

RESEARCH ARTICLE

Cancer Patients' Views on the Family Changes and the Family Social Support

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When someone is diagnosed with cancer, their entire family is affected. This study investigates how patients with cancer perceive changes in their family and the types of support provided by family members. Semi-structured interviews were conducted with eight individuals with cancer (seven women and one man, average age: 55.5 years). The individuals were diagnosed with various types of cancer and had no relapses. Analysed thematically, the results showed two axes, the changes axis (positive, negative and ambivalent changes) and the support axis (emotional and practical support and support adequacy). The results revealed many close links between elements on the two axes. The limitations of the study and future research are also discussed.

Keywords: patients with cancer; family; changes; types of social support; thematic analysis

Cancer is increasingly characterised in the literature as a disease that has a significant impact not only on the patient but also on their families (Hughes, Closs, & Clark, 2009; Pitceathly & Maguire, 2003). When a family member is facing cancer, the family system is confronted with a new situation, requiring them to adapt (Kotkamp-Mothes, Slawinsky, Hindermann, & Strauss, 2005). Since cancer survivorship is increasing (DeSantis et al., 2014), a growing number of families will have to learn to cope with cancer. Thus, the long-term changes that cancer brings both on the individual and the family are of increasing importance as they affect more people.

Changes in the Family

There are a number of changes that occur in a family when a member is diagnosed with cancer. The meta-analysis of Zabalegui, Sanchez, Sanchez, and Juando (2005) showed that the diagnosis and treatment of cancer results in changes in the patient's course of life, daily activities, work, relationships, and family roles. Additionally, there is evidence that the condition of patients during cancer treatment affects many areas of everyday life, such as their family life and the way they communicate (Moradian, Aledavood, & Tabatabaee, 2012). Some of these changes could be considered positive and adaptive while others negative and maladaptive.

As a result of traumatic events (e.g. accidents, life-changing diagnosis), people often experience post-traumatic growth. That means they experience improvements in the following five areas: new possibilities,

personal strength, spiritual change, appreciation of life, and relating to others (Tedeschi & Calhoun, 1996). The latter refers to the improvement of existing relationships.

Patients with advanced colorectal cancer and their caregivers reported experiencing positive changes, such as closer relationships and more empathy for others, clearer life priorities, a greater appreciation of life and increased faith (Mosher et al., 2017). Other studies report improved communication between family members (Kotkamp-Mothes et al., 2005) and an increased involvement of the individual with cancer in family matters (Chung & Hwang, 2012). Additionally, the disruption of past dysfunctional daily routines and family roles has been reported (Buchbinder, Longhofer, & McCue, 2009). This possibly explains the increased involvement of the member with cancer in family matters, as more functioning family roles would benefit the involvement of all members. Tedeschi and Calhoun (1996) have suggested that cancer could be an experience of post-traumatic growth.

At the same time, the negative changes in the family should not be minimised. Individuals with cancer have reported that their family is affected as much as they are (Lee & Bell, 2011). A cancer diagnosis can have a negative impact on the rhythm of everyday life, future plans of the family (Woźniak & Iżycki, 2014) and on the change in family roles (Given, Given, & Kozachik, 2001). According to a qualitative meta-analysis (Boehmer & Clark, 2001), both the individual with cancer and their family feel loneliness, as the family members may suppress their emotions or needs. Thus family members may not seek support even if they need it. Some of those needs may be new to the individual with cancer (da Costa Vargens & Berterö, 2007) or new to the other members in the family.

Changes in the family have been often studied by interviewing the individuals with cancer, sometimes in the presence of third parties (see Chung & Hwang, 2012; Lee & Bell, 2011; Thorne, 1985). However, this may limit what is shared by the individuals with cancer. For example, possible comments on what the family failed to provide may not be disclosed due to fear of offending or of desire to protect.

Taking such bias into account, some scholars have opted for conducting interviews alone with the person with cancer. One group studied breast cancer survivors' quality of life across cultures (Ashing-Giwa et al., 2004). They found that cancer survivors had an overall good quality of life in terms of health, but they had some recurring concerns about health and physical problems, body image and worries around burdening the family. Chung and Hwang (2012) found that breast cancer diagnosis had caused great distress and was transformative for couples. They suggest that more research with patients' interviews is needed. It has been also reported that the impact of cancer in the life of women needs to be studied more, both quantitatively and qualitatively (Mosher et al., 2013).

Social Support

Cohen, Underwood, and Gottlieb (2000) define patients' social support as "*the social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships*" (p. 4). For patients with cancer, the family seems to be the most important source of support, as shown through both qualitative (Ashing-Giwa et al., 2004; Drageset, Lindström, Giske, & Underlid, 2012) and quantitative methods (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007). Good quality social support can help in developing adaptive behaviours in patients (Kotkamp-Mothes et al., 2005). People with strong social relationships have been shown to have lower morbidity and mortality rates from diverse diseases (Due, Holstein, Lund, Modvig, & Avlund, 1999).

Social support is a complex concept entailing various types. The three main types are: emotional, informational, and practical (Gottlieb & Bergen, 2010). Emotional type of support involves verbal and non-verbal communication of interest and concern (Hogan, Linden, & Najarian, 2002). For individuals with cancer, it has been found to encompass the expression of interest and love (Usta, 2012), physical presence (Drageset et al., 2012), and solidarity (Wong et al., 2014). Informational support includes the provision of information used for guidance or advice (Hogan et al., 2002), for example, medical advice (Wong et al., 2014). Practical support refers to the provision of material goods (Finfgeld-Connett, 2005; Hogan et al., 2002), such as help with daily activities (Hirschman & Bourjolly, 2005) and physical labour (Finfgeld-Connett, 2005).

The individuals with cancer do not always perceive social support as something helpful. Sometimes it can be considered a burden or a nuisance (Drageset et al., 2012), turning into what is known as negative support (Boinon, et al., 2014): the family provides resources to their kin with cancer, but in some cases, these resources may not be wanted.

The type and amount of social support an individual with cancer receives influences the course of the disease, their coping strategies (Kotkamp-Mothes et al., 2005), and physical adaptation (Usta, 2012). Social support also mitigates the impact of cancer diagnosis on patients' quality of life (Sammarco & Konecny, 2010). Higher family support has been associated with lower depressive symptoms in breast cancer survivors (Su et al., 2017) and with increased emotional well-being (Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2017). Larger social networks correlate with better quality of life for individuals with cancer (Kroenke, et al., 2013). The bigger a woman's social network is and the more she is integrated within it, the more emotional and practical support is available to her. Also, a woman's physical health is poorer when the perceived availability of practical support is low (Arora et al., 2007).

Present Study

After receiving the cancer diagnosis, the individual undergoes changes (Zabalegui et al., 2005) and these changes create new needs for support (da Costa Vargens & Berteró, 2007). The main support providers for the patient are their family members (Ashing-Giwa et al., 2004), who also experience various changes (Pitceathly & Maguire, 2003). In the past, the main focus of research has been on the support offered by the partner (Kotkamp-Mothes et al., 2005). There is less known about how the rest of the family supports the member with cancer. Woźniak and Iżycki (2014) concluded that other family members' perspective has not been given enough attention in this context. Furthermore, Coyne, Dieperink, Østergaard and Creedy (2017) have argued that little attention has been given to the resources the family offers to their kin with cancer, particularly whether the support is influenced by differences in settings or cultures.

This study aimed to explore the experiences of patients with cancer and their views about their family. This contributes towards a better understanding of what a person with cancer may need from their family members by studying both the changes in their family and the types of support they all provided. This allows the exploration of the closely linked elements of support and changes in the family. In other words, even though both the changes and the support in cancer have been studied, to our knowledge, no study has investigated these concepts in the same population. This is one of the main components contributing to the novelty of the study.

Method

Participant Recruitment

The researcher approached the largest society for patients with cancer and its survivors in Greece, located in Thessaloniki. After the board of directors granted permission, the researcher approached the members at the premises of the society. At the beginning of each visit to the society, the researcher made a general announcement to anyone on the premises about a study regarding family and cancer taking place. When a member of the society expressed interest in the study, the researcher explained, with the help of an information sheet, what the study was

about and what the participation entails. Before signing up for the study, the researcher discussed the inclusion criteria with them. When someone needed to be excluded from the study because of the criteria, the researcher fully explained the reasons. No participant expressed any major discomfort about being excluded from the study. The members that were included gave their contact information, which was recorded. No clinical information was collected from the participant's files. All research records were based on self-reports. The participation, which was voluntary, required no major expenses. The participants received no financial compensation nor incentives.

There were five inclusion criteria that participants needed to fulfill:

1. At least 18 years old
2. Diagnosed with cancer
3. Not having experienced relapses
4. The treatment needed to have ended at least one year before the recruitment
5. The diagnosis could not have been received more than five years before the recruitment

The third criterion was included to improve homogeneity in the treatment stages of the participants. The last two criteria were included firstly to address limitations of past studies (e.g. Mosher et al., 2017). Secondly, it was to reduce the chances that participants would have to share their experiences at the time of undergoing potentially sensitive changes. The final criterion also helped to ensure the cancer survivors would still remember enough details from the time of the diagnosis and treatment.

Procedure and Data Collection

Qualitative methodology was chosen because it allows us to capture the unique needs of patients and their families (Malagon-Maldonado, 2014), taking into account the diversity of the participants' background and experiences. Interviews—especially if they are semi-structured—give the individual with cancer a chance to share their experiences more freely compared to more structured forms of data collection, for example, structured interviews or questionnaires.

This research was conducted under the code of ethics of the Association of Greek Psychologists (Association of Greek Psychologists, n.d.), part of the European Federation of Psychologists' Associations. Additionally, throughout the research project, the researcher consulted with the cancer patient society, particularly with its president, the board of directors and the staff psychologist. These discussions were used to define the interview schedule and design the optimal procedure for conducting the data collection. They all approved of the final procedure and the interview schedule before the interviews took place.

The participants were interviewed alone to address limitations of previous research (e.g. Woźniak & Iżycki, 2014). The researcher conducted the interviews in the society's premises, with the exception of telephone interview at the request of the participant. The researcher has extensive experience with individuals with cancer. All interviews

took place within a timespan of two months, starting from the first call for participants and ending with the last interview. Before the interview, the researcher phoned the participants, to confirm they were still interested in participating. Everyone affirmed their interest and then an appointment was made. The facility was familiar to most participants and the researcher expected that there they could express themselves freely since there was no possibility of anyone, family member or otherwise, to listen in on the interview. The same conditions were requested to be in place for the telephone interview.

All participants were informed about the purpose of the study and the guarantee of confidentiality. Both the researcher and the participant kept a copy of the informed consent form, signed by both parties. The data were collected through semi-structured interviews, which were all audio recorded. At the end of each interview, participants were asked about the interview experience and all of them spoke highly of it. This experience has also been reported in previous studies (see Colbourne & Sque, 2005). The duration of the interviews ranged from 12 minutes to 1 hour and 25 minutes, with an average of 41 minutes. All electronic records were kept in a password-protected file. The audio files were erased after the transcription was finalised. Any personal information on the transcribed scripts was pseudonymised at the earliest opportunity. The interviews were conducted and transcribed in Greek. The researcher undertook all necessary translations needed for publication purposes.

Data Analysis

A constructivist/interpretivist epistemological position was adopted (Robson & McCartan, 2016). In the context this study, this means that the reality of the individuals with cancer is derived from their everyday experiences and the views they hold about those experiences. This position also means that the interaction between the researcher and the participants would inevitably affect the findings. All analysis was conducted by one researcher. Although the researcher adopted a semi-inductive approach, allowing the data to guide the emerging themes while being aware that research is not conducted in a "*scientific vacuum*". The researcher also acknowledges it is difficult to be entirely impartial from theory or previous studies and thus the process may have had some deductive influences.

The interviews were analysed using inductive thematic analysis (Braun & Clarke, 2006). Interviews were transcribed verbatim from the recordings and were checked for inaccuracies. No formal transcription method was used. It has been argued that thematic analysis does not require a detailed transcription (Braun & Clarke, 2006). An open coding approach was used, coding the semantic context, not the latent. Microsoft Office Word was used for organising the data.

There were five steps undertaken for the analysis (Braun & Clarke, 2006). Firstly, the researcher familiarised themselves with the data (during the interview and transcription and by rereading the transcripts multiple times). Secondly, the initial codes were generated by open coding (741 initial codes). Not every statement was coded, but only the ones that were related to the aims of the study,

as it is advised by Braun and Clarke (2006). Afterwards, a search for subthemes in the codes was conducted across the whole dataset (28 subthemes). The same codes could be included in multiple subthemes. The subthemes were then reviewed and altered where necessary to better describe the data. Then they were defined and named. Subthemes that described a similar matter formed the themes (six themes). Finally, these themes were grouped once again in order to develop the final axes according to conceptual relevance.

Results and Discussion

Participants

There were eight participants: seven women and one man. Their ages ranged from 25 to 69 years old, with an average of 55.5 years. All of them were white, Greek and living in urban regions. Four of them were married, one was not, two were widowed, and one was divorced. They had had various types of cancers: two had breast cancer and two had endometrial cancer, one had colon cancer, one had testicular cancer, one had adenocarcinoma and one had thyroid cancer and underwent various treatments (seven participants had had chemotherapy, four had radiation therapy and five had surgery).

The Structure of the Data

The analysis led to two central axes (changes in the family and family support), each containing three themes. The first had a total of thirteen subthemes, while the second had fifteen (see Appendix A). As it is suggested by Braun and Clarke (2006) and because not all subthemes were present in all interviews, quantity-indicating phrases have been put into place that show roughly how many participants reported a certain theme (e.g. all/most/some participants, etc.).

The two axes are connected by the underlying *needs* that arose from the changes caused by the cancer diagnosis (see Appendix B). The findings suggest that the cancer diagnosis creates changes in the family which in turn create new needs and those needs result in the provision of support, which in turn create changes in the family. According to the present findings, the social context and past experiences also influence all of these factors.

Changes in the Family

The participants reported some positive and adaptive changes in the family. These seem to help them handle the difficulties associated with the cancer diagnosis. On the other hand, the participants also described negative and maladaptive changes, which appeared to be unhelpful to the affected individual. Some changes, however, were ambivalent and could not be clearly put in either of the previous two categories because they could have both positive and negative effects. In other words, the changes hold the potential to be either beneficial or harmful, depending for example on the frequency, intensity and circumstances.

Positive Changes. Reacting well to the side effects. The family members of some participants reacted well to the treatment's side effects, either because *"they expected*

what was to come" or because *"they were not bothered by them"*. For other participants, side effects became a trigger for support in the form of humour. A participant mentioned *"[My husband] has a sense of humour. He keeps saying [about constipation] 'come on already, we are constantly concerned with your butt!'" [She laughs]*. Humour as a type of support has also been reported previously in the cancer literature (Wong et al., 2014).

Establishing new responsibilities and roles. This was mentioned by all participants, however, one, in particular, said *"there was a change [in family roles]. When disability is at play, so to speak, and you cannot be as you once were. [...] I didn't have the strength. [...] My children definitely helped me with household chores"*. This has been found in previous studies (Zabalegui et al., 2005). One participant reported that *"my daughter is obliged to look after me"*, a view that has been reported in other studies as well (Liu, Mok, & Wong, 2005). Most participants did little to no housework. Considering the gender roles, age, culture, and societal background of the participants, I believe that it is a big change in their daily routine. The need for adjustments to other family members doing the household chores has been found before (Scott, Lasch, Barsevick, & Pault-Louis, 2011), along with the difficulties it may involve (Given et al., 2001) and the possible negative reactions of the member with cancer (Hirschman & Bourjolly, 2005).

Improving the way they behaved. Sometimes during treatment family members put aside personal distractions, such as work, personal health problems, and previous tension in family relationships. A participant stated that it was likely due to them been considerate towards her and felt bad:

There were no instances of them fighting and stuff, so I thought "It's fine, OK", so they think of me because they had no quarrels between them. [...] They might be thinking about me "she was always in the middle and always felt bad and always...", they might have felt a little guilty... Just guessing now, I am not sure. They ought to [laughs].

Some participants mentioned that they themselves have changed the way they behaved to others. For example, one participant said: *"now I am not getting as angry as I used to, I try to be calmer"*. Similar findings have been noted in the research by Thorne (1985). Another participant said that due to the side effects, her family has changed and now she puts more boundaries in her family and self:

I can tell they have grown more patient. [...] I ask them to be, I want them to do stuff for me because I am easily getting tried... And they do it. [...] I have some boundaries, different boundaries. For them as well as myself. [...] I am not made of stone; thus, I now establish boundaries; they respect them and they love me.

This has been observed in other studies as well (Chung & Hwang, 2012). This could be indicating that cancer might promote self-respect.

Communicating more openly. There were also changes in the communication between members. Some participants reported communicating more openly than they did before cancer. One of them said *"I can express myself more than I used to. [...] Now I am not afraid of how people might react because I am more confident. I trust more what I might say or do"*. Similar notions have been reported in the past in a study focussing on couples only (Boehmer & Clark, 2001). A participant realised that he should express his feelings more because not doing so hurts him. What he said was *"now I understand that some things need to be said, need to be expressed. [...] Otherwise, you "hit the brakes"."*

Greater emotional closeness. The majority of the participants reported that family members, because of cancer, grew emotionally closer and warmer to each other. They overall bonded with one another over cancer. One example of this is: *"We were bonded very, very much. Because they too were hard-pressed and were sorrowed. [...] It goes without saying that we were brought closer. Them visiting and worrying, isn't this...? It showed they worried and they loved you."* An increase in the emotional closeness has been studied previously (Drageset et al., 2012).

Discretion to the participant. The emotional closeness that appeared was not characterised as intruding but as being discreet. Some families appeared to be subtle towards participants in the period of cancer treatment, *"And the kids, too, were discreet, they helped a bit... They were not talking but I could tell they loved me in their own way"*. One participant said even that *"they respected me during cancer"*. A participant stated that *"the best thing my family could do was to be discreet and to understand when I want to talk or when I want to be left alone"*.

Negative Changes. Reacting badly to the side effects. Family members were pressured, worried and even panicked. One participant described the reaction her daughter had when she saw her mastectomy:

When my daughter entered the bathroom and for the first time I was without [breast] and she saw the scar, [...] "Mum, it's just like we see in horror movies, your scar it's exactly like that". But you never stop on being a woman, you never stop to have..., [...] you do not expect to hear such a thing from anyone, a reaction like that. So I had to accept that and... And I accepted it.

This reaction may be considered as criticism because they did not accept their mother as she was. Criticism has likewise been found in past research (Moradian et al., 2012).

Denying cancer. Denying cancer can be an obstacle to providing support (Ashing-Giwa et al., 2004). In some cases, this was expressed by the fact that they did not want to see the ill member without hair; they wanted them to wear a wig. Moreover, the word "cancer" was not spoken in a participant's family. The participant said that it worked for them: *"Perhaps it suited both of us like that. Not that... [we did not know, just] we pretended that there was nothing wrong, but we were trying to lessen it as much as possible by not talking much about it."*

On the other hand, another participant wanted to be herself at home and told her family: *"This is who I am. Right now this is me, this is myself. I can't do anything to change it"*. The same demand has been reported in another study (Chung & Hwang, 2012).

Communicating less. The reduction in communication before and after cancer was sometimes initiated by the participant, their family or both. A participant said that *"there was no real communication in the family"* and another that if she talked to her husband they would not have anything good to say. *"What was there to say? Even if we talked to each other, what we would talk about?"* Withholding information has been reported in previous studies (Boehmer & Clark, 2001) as well as avoiding discussing issues about cancer (Mosher et al., 2013). Studies suggest that withholding information may be motivated by the desire to protect (da Costa Vargens & Berterö, 2007; Hirschman & Bourjolly, 2005). Oppositely, there were also some participants who spoke openly to their children about cancer and the fatigue of chemotherapy.

Division of family and non-family members. Either by hiding information or by removing non-family members from the daily life, a division was found in the results. The family may learn the truth but others may learn something beautified. *"I didn't tell it to people, what happened to me. Those close to me, of course they knew, but..."* Similar results have been found in other studies (see Ashing-Giwa et al., 2004; Hughes et al., 2009; Lam et al., 2017). One participant reported having felt more love from people not belonging to their family. However, the literature indicates that individuals with cancer with maladaptive distress are more likely to avoid peer social support than those with transient distress (Lam et al., 2017).

Ambivalent Changes. Protecting the family from the impact of cancer. Participants also mentioned their desire not to burden family members. To achieve that, they tried to be more independent in going about their activities, even concerning hospital matters; this has been found in many other studies (Ashing-Giwa et al., 2004; Hirschman & Bourjolly, 2005; Hughes et al., 2009; Kwok & White, 2014; Lee & Bell, 2011). A participant reported this by saying: *"I try to speak as much I can, to do what I can so that I am not a burden to them... But can you really?"*

Similarly to a previous study (Hughes et al., 2009), participants mentioned adopting new behaviours to protect their family. A participant describes what it took her to keep her grandson from knowing that she had cancer and how she felt about it:

I had all this stress, to wear the wig, being like, not being... THAT SIGHT... [...] It was exhausting for me, it exhausted me. I wanted to be myself, what else? Having all the other strains, you must also fill your eyebrow and apply blush and put on the wig. It was exhausting... You know for all these things, I used to say "never mind". [...] But what could I do? I had to. I went through it in this way. They used to call me on the phone "we are on our way", I had to [wear] the wig, [laughs] I had to do some things not to show what it was....

The two participants who had young children talked about intending to protect them from the impact of cancer.

Seeking solitude. Some participants said they constantly wanted people around them during their treatments. However, most indicated that they wanted for some time to be alone and isolated; one said:

I sought solitude, I sought it. In fact, I began to isolate even before that, when I started to be unemployed when I started... [...] When I started not to be like, independent, as I used to. I thought that I'm not creative, do you get it? [...] Took a big a turn for the worst [after cancer diagnosis]. It all deteriorated.

Similar reports have been found in previous studies (Pelcastre-Villafuerte, Tirado-Gómez, Mohar-Betancourt, & López-Cervantes, 2007). Nevertheless, a participant said that even if she wanted to be left alone, her family would not let her. This is probably a good example of negative support, in which the abundance of attention is burdensome.

Participants mentioned several reasons for seeking solitude. Some wanted to be independent, to be vigorous and not show their children that they suffered. One participant described:

On the day I had my surgery and when he [husband] said he wanted to visit, I said: "no, I don't want you to come". I tried to stand on my own two feet. [...] I didn't want to be a burden... I said to myself that I will be strong and I will manage on my own.

Some participants reported seeking solitude within treatments because they wanted to wind down, to behave more freely and to rest. Furthermore, individuals with cancer sometimes seek solitude in order to avoid stigmatization by others (Lam et al., 2017).

Important elements for successful family relationships during cancer. The interviews suggest that there are some factors or elements that greatly affect the participants' experience with cancer. Participants reported that it is very important for the whole family to be close, to have people that love them and for them to think of them during cancer. A participant noted they had to be genuine about it:

But the ideal would be for the family to be close. And to show they are close... Not to pretend, not to be stiff. Because the patient needs it. [...] They shouldn't be afraid to talk to each other, talking is good.

Some further important elements were honesty, authenticity, a calm home environment, asking less of the person with cancer; more help when at home and less fear were also mentioned. One participant said:

You want YOUR family... To understand you, whether in good and happy times or in difficult

ones. You expect it, you seek it. And if it is not there, I think this is when you get depressed. I was one of the lucky ones, for having support. I've met people who had nobody... That was a disaster.

Family support

The interviews revealed themes around emotional support and practical support, both of which have been reported previously (Gottlieb & Bergen, 2010). In addition to describing the support that was provided to them, the participants commented on its adequacy and helpfulness or on the lack of the latter qualities.

Emotional support. Reassuring and consoling. Some participants reported that their family was reassuring and comforting. A participant described the support they had received: "*they consoled me and said "you'll get over it" or "you'll get better, we've talked to the doctors" and "there is progress in treatments" you'll get better, do not worry"*"; this type of support has also emerged from a review of the literature (Hughes et al., 2009). A participant pointed out that consoling words should be said when the other needs them.

Expressing affection and love. Besides reassuring, the families also expressed affection and love in order to support the participants. The experiences around cancer led the family members to be more affectionate and warmer and the participants found that helpful. Cohen and colleagues (2000) have described similar behaviour. A participant said the love the family felt for her was made clear when her mother and son prayed for her. She found that this was the most beautiful thing they could do. Maintaining religious practices has been reported previously as a type of auxiliary support (Hamilton & Sandelowski, 2004). One participant summarises:

They were holding my hand and telling me, "it's nothing." Don't pay much attention, it's nothing. With these words, so easy to say, the other takes courage. [...] Rejoices, saying "Piece of cake, it's okay," because my child says so or my husband or my niece....

Expressing interest about the health of the participant.

Especially, one of the participants felt loved when her daughters took interest in learning news from her: "*my children, they were by my side, they went to the doctors, asking, doing, they very much showed their interest.*" Even members who were generally distant would ask if the participants were in any pain and how they were.

Being present. Most participants reported that the family was constantly present (for similar results see Kwok & White, 2014). The presence of family helped participants psychologically, reviving their spirits, giving them strength and willpower; a participant mentioned "*[My husband] was there for me [...] he was always present. During this entire period, he was there and would help me.*" Research on practical support has shown that it is the availability and not necessarily the use of it that is associated with mental well-being (Bloom, Stewart, Johnston, Banks, & Fobair, 2001). It is similarly believed that this is a representation

of the same phenomenon. That it is the availability (in the form of being present) that is supportive and not necessarily any actions. This is supported by the fact that even though sometimes family members were unable to help in any way, there were still on their side when the participants were in pain.

Distracting. Although the family was close, they were not always dealing with cancer. In some cases, they were distracting the member with cancer from cancer. Two participants reported that family distracted them from cancer with activities, “[My husband] would take me out, he would bring me company [...] He wanted to make me have fun, to take my mind off things. Surprises, roses, flowers, gifts he did it all...!” The daughters of another participant would take her out for a walk or lunch. Similar reports of support have also been made before (see Chung & Hwang, 2012).

Practical support. Escorting to the hospital for treatments, tests and receiving results. Similarly to Ashing-Giwa and colleagues (2004), a participant described how they were accompanied to hospital appointments: “every time I had an appointment, either my husband or my daughter would escort me.”

Visits during hospitalisation. A participant mentioned, “I am telling you, my husband would come twice a day and he would help me by being there.” Another participant reflected that her family made her better by visiting her in the hospital as the visits broke up the day. Visiting was also found helpful because family members would bring things the individual with cancer needed. The importance of regular visiting has also been pointed out in previous literature (Hughes et al., 2009).

Helping with household chores. The family support would not end with the hospital's context. Some participants mentioned that their family would help them with household chores by saying “[My mother] tried so hard to be of help. She did chores, she made lunch and dinner, she took care of the children”; this kind of support has been estimated to be one of the most important (Wong et al., 2014).

The participant supporting their family. Also, the participants themselves said they were worried about their family and looked after them (see also Kotkamp-Mothes et al., 2005; Thorne, 1985). One participant provided practical support for her pregnant daughter. Her description:

[My daughter] being that far along, as the months went by... this was hard for her. So... What was I supposed to do? Shouldn't I [help] with making lunch, and even some things concerning the little one [...] after she [granddaughter] was born I would stay up with her and stuff....

Support Adequacy. The-most-significant-other. Similarly to previous studies (Gates, 1988; Pistrang & Barker, 1995), some participants reported that one particular person has supported them more than others:

I can honestly say that it was my husband who was there for me the most [...] my son too would help.

If need be, he too would take to or from the hospital but I think that I felt that my husband was there for me the most. Not even my mother was that close to me.

For one participant, a protective “wall” seemed to have been created around him. A “wall” through which nothing harmful would pass through, whether bad news or a person that would make them feel uncomfortable. The most-significant-other would be selected. The rest of the family would be kept in some “distance”. Notably, the process by which this selection took place was not clarified. For example, it is equally possible that the member with cancer selected their most-significant-other, the former took up the role on their own or even a combination of the two and their past relationship could also be expected to influence this decision. The two of them would form an alliance and not share everything with the rest of the family, for example, details about the nature of the cancer or specifics of their negative feelings. Participants explained that there was no need to “recruit” the whole family.

Family member who was detached. On the other hand, there also seemed to be a family member that was more detached from the others:

“My youngest would come and caressed my head and... She was closer. My eldest he was in a “corner”. He always was keeping to himself [...] it was due to his worrying, what would happen, “will she live?” or “will she get over it?””

The only thing that the detached person seem to do was asking if the member with cancer was feeling alright. Being a member of the family does not necessarily mean that they will be a source of support.

The support was satisfactory. Some participants mentioned that their needs were generally met. In other words, while there was room for improvement, it was overall good. A participant mentioned that the support they received was satisfactory, pleasant and counterweighed the difficulties:

“They took care of me more. On the one hand, I would say that “oh my, this thing that I am experiencing is very bad” and on the other, I would say “look how much they take care of me.”

Positive effects of the support that balance out the negative effects of side effects have also been mentioned in a literature review (Hughes et al., 2009).

The support could not be better. For others, their family members could not do anything better, everything was more than satisfactory, it was perfect. They did everything the member with cancer could have wanted or needed. This has been also mentioned in previous research (Chung & Hwang, 2012). One participant spoke about how her family “they did everything in their power and more.”

The support was not satisfactory. Moreover, for others, the support they received was not satisfactory, either

because there was none or because the support was limited to very specific actions. A participant said:

He did so little. When the need arose he would cook something simple [...] that's all he did, what more could he do? He vacuumed once or twice [...] What can we do about it though? I am being patient with him, so many years now I am being patient.

Similarly, there are reports some patients find the relationship with the family not satisfactory (Lee & Bell, 2011). Possibly, there could be a connection between the quality of the relationship and the support provided.

Need for more emotional support. Some participants felt jealous of the support other affected individuals received from their families. They said that family members should have expressed their love more. Two participants expressed vividly their need for additional emotional support by asking for more understanding. This has also been mentioned in a previous piece of research (da Costa Vargens & Berterö, 2007). One of the participants said that the lack of understanding was an obstacle for them. This kind of need could possibly be attributed to a search for a more personalised support (Drageset et al., 2012). One participant said that her mother and husband did not tell her enough kind words, resulting in her trying to be brave and not needing them:

It couldn't hurt to hug me and say "I'm here, don't you worry, I love you" and "I will not leave you", it would be nice to feel that, but because I didn't feel it even with my mother, I didn't expect it from my husband, do you get it? I mean, this is maybe why I'd put on a very brave face and I do not need something more kind, something warmer. General, she was not like that [my mother]. But look, it was enough for me that she prayed for me, and still is of course, but this is the only way she is capable of showing her love. Okay, what can we do about her? Yes, I really was worried during that time and she is not the kind of human who can express herself so easily. What can I do now? I wish she was different for me, I wish she was a hugger like she's never been, but even her prayers and the fact she felt sad, and... Cared about me and these words, are enough. I guess you are thinking what can we do about it?

Overall, this last theme suggests that some things could change and could be done differently and more effectively for the well-being of the member with cancer. For example, if one participant had more emotional support they may have less negative changes to report, like the decrease in communication or in denying cancer.

Conclusions

The analysis of the interviews highlights that a family with a member diagnosed with cancer goes through many changes. These changes are positive, negative or a mixture of the two. The support received by the individuals with

cancer in response to these changes was found to be emotional and practical. Participants also commented on the adequacy of the support.

Even though only one member is receiving the cancer diagnosis, all of the family members seem to be afflicted. In most of the participants' descriptions, they would say "we" instead of "I", for example, "*we underwent treatment*", suggesting they felt they were not alone in the process.

While all elements of post-traumatic growth (Tedeschi & Calhoun, 1996) were noted in the sample of this study, no single participant reported experiencing them all. As the present study focuses on the family changes and possible improvements, 'relating to others' was mentioned by all participants.

Probably the most important contribution this research has to offer, is its focus on the changes in the family and the social support as perceived by the patient with cancer. The changes and support seem to be closely linked. The results of this study provide an initial link between specific changes and specific kinds of support. The experiences presented in this research were partly found in past research. However, some seem novel.

The research into changes in the family facing cancer and the support they provide is far from complete. This study has contributed to a deeper understanding of what a patient may require their family members to do for them and what to avoid doing. Health professionals should also take the findings into consideration for a more biopsychosocial approach to their patient's health. For example, shortly after a new diagnosis, the member with cancer and their family members could be informed about some of the negative changes that they may find in their family and try to prepare for them by developing coping strategies. Furthermore, when a family member of an individual with cancer reports difficulty in supporting them, then some suggestions can be made according to the support mentioned above.

Suggestions for further research

From the interviews, little to no evidence on informational support arose. The literature also suggests that family may not be an important source of informational support (Usta, 2012). It is likely that individuals with cancer seek informational support from others, like health professionals or the internet. This highlights the fact that individuals with cancer may seek different kinds of support from different people. Further research is required to clarify if this is, in fact, the case.

Some participants mentioned that some of their family members' actions expressed love. This suggests that practical support could include emotional support. It has been previously proposed that practical support is a way for family members to express their love to members with cancer through non-verbal communication (Liu et al., 2005). Therefore, the existing definitions of the types of social support may not fully encompass the complexity and multi-dimensional nature of these structures.

Matters of communication have been previously studied but discretion in communication does not seem to have

been previously reported. The findings describe an open communication among family members, not just between spouses. Participants reported feeling greater emotional closeness without needing to talk about something they preferred not to share. There seem to be some subjects that are not discussed because it would be perceived as disrespectful towards the person with cancer. The term “discretion” was frequently used by participants, giving the lack of communication a meaning of respect and helpfulness. Additionally, in the literature, loneliness has been thought of as something unwanted resulting from poor communication and fear (Pelcastre-Villafuerte et al., 2007). This does not seem to be the case in the reports of the participants of this study. This should be studied further by interviewing both individuals with cancer and their family members. The interviews could be conducted either with both parties present or one at a time.

While it has been previously reported that one member of the family plays a more significant role in the cancer recovery (Gates, 1988; Pistrang & Barker, 1995), there seem to be no reports on a family member becoming detached from the member with cancer. This suggests that being a member of a family does not automatically make one a source of support. The reasons for a member becoming detached from the person with cancer requires further qualitative investigation.

The narratives reported in this study describe a chain of support within the family where one member supports the other without necessarily everyone directly supporting the member with cancer. This could explain why participants perceived that some members of the family seem more detached. The hypothesis of a ‘support chain’ is novel and requires further verification and investigation.

The possible relationship that could exist between the subthemes of “protecting the family from the impact of cancer” and that of the “communicating less” should be studied further. It is conceivable that the drive to protect family members may lead to a less open exchange of information. Further research should disentangle this relationship.

In addition, further research should be conducted around the occasions it occurs and the effectiveness of a family’s efforts at distracting the member with cancer from their disease. Additionally, conducting narrative analysis about changes and support in order make even more apparent what happens in a family during cancer is also advised. Finally, family members seemed to be dealing with many problems. To that end, it is suggested for additional studies to explore the support needs of family members via interviewing them.

The participants were not asked about any non-family sources of social support. While the literature suggests that family are the most important source of support (Arora et al., 2007; Ashing-Giwa et al., 2004; Drageset et al., 2012), they might not be the only one (Finfgeld-Connett, 2005; Hughes et al., 2009; Thewes Butow, Girgis, & Pendlebury, 2004). Thus, future studies should explore other sources of support and their relations between the changes and the support they provide to the individual with cancer.

Limitations

There are some limitations that should be taken into account when interpreting the results. All data analysis was conducted by one researcher. This limits the possibility of another researcher having to offer a different interpretation of the results. Additionally, this study reports on the subjective view of the cancer. It is possible that the account of the family on the same events and experiences may differ. While this study considered the subjective experience to be more important to focus on, future studies should also investigate and compare the two.

The inclusion criteria limited the participants that could be included, and this resulted in a small participant number (eight). Also regarding the criteria, the findings described here may not reliably represent the individuals with cancer who are in a different stage of the treatment. Additional research is needed to establish whether support received from family members is affected by the stage of recovery.

All clinical information recorded was based on self-reports. Thus, there is a possibility that it may not have been fully accurate. However, since the depth of clinical questions was kept to a minimum (e.g. the type of cancer, with no mention of its stage), this is considered unlikely, although possible. Additionally, not having specific information about the stage of each participant’s cancer is also a limitation. Although the inclusion criteria should ensure a relevant consistency.

Regarding the participants, they all were members of the same association and this might in some way influence their experiences from other cancer survivors. Participation bias is also likely to have been an issue since participants entered on a voluntarily basis. Women were over-represented in this study, which affects the generalisability of findings to males. However, studies have suggested that the impact of cancer in women needs to be studied further (Mosher et al., 2013). Thus, the present study contributes to our knowledge on how women experience family support during cancer.

The fact that all participants were part of the same ethnic group, could be considered both a limitation and a strength. Although this limits the generalisability of the findings to other populations, it provides a more in-depth representation of one setting. Furthermore, it provides initial findings that can latter be utilised when comparing different contexts.

Additional Files

The additional files for this article can be found as follows:

- **Appendix A.** Summary of Results. DOI: <https://doi.org/10.5334/jeps.403.s1>
- **Appendix B.** Relationship of the axes resulted from the analysis. DOI: <https://doi.org/10.5334/jeps.403.s2>

Competing Interests

At the time, the author was a volunteering member of the administrative council of the cancer patient society the participants were recruited from. No other competing interests exist.

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