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Adolescent adjustment to maternal cancer: an interpretative phenomenological analysis (IPA)

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Abstract

Purpose – As an Interpretative Phenomenological Analysis (IPA), the purpose of this paper is to provide an in-depth understanding of adolescent experiences of maternal cancer to identify the individual and contextual factors that shape adolescent experiences and evaluates the potential applicability of the Family Ecology Model to the illness context.

Design/methodology/approach – This analysis is focussed on three female adolescents who completed semi-structured interviews, which were subjected

to IPA. Maternal illness is a challenge for adolescents, which can be improved or undermined by their contexts. The analysis yielded three sub-themes: family structure, social supports, experiencing maternal cancer at a time of transition and the lasting impact of cancer.

Findings – This study found that adolescent experiences of maternal cancer depend on their contexts from an ecological perspective the type and quality of adolescent interactions determine coping and adjustment. Maternal cancer can be difficult as adolescents are already facing specific developmental challenges. Future research can benefit from adopting an ecological perspective to further understand adolescent experiences to support adolescent that may be more vulnerable and benefit from additional supports. This is not a generalisable piece of research but it provides a very deep and detailed understanding of the impact of maternal cancer on adolescents' developmental course and determines how the complexity of their contexts can serve as a risk or a protective factor at this challenging time.

Originality/value – This paper contributes to the body of research by providing a comprehensive understanding of adolescents facing maternal cancer. The Ecological Model supports the findings of this research and proves to be a good model to understand the complex interplay between adolescents and their environments when facing a difficult challenge like maternal cancer is.

Keywords IPA, Adolescents, Ecological model, Maternal cancer

Paper type Research paper

Introduction

This study contributes to the body of knowledge by providing a phenomenological understanding of adolescent experiences of maternal cancer. These experiences were shaped by individual and contextual factors. The analysis is informed by the Family Ecological Framework using Interpretative Phenomenological Analysis (IPA), as this method is focussed on ascertaining how people make meaning of their life experiences (Pietkiewicz and Smith, 2012). Parental cancer can be a stressful situation for young people as there may be changes in the parent-child relationship and interactions, as well as the fear of possible parental death due to the illness (Su and Ryan-Wenger, 2007). Some adolescents self-report more difficulties and emotional problems (Giesbers *et al.*, 2010) and they may face more caregiving tasks while balancing their own developmental needs such as identity formation and puberty (Sieh *et al.*, 2010).

Psychosocial impact of parental cancer

Children and young people are significantly impacted by parental cancer; they experience more psychosocial problems, internalising difficulties, psychological issues and posttraumatic stress disorder, compared to their peers (Morris *et al.*, 2016). Particularly vulnerable are those who also react with anxiety, and specifically daughters of parents facing a recurrent diagnosis (Huzinga *et al.*, 2005). Anxiety, depression and reduced self-esteem are symptoms experienced by young people (Morris *et al.*, 2016; Shallcross, Visvanathan *et al.*, 2016). Cancer poses challenges for adolescents

as some may feel worried about inheriting the disease, recurrence and uncertainty as to parental recovery (Davey *et al.*, 2003; Morris *et al.*, 2016).

Previous psychological research has found no differences between adolescents experiencing parental cancer and those who were not. Vannatta *et al.* (2010) evaluated family functioning, internalising and externalising problems and psychological symptoms and found no differences between both groups. Other studies have found that the majority of young people experiencing parental cancer cope successfully, but some report psychosocial problems (Krattenmacher *et al.*, 2012). Studies have also reported positive gains from the experience such as maturity and appreciation for other people in their lives (Davey *et al.*, 2005). Being an adolescent at the time of maternal cancer can be challenging, the developmental implications of adolescents' experiences are further explored in the following section.

On the other hand, studies have identified reasons why some adolescents cope successfully and others struggle. Some of these skills are individual including young people's ability to cope with stress, vulnerability to distress, resilience, ability to deal with emotions and gender (Edwards *et al.*, 2008; Jantzer *et al.*, 2013). Other resources are part of adolescent ecologies including family functioning, family cohesion and social support (Costas-Muñiz, 2011; Forrest *et al.*, 2009). These studies explore individual and contextual resources, otherwise ecology, which can explain differences in adolescent experiences. None of these studies was focussed on a Family Ecological Framework, which suggest that the potential use of this theory to understand adolescent experiences is under recognised to date.

Developmental impact of parental cancer

Research has described adolescents as being vulnerable at the time of parental cancer as they face conflicting demands, such as a developmental need for separation from the family and their need to establish relationships outside their families (Visser *et al.*, 2004). Time is a relevant component of Family Ecology. Chronosystems examine the impact of developmental changes and continuities in a person's environment over time. There are normative transitions[1] such as school entry and puberty. Non-normative transitions can be death or illness (Bronfenbrenner, 1986). These transitions can have an impact on developmental changes. Adolescents can respond to maternal cancer with strength, resilience, hope and provide for their ill mother while at the same time they still require limits, nurturing and security (Compas *et al.*, 1994) and a continuous connection with their mother (Davey *et al.*, 2005). Parental cancer can be a vulnerable and isolating experience for adolescents as it is contrary to demands associated with their developmental stage, which include a need for security and development of self-identity (Finch and Gibson, 2009). Additional caregiving roles and responsibilities can deprive adolescents of engaging in social activities and relationships (Pederson and Revenson, 2005).

Family structure and adolescent experiences of parental cancer

Previous psychological research has described the impact that cancer can have on adolescents when they are facing parental cancer and how family structures impact on these experiences. Children from families categorised as “well-adjusted” were more satisfied with how they coped with cancer as they

were able to cope with problems, provided mutual support and managed to shift their roles to fit the illness demands; “poorly adjusted families” instead grew further apart (Hilton and Elfert, 1996). Higher levels of family unity and open communication between family members resulted in less conflict and less symptoms of depression, anxiety and hopelessness (Costas-Muñiz, 2011). According to Hilton and Elfert (1996), families with adolescents can experience a “turmoil”, more so than other families, but Vess *et al.* (1985) reported that families with younger children experienced less conflict and had a more effective reallocation of roles. The impact of family structure is not clear in the literature, which suggests the need to explore in further detail the impact of family ecology on adolescent experiences.

The family ecology model

Family Ecology (Bronfenbrenner, 1979; Pederson and Revenson, 2005) was selected as the supporting theoretical framework for this analysis. Family Ecology Theory is the study of the interdependence and interaction between family, individual family members and their environment (Fiss *et al.*, 2013). The family ecology emphasises the biophysical environment and particularly the concept of adaptation compared to other family systems theories (White *et al.*, 2015).

Tudge *et al.* (2009) described the four elements that make up this model: “process”, “person”, “context” and “time”. The “person” component consists of the biological, genetic and individual aspects that the person brings to any situation. The “context” component is divided into four aspects: The

“microsystem” is the environment where people spend the majority of their time (school, home); The “mesosystem” are the interactions between “microsystems”; The “exosystem” are indirect influences that have an impact on development even if the person is not actually situated there (e.g. maternal work causing stress on the child); and The “macrosystem” is the extended culture or social group that determine beliefs and lifestyle. The “chronosystem” is defined as the developmental history of an individual, including the developmental impact of events and experiences (White *et al.*, 2015).

The Family Ecology Model has been used to understand how contextual factors have an impact on individuals and families. It has been applied to understand different circumstances including relationship conflict, parental divorce, adaptation of newly single parents (Demo *et al.*, 2005). This model has also been used to understand the development impact of illnesses in children with cerebral palsy (Fiss *et al.*, 2013) and with primary headache (Napoli *et al.*, 2002). Pederson and Revenson (2005) designed an application of the Family Ecology Model to chronic illnesses, however, this model has not been fully evaluated empirically. The model suggests that illness affects family functioning and has an impact on stigma, physiological stress responses, distribution of roles and responsibilities in the family and daily routines. These processes can interact with each other and have an impact on family functioning and adolescent wellbeing. These studies suggest the potential use of the Family Ecology Model to understand how family and the environment interact with individual characteristics to determine illness experiences.

Interpretative phenomenological analysis

IPA (Smith *et al.*, 2009) is a qualitative, experiential and psychological research approach, which focusses on how people make sense of major life experiences. It examines detailed human lived experience, where participants are situated in their context and their personal perspectives are explored. Smith and Osborn (2007) explained that IPA could be particularly useful when the topic of interest is dynamic, contextual and subjective; under-explored and also for topics related to identity, the self and making sense. IPA is, therefore, a suitable method to understand dynamic individual and contextual elements interacting to explore lived experiences. IPA, as an idiographic method is characterised by small samples (Pietkiewicz and Smith, 2012; Hill *et al.*, 2009). IPA can be used to provide in-depth analysis about a participant's experience. In this case, for data triangulation, three interviews were purposefully selected from a larger pool of interviews to provide a detailed account of participants' experiences. These three interviews were purposefully selected as they were longer and more detailed compared to other adolescent accounts and therefore it was possible to provide a more in-depth understanding of their experiences.

IPA has been widely used to explore experiences of people with cancer, particularly from the perspective of the ill person including adult (Hill *et al.*, 2009; Holland *et al.*, 2016), child (Griffiths *et al.*, 2011) and adolescent populations (Al Omari *et al.*, 2016). The method has been less used to explore the experiences of other family members at the time of illness; some have explored dyad experiences (Antoine *et al.*, 2013). Stanescu and Romer (2013) explored the coping strategies of adolescents with a parent living with brain injury, but this is the first study using IPA to specifically

target adolescent experience when their mothers are diagnosed with cancer.

The objectives of this study are: to provide an in-depth understanding of adolescent experiences of maternal cancer to identify the individual and contextual factors that shape adolescent experiences and contribute to the understanding of individual differences in coping and adjustment processes; and to evaluate the potential use of the Family Ecology Model to understand adolescent's experiences of maternal cancer from a phenomenological perspective (IPA) and determine the applicability of this theoretical framework to the illness context.

Methods

Design

This research was part of a larger study focussed on understanding adolescent adjustment to maternal cancer, specifically the personal experiences and psychological factors that promoted adjustment (Rodriguez, 2016; Rodriguez, 2018). This study used mixed methods. The quantitative phase was completed by 40 adolescents with 15 adolescents completing semi-structured interviews. Three of these adolescents were selected to carry out an IPA (Smith *et al.*, 2009).

Recruitment and sample

Participants for the larger study were recruited via two methods. First, mothers of adolescents attending cancer support centres and breast centres

were provided with information about the study and they informed their adolescents. Adolescents also self-recruited through university student distribution emails. This study was fully approved by the NUI Galway Research Ethics Committee. All potential participants received information sheets and consent forms. Careful consideration was given to the ethical implications of this study as the researcher was aware of the sensitivity of the topic addressed.

A total of 15 adolescents agreed to complete semi-structured interviews with the main researcher. Three interviews were purposefully selected for this analysis, as they provided the most detailed accounts of how adolescent contexts and ecologies had an impact on adolescent experiences; these three interviews were examples of the most challenging experiences faced by adolescents. These participants were selected also because they shared similar demographic profiles, age and gender (Pietkiewicz and Smith, 2012). They were also going through the developmental transition of going to university when their mother was ill.

These three interviews belonged to Fiona, Caroline and Barbara (Table I). Names have been changed to protect confidentiality. Fiona and Caroline were 17 and 19 years old, respectively, at the time of the interview. Both moved away from home to begin their university experience almost at the same time they were informed about their mother's diagnosis. Barbara was 20 years old and withdrew from university to take care of her mother. Barbara and Fiona's mothers had a breast cancer diagnosis and their interviews happened two years after diagnosis.

Data analysis

Participants talked about their experiences of maternal cancer including the availability of supports, coping mechanisms and difficulties encountered. Interviews were transcribed and analysed by the main researcher using IPA. Smith *et al.* (2009) proposed a series of steps to carry out an IPA analysis. Analysis began with reading the transcripts to become familiar with them, followed by initial noting of semantics and language use in a descriptive, linguistic and conceptual manner. Exploratory notes became emergent themes that were subsequently analysed in light of the proposed theoretical framework: family ecology. This process was repeated with each transcript. After this, a “compare and contrast” process was carried out to identify similarities, discrepancies and patterns across the three transcripts. Emergent themes were reorganised to produce super-ordinate themes. This process was audited by an external researcher with expertise in IPA.

This paper focusses on one of the two themes that emerged from the analysis, “Illness: a family experience”. This theme describes maternal illness from an ecological approach, understanding the impact that maternal cancer had on the individual but also on the context that adolescents were in, including the illness itself, family, friends, university, external supports and hospital settings. The other theme, “Becoming my mother’s mum”, is focussed on adolescent caring roles from an individual perspective and is reported elsewhere (Rodriguez, et al., 2016).

Results

The theme Illness: a family experience describes how there was a consensus that maternal cancer is a very challenging experience. Adolescent

experiences differ in terms of family structures and communication, social support, development and the lasting effects of cancer. These aspects of adolescent environments lead to differences in adolescent experiences.

Family structure

Family structure was an important determinant of the three adolescents' experiences. Some factors such as "open communication [2]" in the family facilitated the process of adjustment to maternal cancer. Barbara's family was separated at the time of maternal cancer. Her father and sister had left the household prior to the maternal illness and were not involved in the family adjustment process. In the case of her sister, she used negative terminology of deficit (didn't, couldn't, never): "[...]my older sister didn't help in the end because she just couldn't deal with it so we never really hear from her, she didn't come over" (Barbara). These examples illustrate that communication in Barbara's family was comparatively limited and less open than in the other two families. Furthermore, she was unable to express herself to avoid upset and sensitivity particularly with her mother. Barbara described herself as her mother's "listener" but this was not reciprocal, "She is highly sensitive about the whole subject so I try not to cause any grief about it. I just listen to her if she needs to talk about it [...]" (Barbara).

Table I.

Irish adolescent interviews- sociodemographic data

Interview	Interview Type	Gender	Age	Cancer type	Time in months since diagnosis	Interview length
5	Face to face	Female	17	Breast	18	31:08
11	Face to face	Female	20	Breast	25	34:21
12	Face to face	Female	19	Gastrointestinal	14	56:18

Fiona described that cancer did not change the dynamics of her family in a negative way. For her, it could be considered as a positive because she described her family as being “good” yet not “traditionally close” before the diagnosis. The illness brought them closer as a family, even though it was a “bad” way to achieve it. Prior to this, she did not have a particularly close relationship with her sister. While the illness did prompt a mutual concern for their parents’ wellbeing, it did not bring them closer as sisters: “It brought us closer a little bit like to be more supportive of mum and dad a bit but me and my sister really didn’t change anything” (Fiona).

Like Barbara, Fiona had limited sources of communication, mainly because she did not have anybody to talk to in the family, as she did not have a close relationship with her sister or her father. Fiona also filtered the information she shared with her mother to avoid worrying her. Two years after the diagnosis, this interview was the first opportunity to share her experience with another person:

I’ve never spoken to anyone about it properly apart from my mum but I wouldn’t tell her half of this so like (yeah) I didn’t want to worry her more and I don’t talk to my sister much yeah and my dad is nothing like an emotionally open person so I wouldn’t really haven’t talk this much with

anyone (Fiona).

By contrast with the other two participants, Caroline's family members were supportive of each other. Here she uses terms that refer to a connection and nurturing relationship (looking after, being there, and keeping an eye):

[...] just generally looking after [...] and just being there for her, my father and I suppose my siblings, even to some extent and I suppose her parents, my grandparents just keeping an eye on them too for her cause she would be a carer for them a lot too (Caroline).

Caroline, as opposed to the other two young people, was allowed be involved in family decisions about maternal treatment, which may have given her a sense of control and an opportunity to express her opinion.

Another aspect of the family context that affects adolescent experiences is the role of the father. Caroline described that she had a very supportive father and this helped her cope:

"[...] my father would have treated me with a lot of respect, he used to tell me that he was very proud of me [...] he was treating me like I could comprehend as if I was an adult [...]"

(Caroline). Fiona described that her father could not be a source of support to her at the time of maternal illness as he was struggling to cope with the situation himself. "[...] my dad is

just like short tempered and like he doesn't cope well with change with stuff and he can stress out himself quite a lot" (Fiona). Barbara's father was not part of her daily life anymore and this caused more distress to her than the other two participants, "My dad was already gone at that stage".

Social supports

Social supports were important for the three adolescents, particularly for Barbara and Fiona who lacked strong family supports. Barbara had three sources of external support: a neighbour, an aunt and friends. The first two of these offered transient support. Her neighbour's support was focussed at the time of diagnosis disclosure, but mentioned she lacked support at the time of treatment. Barbara particularly appreciated her aunt's help, as she had travelled from another country to help them, but again this was temporary. Barbara's best friend and roommates were essential as an ongoing support, as she described that they supported her and let her express herself. Barbara also had a boyfriend, but could not talk to him about maternal cancer as he had struggled with his own cancer experience previously:

[...] my aunt came over [...] at the time when she was diagnosed I didn't really have many people [...] but when my mum went through chemo I had a lot of support through like my roommates and stuff, they were very good with it (Barbara).

Like Barbara, Fiona also described her friends as essential in her coping process. Fiona was going through a transition between old and new friends as she had moved away from home to attend university. The support provided by her university friends was appreciated, mostly when they understood her. Fiona decided not to inform all of her friends, to avoid having people constantly asking her how she was doing. She needed space even from those friends who she had told about her mother's illness:

I'd made really good friends last year they [...] would come up to my room and knock on my door and [...] I just stayed in bed and pretended I wasn't

in [...] They said we knew and I was like well how did you know? Sometimes we heard the radio or the music being switched off and I was like yeah well, they understood totally [...] (Fiona).

Two of the adolescents availed of formal counselling as a form of social support. Barbara described that during maternal treatment she went to a university counsellor for help. Caroline also decided to seek professional support when she identified the “warning signs” in herself that the experience was becoming difficult to handle on her own:

I would have an awful lot of emotions to deal with and that I would need that extra bit of support so my mother going through this experience made me go and seek that support from student counselling [...] I kind of recognised the signs in myself and I took the steps [...] (Caroline).

Experiencing maternal cancer at a time of transition

All three adolescents shared the experience of joining university at the time of their mothers’ illness and moving away from home. Each of them experienced this developmental transition quite differently and adjusted to different degrees. The critical question for them was whether they were able to embrace this developmental transition in the midst of family illness and turmoil. Each strived to adjust to the developmental demands that this brought, but Caroline was the only participant who could balance the demands of university with the maternal illness. She had the most family resources available to her. Fiona and Barbara struggled with adjustment, culminating with Barbara withdrawing from university. She described having to provide support to her

mother at a time when she herself needed help with her own adjustment:

I was going through a lot when I first went into University, I don't think I was prepared for it at all but I didn't really talk to my mum about that anymore, like I really just tried to help her (Barbara).

Fiona had travelled far from home to attend university. She felt a conflict in being away from her mother at her time of need. This prompted her to withdraw from others, feeling set apart from her peers and struggling academically; this had a knock-on effect on her experience of college life. She describes here the confluence of stressors that made things difficult for her, a set of factors that had a lasting impact as she found in her second year:

I wasn't going to class so that made me feel even worse cause I was falling behind with school [...] My [...] teacher was getting very frustrated with me and I just felt like everything was going wrong and this is not how it is supposed to be. I felt guilty for being away, I felt guilty [...] it affected like my whole first year at least as if as domino effect it affected my second year [...] like freshers and all that stuff we were supposed to be just having fun and meeting loads of people and getting drunk and stuff [...] (Fiona).

Compared with Fiona and Barbara, Caroline's adjustment was relatively seamless. There is only evidence of one day that she was not able to attend university: "[...] that Thursday I went home with my parents and I didn't feel able to go to university the next morning cause I was so alarmed at the state that my mother was in [...]" (Caroline).

The lasting impact of cancer

The pattern of adjustment seen in the earlier sub-themes was reflected at the time of the interview. Both Barbara and Fiona spoke of continuing challenges, whereas Caroline described her life as getting back to normal. Barbara explained that though cancer treatment had finished, illness demands continued to impact on her life. Her experience of the aftermath of maternal cancer was one of continuing destabilisation and struggle: “then after treatment I think it’s like people expect, people do better but they are not, they are still so sick and so upset about everything, you know, they are not better, I don’t think”. Barbara also described that her mother was still struggling: “[...] she is really self-conscious and I think that she feels like her womanhood is gone [...]”.

Caroline instead believed that her mother was getting back to normal and was “back to herself”. She was able to identify positive gains from maternal illness in her life. She explained that cancer changed her perspective on life and increased her appreciation for her mother. Cancer also improved relationships in her family: “It’s opened things up to talk about emotions more, It’s open things up about being more sentimental and it has made us closer, very much so”. This is an interesting finding as Caroline’s interview took place close in time to her mother’s diagnosis, which would suggest that she had less time to process the experience and yet had a positive outlook.

Fiona did not describe major psychological or physical changes in her mother, except for a secondary physical effect to her arm following lymph node removal surgery. Fiona’s major concern seems to be the possibility of recurrence as her mother is older than mothers of her peers, which may mean

she would struggle to overcome cancer again. Fiona used “terrified” twice in the same sentence to emphasise her current state but also she seems to have a negative outlook to the possibility of her mother having cancer: “It’s going to go wrong [...] I am terrified of it coming back [...] she is 63 now so [...] I know in my heart that that would be it” (Fiona):

I can’t know if it would have made a big difference at the time because now I’ve had enough time like to gather my thoughts about the whole thing [...] for my own well-being it probably would have been good but at the time, in those first two months or so mmm [...] I don’t know (Fiona).

Discussion

This study used the idiographic nature of IPA as a qualitative method to explore three adolescents’ experiences of maternal cancer to derive both common and distinctive elements. Their accounts illustrated the impact of relationships between family members, social support and developmental timing on the adolescents’ ability to adjust [3] to the disruption posed by cancer. Although each had come through the experience, the degree to which they were able to draw on family resources and other social supports had an impact on their ability to accommodate their own developmental transition. At the time of the interview, between 14 and 25 months post-diagnosis, similar patterns of adjustment were echoed in the adolescents’ accounts of their current status. These findings suggest the need to incorporate ecological models of family functioning and developmental transition to

better acknowledge the importance of these determining factors. This study draws attention to the Family Ecology Model (Bronfenbrenner, 1986) as a framework that can accommodate how adolescent contexts have an impact on their experience of maternal cancer and the impact this event had on their development (Demo *et al.*, 2005).

According to the Family Ecology Model, adolescent experiences are shaped by their families, for example, those that had less cohesive families had a bigger burden compared to adolescents from families that were able to communicate more openly with each other and share the caring burden. Previous research has suggested that the diagnosis and treatment of cancer is a stressful situation for patients and their children, the condition of one family member influences the condition of the others (Huizinga *et al.*, 2011; Su and Ryan-Wenger, 2007).

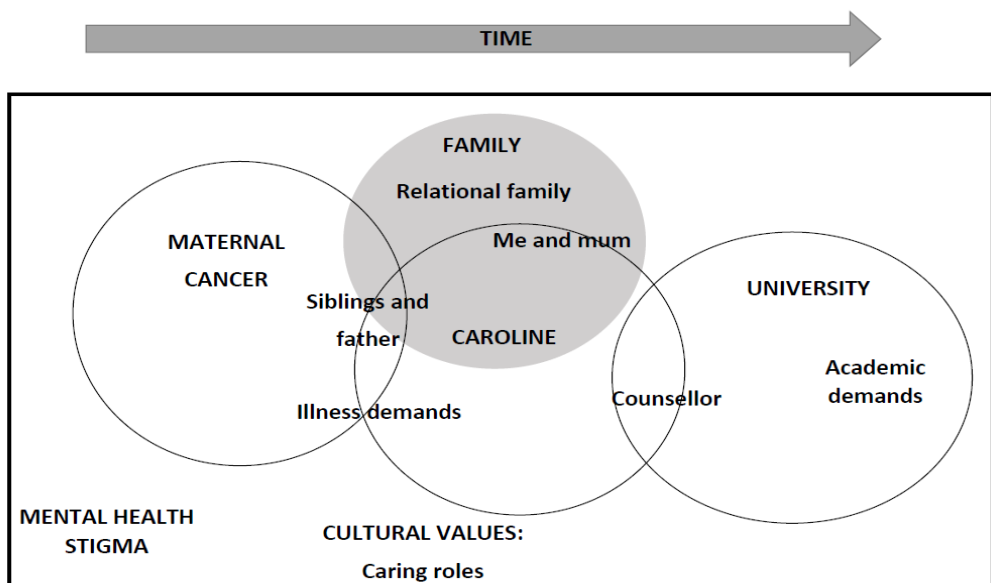
According to the Family Ecology Model, microsystems are the immediate surroundings of a person (Bronfenbrenner, 1986), and consists of their roles and relations (Demo *et al.*, 2005). Adolescent microsystems in this study were composed of their friends, nuclear families and extended families. These microsystems were reflected in the sub-themes on “Family Structure” and “Social Support”. From a Family Ecology perspective, microsystems were essential sources of support for adolescents. Pederson and Revenson (2005) have suggested that social support enable young people to use coping strategies more effectively by reducing emotional stress, increasing understanding of the problem and increasing motivation to take instrumental action. The role of fathers has been previously described as crucial. Fathers can keep the family systems functioning, take over roles and responsibilities and provide emotional

support for partners and young people (Wolf, 2015). Friends in the microsystem were also important as they supplemented the lack of family support for adolescents in less cohesive families. Previous research described that friends were a source of relief for adolescents, as they provided a “protective zone” where adolescents did not have to think about the illness anymore (Huizinga *et al.*, 2011). Although friends support seems positive, Feiske *et al.* (1998, cited by Bal *et al.*, 2003) suggested that adolescents who rely on their friends as their major source of support are at a higher risk of failing to adjust[4] and suggests that the person lacks family resources for protection.

The mesosystem consists of the interrelations between two or more microsystems (Demo *et al.*, 2005). Adolescent mesosystems are described in the sub-theme “Experiencing maternal cancer at a time of transition”. This subtheme describes the interaction between adolescent University experience and maternal illness. Adolescents had to adapt to both ecologies simultaneously and only one adolescent could successfully accommodate both experiences, the other two adolescents struggled and one had to withdraw from university. This sub-theme provides evidence to suggest that adolescent’s mesosystem can be strongly influenced and strained by maternal illness. It is a source of struggle and difficulty for them and not all of them can resolve the challenge successfully.

In this study, therefore, adolescents had a similar composition in their microsystems but it was the quality of interactions in their mesosystem that caused differences in their experiences. Figure 1 shows adolescent composition of their microsystems and the overlapping circles represent the strength of their interactions in their mesosystem. In the case of Barbara,

her family and university were far apart. Her family did not provide support for her with the exception of her aunt. University was very far away from her home and she finally had to withdraw to take care of her mother. Barbara had the closest relationship with maternal illness and was her mother's sole carer and fully dedicated to fulfilling this role. In Caroline's case, circles are more balanced as she managed to successfully accommodate her experience with university and maternal illness. Her family was very cooperative and she was very close to them in a very positive way (Figure 1).



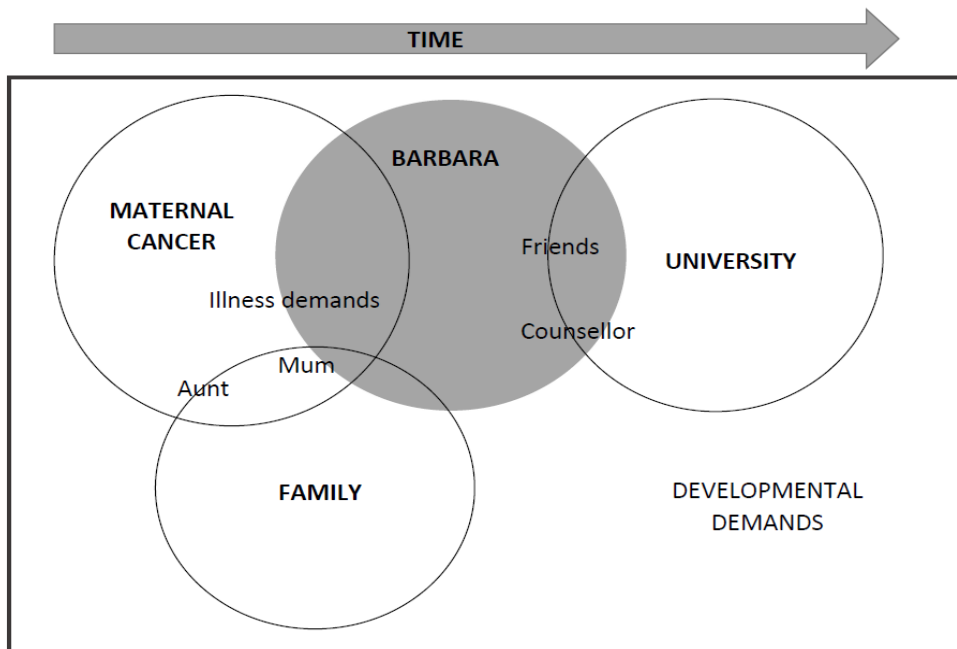


Figure 1. Examples of adolescent family ecology models

Another component identified in this study was the macrosystem which is composed of external settings and cultural values that have an impact on the individual (Demo *et al.*, 2005). The impact of the macrosystem was evident in this study in adolescents “duty of care” and their will to provide support to their ill mother and their family at this time of need. In Fiona’s case this “duty of care” translated into guilt when she was physically separated from her mother and could not care for her. This shows how strong the macrosystem can impact on adolescents’ experiences at the time of maternal cancer, even if microsystems and mesosystems interactions have been identified as having the greatest direct effects (White *et al.*, 2015).

The chronosystem is concerned with the developmental history of an individual and its effect on development (White *et al.*, 2015). In this study, the

chronosystem can be clearly seen in the sub-themes “Experiencing maternal cancer at a time of transition” and the “Lasting impact of cancer”. The experience of maternal cancer during adolescence is significant because these young people are going through developmental transitions that are demanding for them and at the same time maternal illness brings new and additional challenges (Tudge *et al.*, 2009). The chronosystem is also concerned with the trajectory of maternal cancer in adolescent’s lives over time since the Family Ecology Model view this theory as applying throughout the life course of an individual (White *et al.*, 2015). This study identified that the challenges of maternal cancer can continue beyond the completion of treatments. New challenges emerge over time, the fear of recurrence and the fear of developing cancer themselves. Adolescents need to accommodate these new challenges and continue to live with them suggesting a longer-term impact on their developmental processes (Bronfenbrenner, 1986). This may need to be explored further in future research as this study focused specifically on the first 24 months after diagnosis. Sears and Sheppard (2004) identified that adolescents struggled when their role in the family went from child to adult and they were expected to “shoulder” adult roles prematurely.

Conclusion

The analysis found that the Family Ecology Model (Bronfenbrenner, 1986) is a suitable theory to understand adolescents’ process of adjustment to maternal cancer and the impact this event has on their development. The theory identifies the areas where adolescents can experience the most challenges and struggles and the difference between those that can and cannot

accommodate them. The mesosystem in this case seems the most problematic for young people. This is relevant for practitioners as they can identify which adolescents may be more vulnerable and tailor interventions to help adolescents adjust to these demands and challenges. The analysis also found that IPA can provide a detailed insight into adolescent experiences of maternal cancer. It can also provide detailed information to complement the use of the Family Ecology Model to obtain in-depth understanding of adolescent developmental and adjustment experiences to maternal cancer.

Future research may benefit from the application of this theory to understand young people's experiences over a longer timeframe, as this study was limited to 24 months. This research could also be carried out when fathers are diagnosed with cancer to understand how parental gender can impact the adolescent experiences. One of the innate limitations of the method is that it does not achieve generalisation and, therefore, the findings are restricted to a specific cohort.

Notes

1. Normative transitions are milestones that are expected to happen at a specific age by a specific group of people in a particular culture and society, for example, starting school.
2. Open communication refers to effective communication channels that facilitate conversations between family members that are not restricted to specific topics or contents only.
3. Adjustment in this study was defined as the psychological processes that happen over time through which a person manages, learns and

accommodates multiple changes caused by changing circumstances in life (Brennan, 2001).

4. Fail to manage, accommodate changes caused by changing life circumstances.

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Appendix 1

- (1) What are you currently concerned about?
- (2) Do you have enough people in your life with whom you can talk to about these concerns?
- (3) What are your roles/responsibilities in your house?
Have you noticed changes in these roles or responsibilities recently?
- (4) Have you noticed changes in your usual activities since your mothers' diagnosis and treatment (Sports, school, family time, friends time, others)?
- (5) What activities have you done recently to relax and/or have fun?
- (6) 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?
- (7) What kind of support did you feel you needed the most?
 - Tangible/Concrete (visible, practical, like loaning a book to a friend)
 - Emotional (feelings, relationships, like talking to a friend)
 - Esteem (positive characteristics people recognise in you)
 - Advice (help with a decision or provide information)
- (8) Who informed you about your mothers' cancer diagnosis (father, mother, sister, brother, another family member, teacher, friend, health staff)?
- (9) 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?

- (10) 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)?
- (11) Have you noticed changes in the relationship with your mother since diagnosis?
- (12) Has the experience of maternal cancer made you realise who you can really count on?
- (13) Has this experience of having a mother diagnosed with cancer affected or changed people around you in ways you didn't expect or understand?
- (14) What would you recommend to other adolescents facing the same experience as you?
- (15) How can health professionals (physicians, nurses, psychologists) help you?