count on?
- Has this experience of having a mother diagnosed with cancer affected or changed people around you in ways you didn't expect or understand?
- What would you recommend to other adolescents facing the same experience as you?
- How can health professionals (physicians, nurses, psychologists) help you?

Secondary data analysis is suitable when data collected are used to answer a new research question to the one for which it was originally obtained.<sup>22,23</sup> Rew et al<sup>23</sup> described that in secondary analysis of qualitative data it is possible to examine data in more detail to identify latent content that can reflect the underlying meaning of the original responses. One of the advantages of this method is the possibility of developing research questions that require further study, validation, and further understanding of health care issues.<sup>22-24</sup> Cheng and Phillips<sup>25</sup> emphasized the advantages of secondary data analysis in the health research field including reduced costs compared with conducting an original study. It also encourages creativity to cross-link information from different sources and identify potential new interventions for emerging problems that can be tested in prospective studies.<sup>25</sup>

A secondary thematic analysis<sup>26</sup> was carried out with the original interview transcripts. All interviews were uploaded to NVivo for analysis. *Step 1: Familiarizing yourself with the data* consisted of repeatedly reading adolescent interviews to identify meanings and patterns related to the theme of resilience. *Step 2: Generating initial codes*. This stage was driven by the research objective, understanding the role of resilience in adolescents based on the theoretical definition of resilience as a capacity, a process, and a result. Protective and risk factors were also identified at this stage. *Step 3: Searching for themes*. Initial codes were sorted into potential themes. The relationship between codes was evaluated to determine how these could be grouped. *Step 4: Reviewing themes*. In this phase, a refinement and further validation of the four themes were carried out to ensure the codes identified fit appropriately with the themes. *Step 5: Naming the themes*. Based on the content and characteristics, four main themes were identified, and subthemes were also provided with relevant names. *Step 6: Producing the report*. This final step consisted of the write-up of the results section, supported by evidence from adolescent quotes to support themes identified.<sup>26</sup> Subsequently this article was written for publication and dissemination of the findings. Fifteen adolescents between the ages of 15 and 20 years completed semi structured interviews until data saturation was reached.

### 3. RESULTS

This secondary thematic analysis set out to explore resilience in adolescents experiencing maternal cancer. Thematic analysis was chosen as this is a widely used method in psychology, healthcare, and social research.<sup>27</sup> It is a suitable method for sample sizes between 2 and over 400 to address a wide variety of topics including understanding experiences, perceptions, and practices.<sup>27</sup> Lee et al.'s<sup>3</sup> model of resilience as a capacity, process, and result was used to inform the data analysis. Fifteen adolescents between the ages of 15 and 20 years completed semi structured interviews until data saturation was reached. Five participants were male. Though maternal diagnoses varied, the majority of patients were diagnosed

with breast cancer. Further details of these adolescents are included in Table 3.

**Table 3: Irish Adolescent Interviews – Socio-demographic Data**

Interviewee*	Interview Type	Gender	Age	Maternal cancer type	Time since diagnosis (months)	Interview length (minutes)
1	Telephone	Male	18	Breast	12	13:32
2	Telephone	Female	16	Breast	24	19:47
3	Face to face	Female	18	Breast	24	47:16
4	Face to face	Male	18	Breast	23	24:37
5	Face to face	Female	17	Breast	18	31:08
6	Face to face	Male	15	Breast	18	19:35
7	Skype	Female	17	Breast	24	40:53
8	Face to face	Male	16	Colon	10	18:05
9	Face to face	Male	14	Colon	10	13:03
10	Face to face	Female	16	Colon	10	29:00
11	Face to face	Female	20	Breast	25	34:21
12	Face to face	Female	19	Gastrointestinal	14	56:18
13	Face to face	Female	17	Breast	14	29:24
14	Face to face	Female	17	Gastrointestinal	11	22:36
15	Face to face	Female	17	Gastrointestinal	29	28:30

The analysis identified four themes which provide an in-depth description of adolescents' lived experiences when their mother was diagnosed with nonterminal cancer. *The Journey of Maternal Cancer* describes adolescent stresses and challenges experience over time. The second theme is a detailed description of adolescent *Protective Factors* and how this supported adolescents at the time of maternal illness. The third theme describes the *Risk Factors* that adolescents faced, and the fourth theme summarizes the *Positive Outcomes* that adolescents self-identified as a result of having experienced maternal cancer.

### 3.1 The Journey of Maternal Cancer

Adolescents described the challenges they faced when they first found out that their mothers had cancer. They used metaphors such as not being able to breathe and being in shock. They also struggled to cope and were not sure of “*how much more you can take*”:

*... well the first stage is just, I could not breathe at all and all the time like there was no room for it because it was bad news and more bad news and hard time and like you do not know just how much more you can take at that point like I just could not handle seeing my Mum like that ... (Adolescent 11).*

#### 3.1.1 Change over time

Adolescents however had a capacity to change their first impression over time and got “*used*” to their mother's illness

*... then the second stage it was still like really hard seeing her sick but like it was easier for me, I just found it easier because you nearly get used to the fact that your mum has cancer and it's like ‘okay, yeah my mum has cancer, its fine’ and you like milking it with other people and they are much nicer to you (...) got a lot of free stuff ... (Adolescent 11)*

Maternal physical changes because of secondary effects of treatments were identified as one of the difficulties

adolescents faced, but these also became part of their “normality.”

*I did not really like seeing her with no hair so I preferred when she kind of wore a scarf and stuff but she did not like wearing the scarf in the house because it was too warm. But overtime I just got used to it, I did not even notice like after a while because it became normal (Adolescent 6).*

Over time, however, adolescents still faced challenges once their mothers were healthy. This was a new change and a new challenge for them to deal with, and they described how this was also difficult for them:

*I suppose when she was going through the treatments I understood how to cope with all that. And now that we are at the other side kind of coming to the end of it I do not really know what to do (...) now that she is healthy again she is a bit more able to do things but I still feel I still need to help her out even though she does not need it (...) I am kind of confused as to what, how much help she needs or are what point do you let survivors kind of return back to normal life (...) I was only there for support really but it still feels like I was going through it all the same, its kind of that weird connection (...) I am not entirely sure where to go from here (Adolescent 2).*

### **3.1.2. Coping and adapting**

Adolescents described having their own way of evaluating how well they thought they were coping with maternal cancer. Some were surprised at their reaction to maternal cancer and were expecting to be very nervous, anxious, or crying: “as it went on I just realized that I just hadn't been that upset so I just realized I think I am coping okay cause I am not crying and I am not dwelling on it” (Adolescent 6).

Other adolescents found reasons or had an awareness of how they managed to change their first impressions of maternal cancer over time. This capacity to adapt to maternal cancer, however, was dependent on different strategies used by adolescents which can be linked to protective factors and avoiding risk factors.

## **3.2 Adolescent Protective Factors**

Regarding protective factors, some adolescents mentioned the use of self-reflection and time for awareness. Time, however, involved a “balancing act” between time invested in the situation and time not focused on the situation. Some adolescents described activities they did to “clear their head” such as listen to music, go for a walk, running, sports, play guitar, watching a movie, and baking. *I want to still be aware of it but I would never kind of sweep it under the rug or just kind of have a passive stance for it (Adolescent 1).*

Adolescents also mentioned aspects in their environments that helped them deal with maternal cancer such as surrounding themselves with positivity, friends, and activities they enjoyed. Extended family members, community members, and schoolteachers were also described as important sources of support that contributed to adolescents having their usual routines and activities as usual. This included cooking dinner, providing lifts.

*I was inconsolable so I hang up the phone and I was sitting on the steps and I just could not stop crying and crying then my friend came and he just sat down and put his arm around me and we did not talk, I could not talk about it (Adolescent 1).*

Mothers had an important role in supporting adolescents. Adolescent described their mothers consoled them and openly communicated with them about the illness



*(...) it's not good to have it all bottled up either so it's good to talk to someone but it is best to talk to your Mum about it because they reassure you the most that they are still there they are still doing their everyday things, they are not going anywhere (Adolescent 1).*

Some adolescents required professional support to cope with maternal cancer. Therapists were also part of adolescents' social supports at that time.

*I did crash when mum started to go to chemo and I had to go to therapy (...) but I think it was really the best thing for me because I just cried and talked about everything. I think it really did help me being able to talk to someone that was really objective to the situation (Adolescent 11).*

### **3.2.1. Access to information**

Access to information was very important for some adolescents. Some felt that having all the facts about the illness helped them cope with it, but also the reassurance from their families that they would be informed about changes in the course of the illness was important: *'It's better to know than not to know'* (Adolescent 13). Others, however, were fearful of information and the impact this would have on them. Adolescents showed awareness of what kind of information they wanted and how much of it they wanted: *I did not want to Google any- thing too much because I was afraid I'd get an answer I did not like or something* (Adolescent 15).

*I knew everything that was going on and I knew the chances of everything happening so that gave me some relief that in my mother's case everything was quite positive and there was a very good chance that things, and knowing that if the circumstances changed I would be made aware of it so (Adolescent 12).*

### **3.2.2. Keeping "normality"**

Keeping "normality" despite maternal cancer was important for some adolescents, and they managed to adapt to the circumstances for example study for exams in the hospital.

*... you cannot get bogged down in it really, keep going no matter what and make sure everyone around you is okay too. You have to get on with your normal life and study, that was something that I had to do and I did it, there was no getting upset when you had to get an essay done, make sure that it is not going to affect your life more than it has to. You have to make sure that you are getting on with your things (Adolescent 13).*

This analysis also found adolescents felt they had to be able to cope and withstand maternal cancer, although it is not fully clear whether this really helped them cope or instead generated pressure on them as they felt they had to "keep going" and "be strong." This may have stopped them from allowing themselves to be upset by the impact maternal illness had on them:

*I suppose I just thought of my Mum...like she...I am not the one that is going through cancer, she is so I had to be strong for her. She was the one getting through this and she was fine. I'd never seen her upset or anything so why am I upset (Adolescent 15)*

### **3.2.3. Supporting others**

Supporting others, particularly their mothers and families, was a conscious decision some adolescents made during maternal cancer

*I knew that whenever she was getting chemotherapy that I would definitely do some more house work and just so she would not be so tired, but never really expected of me it was just something I wanted to do you know to make sure she got more rest (Adolescent 2).*

Adolescents explained that taking a caring role helped them to reduce their worry and stopped them from getting upset: “*I took up a caring role I think that helped me to not have to worry as much about how I was feeling because my concentration was on looking after other people, I suppose it distracted me very much from getting too upset myself ...*” (Adolescent 12).

### **3.2.4. Trust in the medical team**

Hospital environments were difficult for some adolescents; however, trusting the medical team helped adolescents cope, although not all of them met their mother's medical team or had access to the facilities. All adolescents, however, felt reassured when they knew the treatment was working, independent of what the source of this information was:

*... when you see like the name of the doctor like head of this or head surgeon or all this fancy terminology (...) and you are like ‘Oh wow’ (...) Your mum's life is in their hands and they know what they are talking about, it was a bit daunting but (...) you know they have their best intentions there. They worked very hard and they did their best (Adolescent 15)*

Some adolescents described that getting to know the facilities where their mother was being treated provided them with the security that their mother was in “*safe hands*” and properly taken care of:

*... the facility was fantastic and really like state-of-the-art and everything so it was kind of a comfort to know that she was in safe hands (...) see it gives you peace of mind like to know that your Mum is being taken care of and the right treatment and right things are being done for her so that was good (Adolescent 5).*

As part of a very unique experience, these adolescents experienced a nonterminal cancer diagnosis in their mothers, and, therefore, this provided a degree or reassurance that it was highly likely that their mother would recover from the illness:

*... it was made clear to us at the start, like after the diagnosis and everything, that what she had was curable and I was definitely going to be cured there was virtually nothing worse happening so I just took it on board and I did not really need to talk to anyone I suppose (Adolescent 7).*

### **3.3 Adolescent Risk Factors**

Some adolescents struggled to deal with their emotions and were particularly confused about what they were allowed or expected to feel.

*... it's a combination of feeling crap because it's such a bad thing and then you feel guilty cause it's not really happening to you, so like ‘okay I feel bad but should I feel this bad, how bad am I allowed to feel?’ because it's not me. It's confusing like that because you do not want anyone's sympathy because you feel you do not really deserve it*

(Adolescent 5).

On occasions, some adolescents struggled to communicate about maternal cancer, and mentioning the word was difficult. Some were fearful of the reaction that other people would have and how to deal with this situation: *“I had people that I know I could talk to about it but I didn't really want to talk to anyone about it because I felt like their reaction would make me feel worst like I felt like they would scare me more”* (Adolescent 1). They did not want sympathy from their peers or to be treated differently, and this is why they did not speak about what they were going through: *I do not want people always watching what they say or feeling guilty if they let some sort of comment about it and wondering how that would affect me* (Adolescent 1).

One adolescent had experienced a family breakdown previously to the diagnosis of maternal cancer, and she had few social supports available at the time. This increased the challenge of dealing with maternal cancer, and she even had to stop attending college

*... you just get desensitized after a while hearing about everything like when my parents fighting and then that type of thing is just you know and then my older sister did not help in the end because she just could not deal with it so we never really hear from her* (Adolescent 11).

Mothers were described as protective factors, but some could instead be described as a risk factor for adolescents. One adolescent described how her mother struggled with the diagnosis and felt like a “bad mother.” Mothers were sensitive about the diagnosis, and adolescents could not speak with them and perceived their mothers as not accessible.

*... she was kind of feeling bad that she wasn't a good enough Mum so it was really hard to like help her (...) you could not talk to her because she was so sensitive about it and everyone was really very scared to talk about it but now me and her can have conversations about it fine, she still gets really upset about it ...* (Adolescent 11).

Adolescents also described that other family members struggled to cope as well and were not accessible for them as sources of support through maternal illness: *“(...) cos like my Dad freaked out coz he couldn't cope so she was always haven' to look after him as well so yeah I dunno it's complicated ...”* (Adolescent 5).

Visiting their mothers in hospital was good for some adolescents that wanted to accompany their mothers during treatments or appointments; however, some adolescents were not comfortable in hospital settings or were afraid of blood so they did not want to be in those settings and found them distressing: *“(...) just kind of found it unsettling being in the hospital even if I want to be a nurse and I do like hospitals but because it was Mum and it was kind of scary I just felt really nervous in there so I didn't really like going there”* (Adolescent 6).

Some adolescents had an awareness of factors that could be detrimental for them such as isolation and suggested these should be avoided.

*... the best thing to surround you with are your friends and activities that you enjoy do not try and isolate yourself like if you feel, if one day in particular is really bothering you do not try and isolate yourself like try and do if anything try to do the opposite and try to include yourself in other things ...* (Adolescent, 1).

Adolescents mentioned preconceived and negative perceptions about cancer as aspects that made the experience

of maternal cancer more difficult for them, particularly when information was mainly focused on the number of deaths and not survival rates.

*(...) a lot of people see cancer like a terminal illness and it is highlighted so much when someone, when that is the cause of their death it's like people like 'oh yeah' as if it is nearly expected when you have cancer then that is the end result (Adolescent 1).*

### **3.3.1. The “ups and downs”**

Even though adolescents had an overall perception that their initial reaction to maternal cancer was very difficult and this changed over time, some described having “moments” whereby they struggled: “*You would have the odd day where I'd be like 'I can't do this anymore' cause I'd be so, you know, you'd be so worked up with school...but...you just have to keep going really*” (Adolescent 15). There was also a sense that they had to “go on” and had no other alternative.

Adolescents also experienced challenges at different times during the course of their mother's illness. Adolescents worried about the outcome of treatments such as surgery, but this changed once they knew their mother was doing well.

*...I worried about the surgery, like right before in case anything went wrong and (...) during the chemo it was okay, it was just kind of different round the house but it wasn't too difficult, like once the surgery is over, like once it went well, I just looked forward (Adolescent 8).*

Adolescents also described specific moments where they struggled with the reality of maternal cancer. Despite being with their mothers and supporting them through the illness and treatments, adolescents felt very powerless and helpless.

*(...) probably the first time I went to chemo like I was fine until they hooked up the bag and like, you know, were giving it to her and you hear the beeping of it and it's just like it's so real when you are surrounded by all this sick people and it's just hard to deal with like that you cannot help them but you just sit there with them (Adolescent 11).*

Over time, even when mothers overcame the illness, adolescents continued to struggle over time and “wondered” and worried whether the cancer would come back.

*And that the worst part is over and that for now things are the way they were before but I do not realize that. I do not realize that my Mum is the very same now that she was this time last year and I just feel like constant wondering when, I feel like it's inevitable that it will come back (...) and I want to get out of that mindset I want to (...) feel like, yeah it was there, it's gone that's all, just put a lid on it... (Adolescent 1).*

### **3.4 Positive outcomes**

Positivity was described as an outcome of maternal illness that helped adolescents through the experience: “*When she was sick like I learnt a lot about being positive and to keep going, that was kind of my motto if you like...just to keep positive, you can't just stop and do nothing because what's the point in that*” (Adolescent 15).

Adolescents described growing up and maturing much faster than their peers as a result of maternal cancer,

especially when they took over roles such as minding younger brothers and sisters. This had a positive impact in their lives such as being mature and independent when they went to college.

*I grew up very fast and that way like looking after my brother I do not think that many people had that push to mind a kid. In my school there would not have been many do that. I had that and it's not exactly a bad thing like and then college at 17 and many people they do not feel ready at 17 and I always wanted to come and just get out and wanted to come so I think that stood by me really just being able to help and get on with things like that (Adolescent 13).*

Family closeness was also perceived as an outcome of maternal cancer that supported adolescents through this experience. Adolescents described they had a higher level of appreciation for their families, and some also developed closer relationships with their mothers as a result of the illness experience.

*I always like always obviously really appreciated my Mum and my family and everyone but since then, because you take for granted, you know, that they are always there, that they are always going to be there that they are an invincible kind of thing like, then once something like that happens (...) it just makes you question if what you have outlined, what you took for granted it just puts that into depth then (Adolescent 1).*

Other adolescents also identified that they had a more positive outlook of life and did not get “bogged down” over “little things” such as their studies. Adolescents also described that they changed their perspective on arguments and how much time they spent being upset.

*... I just have a brighter outlook on life I think, like you know if someone is sad or if I was sad even...I just think of all the people...cause there is always going to be someone in a worse situation than I am. I get bogged down over the amount of study I have to do or there is no food in the house or just little things like that, like no that is silly... (Adolescent 15).*

Adolescent's outlook on cancer and illness also changed, increasing their awareness on how serious this is and the impact it has on people's lives as well as the vulnerability of human life. Others developed empathy towards other people and particularly young people that had experienced maternal cancer and maybe did not have a positive outcome:

*... it gave a lot of meaning to it that this is not just some illness that is listed in a book, that this is something that people go through, this is something that changes people's lives...this is a very scary illness to people and from what I have seen from what happened to my mother this is what happens to people with an illness like this ... (Adolescent 12).*

#### **4. DISCUSSION**

Research on adolescents experiencing parental cancer has identified resilience as a crucial component of an adolescent's ability to cope with parental cancer (6; 2). This research was focused on exploring the role of resilience in adolescents experiencing maternal cancer and determining whether resilience could be classified as a capacity, a process, or a result, as well as identify the protective and risk factors that impact on adolescent resilience at the time of maternal cancer.

This study found that resilience is a capacity of adolescents experiencing maternal cancer as most adolescents were capable of adapting to the diagnosis which they expressed themselves, validating their own

capacity to cope with the diagnosis. The capacity for adaptation has been defined as a crucial component of resilience building<sup>16</sup> and is the capacity for change and accommodation that facilitate thriving. Adolescent adaptation, however, was influenced by protective and risk factors that increased or reduced adolescent's capacity to cope with maternal cancer. Evidence of resilience as a result was identified in adolescents' identification of positive outcomes obtained due to maternal illness, despite the challenges and difficulties they experienced. Adolescents even validate these outcomes as beneficial for their lives and having a positive effect on other aspects of their lives. Some challenges identified in this study were very unique to the situation adolescents were facing, specifically coping with physical changes in their mothers as secondary effects of treatment such as hair loss.

Protective factors identified in this research are similar to those previously identified by research carried out with this age group also experiencing parental cancer.<sup>2</sup> These were closeness with family members, communication, perceiving the ill parents as helpful, support from others, self-reliance, peace of mind, and having opportunities to escape. Other protective factors experienced by this group of adolescents which had been described by the literature before were emotional competence, organized home environments, and active coping.<sup>3</sup> Adolescents in this study mentioned additional protective factors such as self-reflection and spending time being aware of the situation. As mentioned in previous research, the capacity of an individual to adapt to challenges depends on the relationships with others.<sup>17</sup> Informal social support from friends and family were described in this study as important; however, professional sources of support from therapists were also included as valuable sources of support for adolescents.

Very unique to the experience of these adolescents is the access to information about the illness; however, adolescents required different levels of information. It was not uniform. Another peculiar protective factor that these adolescents had was their trust in treatments and the medical team that was taking care of their mothers. This provided them with the reassurance that their mother was going to recover, particularly because the diagnoses were not terminal.

Adolescents in this study also strived to keep "normality" in their daily lives and activities; however, they still needed to carry out changes and adaptations to those normal activities in a new environment and under new circumstances. These changes were, therefore, individual and environmental transformations to accommodate the new circumstances and return to a level of functionality similar to the one they had before the cancer diagnosis.<sup>16</sup> Some of the risk factors identified in this study were the opposite to protective factors including lack of family communication, emotional suppression, perceiving the ill parent as unhelpful, feeling help- less, and concerns about future losses and barriers to closure.<sup>2</sup> Adolescents in this study particularly struggled to handle their emotions as they were not the sick ones even though maternal cancer had a significant emotional impact on them. Adolescents in this study emphasized the need to avoid isolation. Two risk factors were also very unique to the maternal cancer experience. Some adolescents struggled to cope with hospital settings and did not like to go to them and felt nervous. Negative preconceptions about cancer were also a challenge for adolescents to cope with as their experience of cancer was linked to death and not accounts of survival and treatment success. An important finding of this study is that all adolescents had a unique set of protective factors and/or risk factors; however, most of them could adapt to maternal illness and identified positive outcomes from the experience. This is in line with previous research which has suggested that there is not a unique or "right" path to resilience; there can be several.<sup>19</sup>

Resilience in adolescents experiencing maternal cancer needs to be understood in the context of time and the course of the illness, as this study found adolescent's initial reaction to maternal illness changes over time, but it is also influenced by the different stages of the illness: diagnosis, treatment, and recovery. At the time of diagnosis, adolescents struggle to deal with the diagnosis, and there is no evidence of successful adaptation or

normal functioning; adolescents, instead describe how they are not aware of their capacity to cope. This is in line with previous research which suggested that all individuals possess resilient characteristics; however, these may only manifest in the face of adversity.<sup>28</sup> Over time, individual, social, and environmental protective factors are used to adapt to the diagnosis, and adolescents themselves feel that they have coped successfully; however, treatments and drastic changes question adolescent's "normality" introducing worry and concern in their lives again. The importance of time has been identified by previous research where resilience was described as a capability that changes over time which is also enhanced by protective factors in the individual and their environment.<sup>29</sup> Masten and Monn<sup>19</sup> have coined the term "*adaptation pathways*" to refer to the "*ups and downs*" of adaptive success, breakdowns, and recovery or any fluctuations in the adaptive course of an individual over time. Pathways that lead to positive adaptations following significant periods of challenges can be described as path- ways of manifested resilience.<sup>30</sup>

Another important finding of adolescent resilience when they experience maternal cancer is the need to explore adolescents' experiences beyond maternal cure; even though mothers were successfully treated, adolescents continue to experience difficulties. Maternal return to health is another challenge for adolescents as it required of their adaptation to another "*normality*" where their mothers did not require as much support as when they were ill. Over time, adolescents also experience fear and worry of cancer returning which questions adolescent return to normality. Even though maternal cancer can have positive outcomes that contribute to their reintegration, returning to normal functioning requires time beyond mothers' return to health. The fear about future loss and barriers to closure have been identified as important barriers to the development of resilience<sup>2</sup> which suggests the need to support adolescents to overcome this barrier when they experience maternal cancer as this may leave them in a position of vulnerability into the future and would reduce their capacity to adapt. Masten and Barnes<sup>17</sup> have defined resilience as a "*adaptive capacity*" at a given time and context; however, this capacity can be accessed for current or future challenges that an individual may be facing. Therefore, ensuring the development of resilience is a useful capacity for adolescents to have during maternal cancer and into the future.

From a positive youth development approach, this study found that adolescents are autonomous and can make conscious decisions of taking the "positive route" towards resilience and positive out- comes.<sup>2</sup> Positive Youth Development is based on the principle that every young person has the capacity for healthy and positive development.<sup>31</sup> Resilience has been described as a contributor to positive youth development,<sup>3</sup> and this is evident in adolescents' self-reports of gains from a difficult experience such as maternal cancer including positivity, maturity, a more positive outlook of life, appreciation for loved ones, and family closeness. A positive outcome which was very unique to this group of adolescents was an increased understanding of the seriousness of an illness like cancer and having empathy towards patients and their families.

This study provides a detailed exploration of the role of resilience in adolescents' lived experiences of nonterminal maternal cancer, which can provide a more in-depth understanding of the reasons why there are conflictive findings in the literature regarding the impact of parental cancer on adolescents. Some adolescents can cope and adjust successfully to maternal illness, but others struggle significantly.<sup>5,12-14</sup> Resilience may be a key concept for adolescents' successful adaptation to maternal cancer.

Regarding limitations, this study was cross-sectional which means that the developmental understanding of resilience in adolescents experiencing maternal cancer is limited. Research has suggested that longitudinal analyses may be more appropriate to identify growth and development.<sup>31</sup> Additionally, one of the criticisms for resilience theory is the fact that it is unclear as to how long it takes for negative or adverse experiences to impact on an individual's resilience.<sup>32</sup> As specific events may be more suitable than others to facilitate

resilience capacity,<sup>32</sup> comparative research may help to further understand the impact of maternal cancer on resilience capacity in adolescents.

Another limitation of this research is that it only included adolescents whose mothers were experiencing a nonterminal diagnosis so the role of resilience identified can only be understood for a specific group of adolescents. Further research is required to understand the role of adolescents' resilience at the time of maternal terminal cancer.

This study did not consider age differences and gender differences in the analysis, as the sample was qualitative and small. Research has suggested differences by age and gender in resilience, for example Hu et al<sup>28</sup> suggested females are socialized differently and may have lower levels of a sense of mastery and self-efficacy than males.

Another important limitation of this research is the lack of a definite set of indicators to define positive development and resilience. Different criteria such as adaptation, competence, success, absence of symptoms, success in life, and academic achievement have all been used as possible indicators<sup>19</sup>; therefore, the evidence of positive adaptation and coping identified in this study may not be the most thorough criteria, and further research in the field is required to define indicators of resilience capacity in this cohort of adolescents in these circumstances.

## 5. CONCLUSION

Overall, this study found resilience as dynamic, as it changes over time for adolescents that experience maternal cancer. These changes and adaptations are a result of the changing course of maternal illness and the different stages of the illness and its treatment over time. Adolescents have the ability to adapt to change, but this capacity is shaped by protective factors and risk factors in adolescents and their environments which may go through changes over time and also challenges that are very unique to having a mother diagnosed with cancer. Balancing protective and risk factors can be understood as the process of resilience to allow adolescents to return to normality or adapt their normality to the new circumstances they found themselves in due to maternal cancer. This finding is in line with the definition of resilience by Masten (<sup>33</sup>, p.10) where resilience is defined as the capacity of a dynamic system to adapt successfully to challenges or disturbances that threaten its function, viability or development, system being an individual, family, or an ecosystem. Most adolescents managed to navigate successfully through maternal cancer and were able to identify positive outcomes from a difficult and life-changing experience. It is also important to consider adolescence as a developmental stage and the impact this may have on resilience; Hu et al<sup>28</sup> explained that young people are less able to experience resilience, as they may need a longer-term adaptive solution than adults. Therefore, it is important to provide long-term supports for adolescents and carry out longitudinal research to understand the trajectories of resilience in adolescents who experience maternal cancer, particularly to understand those that did not report positive outcomes or struggled to adapt. Overall, this study suggests that resilience has a crucial role in adolescents' experiences of maternal cancer.



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