



“You nearly feel a little bit like you’ve less right to grieve”: a qualitative study on the impact of cancer on adult siblings

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Abstract

Purpose Family members of cancer patients experience a range of challenges and are impacted in various ways by cancer. To our knowledge, the impact of cancer on adult siblings has yet to be explored. Sibling relationships are one of the longest relationships individuals have across the lifespan. Thus, the current study sought to investigate the perspectives of siblings of those who previously had cancer.

Methods Ten participants were recruited using purposive sampling. A qualitative, cross-sectional design was implemented with both virtual and in-person semi-structured interviews. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

Results The researchers identified five themes relating to both the impact of cancer on siblings and the supports they received: *changes in family relationships, sibling’s grief is forgotten, benefits of social support networks, supporting their sibling and caregiving and self-support.*

Conclusions Cancer organizations and support services should focus on signposting services for siblings in order to ensure they can access support. Further research is needed with siblings to gain greater insight into what supports siblings feel are available for them to access, whether there are any for them to access or how supports can be improved.

Implications for Cancer Survivors The provision of appropriate psychological support for siblings of cancer patients will ensure they can provide optimal support and care to their siblings. This will in turn benefit cancer patients along their cancer trajectory as adequate support from their caregivers will enhance their quality of life.

Keywords Cancer · Oncology · Cancer caregivers · Supportive care needs

Introduction

Cancer incidence and cancer mortality is growing rapidly across the globe. This is reflective of both the aging and growing population [1]. The number of cancer survivors continues to grow in the USA, and there are new cancer diagnoses resulting from a growing and aging population [2]. There are also increases in cancer survival because of advances in early detection and treatment [2]. Although data is not available on the number of siblings among these survivors, cancer researchers anticipate that there are many siblings impacted by the cancer diagnosis, treatment and, in many cases, bereavement [3]. Sibling relationships are

significant as they are often the longest family relationship that most individuals have in their lifetime [4]. Sibling relationships often have greater longevity than friendships, spousal or parental relationships making them universally central across the lifespan [5, 6].

Attachment theory has been employed to explain the emotional support that sibling relationships can provide [7]. This can be applied to sibling relationships as the emotional bond that adult siblings have stems from their ability to identify with one another [7]. Some other theorists (e.g. Cicirelli [8]) propose that siblings function to help and provide social support to one another and that sibling bonds can endure over time despite physical distance. Siblings may also function in a variety of roles for their siblings such as companions and confidants [9]. In later years, siblings can also function as role models [10]. In a study among elderly siblings, siblings were seen as a source of aid in times of crisis, and siblings were deemed a source of psychological support and

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companionship [11]. It was also found that support is tied to strong emotional ties between adult siblings [7, 12]

While cancer survivorship research may not have examined the specific impact of cancer on siblings to date, the impact of cancer on other family relationships and family relationships more generally has been explored in various studies. For instance, the negative emotional impacts of cancer on family members have been explored. In the case of paediatric cancer, cancer impacts both the patients and parents [13]. In the case of adult children, they often feel a sense of filial responsibility when a parent becomes ill with cancer [14]. Family members of cancer patients experience psychological distress and often have higher levels of anxiety and depression than what was found in the general population, and in some instances, they have higher levels of anxiety and depression than the cancer patients themselves [15]. The constant indisposition and the threat of death may impact the coping abilities and distress levels of the family members [16].

In addition to these negative impacts of cancer on family members, there has been evidence in the literature of potential positive impacts for family members [13, 14, 17]. Levesque and Maybery [14] identified positive or benefit themes that included having improved relations with the parent that had cancer and improved family matters. Similarly, D'Urso, Mastroyannopoulou and Kirby [17] and Weiner and Woodley [13] found that improved family relationships emerged during a family cancer diagnosis. Overall, a cancer diagnosis may create increased family cohesion within the family [13, 17].

In the limited cancer literature to date on siblings, to our knowledge, only child siblings were included [18]. For instance, in a study relating to child siblings' experiences of cancer, Weiner and Woodley [13] determined that siblings of children with cancer experience emotional changes and changes to their relationships, their family and home life and their extracurricular activities; however, siblings manage to find ways to problem-solve and cope. In a similar manner, Neville et al. [19] and Prchal and Landolt [20] also found empirical evidence for siblings of cancer patients engaging less with friends and hobbies. Furthermore, Arora et al. [21] found evidence for siblings experiencing a wide array of emotions such as shock, guilt, anxiety and sadness. As outlined in the findings of D'Urso, Mastroyannopoulou and Kirby [17], siblings experience increased empathy and resilience, better family relationships, a disruption to routine and greater responsibility. Many siblings also experience feelings of anger, isolation and being left out due to the family's attention being shifted to the ill sibling [22]. This is reinforced by Nolbris, Enskär and Hellström [23] and Prchal and Landolt [20] who argue that siblings of cancer patients are often marginalized and left alone to cope with their feelings

leaving siblings to assume extra responsibilities and adopt new roles during the cancer [19, 22].

In light of the above, it is evident that there is a clear gap in the literature in relation to adult siblings' experience of cancer. Moreover, the significance of sibling relationships cannot be overlooked due to their longevity, emotional support they provide and the variety of functions they can have [5, 6, 20]. Familial cancer literature to date has identified several associated impacts of a cancer diagnosis on family members including emotional changes, relationship changes, socialization changes and intense emotional responses [13, 17, 19–21]. Following the above, there appears to be a dearth of research on the impact of cancer on adult siblings. Whilst there is a small amount of literature pertaining to the impact of a cancer diagnosis on siblings in childhood and young adulthood, there appears to be a gap in the literature for assessing the experiences of siblings of cancer patients, as explicitly identified by Cheung and colleagues [18]. In line with the suggestions of Hagedoorn, Kreicbergs and Appel [24], this study will focus on gaining an understanding of sibling relationships and family dynamics, which will provide greater insight into how to refine interventions for siblings and family members of cancer patients.

We hope that this research may have potential relevance to assist with the design of future interventions that aim to address mental health, support services and well-being among siblings of cancer survivors. Assessing the impact of cancer on siblings could allow them to better perform in a caregiving role or manage the diagnosis better [25]. In a similar manner, the present study is aiming to explore where an intervention could facilitate emotional support and improve dyadic coping as identified by Hopkinson et al. [26] and Baik and Adams [27].

Ultimately, to the best of our knowledge, this is the first study that examines the impact of a cancer diagnosis and treatment on adult siblings. This study will aim to:

- i) Explore the positive and negative impacts of cancer on adult siblings including bereavement
- ii) Understand how they are supported

In conclusion, there is a clear lack of research on siblings of cancer survivors, and this study will aim to bridge this gap by addressing these two key aims.

Methodology

Design and methods

A cross-sectional qualitative approach was identified as particularly useful for the current study as the diagnosis and

treatment of cancer can have devastating emotional, social and physical effects on survivors and their families [30]. The cross-sectional approach was implemented by conducting interviews within a 4-month period and subsequent analysis across a 2-month period. A significant benefit of qualitative research is that it can help with meeting patients' or participants' future needs, and as qualitative research is largely inductive and explorative in its procedures, it is suitable for situations where impacts need to be investigated [32].

Participants and recruitment

Participants were recruited to partake in semi-structured interviews designed to capture the experiences of siblings affected by cancer. Purposive sampling was utilized to target this specific group, whereby we attempted to ensure that participants represented a mix of gender and cancer type. Participants were also recruited based on a set of inclusion and exclusion criteria. The inclusion criteria required that participants were over 18 years old and had a sibling who was previously diagnosed with cancer in the last 15 years. This timeframe was chosen in order to ensure that individuals whose siblings had a lengthy cancer trajectory (e.g. > 10 years) were included. In particular, there were three instances where the timeframe since diagnosis was 15 years and, in two of these instances, the initial diagnosis took place 15 years prior, but the cancer trajectory continued and spanned 10 years (i.e. receipt of active treatment within the current health services ended within the last 5 years). The remaining seven participants experienced their siblings' cancer more recently with timeframes of between 3 and 10 years ago. Participants were excluded if they were non-fluent English speakers. Participants who had undergone cancer themselves but currently considered themselves "cancer-free" were able to participate; however, those in active treatment or with active cancer were excluded.

The first author sent an email to cancer organizations including Breakthrough Cancer, the Irish Cancer Society and the Marie Keating foundation. This email contained the recruitment notice and contact details for the first author. The Marie Keating foundation shared the notice across its channels. The first author also supplemented this recruitment strategy with advertisements on LinkedIn and in an Irish psychology email thread in order to engage with communities that may have been interested in taking part. Social media recruitment facilitated access of groups and individuals that are often hard to access [34]. Once a potential participant flagged their interest by emailing or messaging the first author, the first author responded to them with the plain language statement and consent form. The email address or contact details used to reach out to the first author were not stored and were used solely for correspondence related to arranging an interview time and date.

Data collection

The first author carried out face-to-face interviews in participants' homes or a neutral venue (e.g. university campus), whilst virtual interviews were conducted via Zoom. As data collection took place during the COVID-19 pandemic, only three interviews were conducted face-to-face, and the remaining seven interviews were carried out using Zoom, a remote video conferencing application. The average length of the interview was 43 min and interviews spanned from 32 min to 1 h and 3 min. Participants could sign an online consent form in advance of a face-to-face or virtual/phone interview and return it via email, or where face-to-face interviews took place, they could sign a physical consent form at the interview. The interview commenced with a couple of minutes of problem-free talk where the first author established a level of rapport with the participant. The interview then moved through a semi-structured format where participants were asked how they felt during their siblings' cancer experience, what they did to help themselves, what others did to help them and their view on supports available.¹ These semi-structured interview questions had initially been designed by the first author and were further refined and amended following piloting them with the second author, given his extensive experience in psycho-oncology research and status as a sibling-in-law of a cancer survivor.

Data analysis

The research team analysed the data for content relating to cancer impacts and modes of support among participants. The first author used Braun and Clarke [35] method for inductive thematic analysis as a structured guide for this analysis. Thematic analysis is effective as it allows the researcher to form relationships between issues and topics that emerge from the data and allows researchers to link their data to replicated data and compare the data among participants [36]. This involved (1) data gathering and subsequent anonymization; (2) coding; (3) identifying themes; (4) ensuring the thematic material related back to the coded data extracts to ensure coherence; (5) establishing, defining and naming the themes; and (6) writing up the results. During the transcription process, over 7 h of audio were transcribed, and any information that made participants potentially identifiable was omitted from the transcripts. Subsequently, the initial process of descriptive coding was undertaken and followed by a process of "coding the codes", where codes became more interpretive with the aim of linking together and converging various codes. Following this, themes were extracted, defined and refined. Quotations from

¹ Interview schedule available upon request.

Table 1 Participant demographic characteristics

ID	Sibling	Type of cancer	Initial diagnosis	Bereaved/alive
Amy	Sister	Brain tumour	2007	Bereaved
Anne	Brother	Brain tumour	2007	Bereaved
Paul	Brother	Leukaemia	2019	Bereaved
Lisa	Brother	Testicular cancer	2012	Alive
Orla	Sister	Leukaemia	2016	Alive
Amanda	Brother	Lung cancer	2017	Bereaved
Isabel	Sisters (×2)	Lung cancer and leukaemia	2015 and 2016	Bereaved (×2)
Charlotte	Brother	Brain tumour	2007	Bereaved
Ken	Sister	Breast cancer	2013	Bereaved
Maria	Sister	Leukaemia	2019	Alive

Note. IDs provided are pseudonyms.

participants were utilized to illustrate themes. The second author was involved at each stage of the process to ensure cohesion. As outlined by Lincoln and Guba's [37] criteria for credibility, the second author checked that the quotes and themes were valid based on the sample and in the context of their own knowledge of the subject area. Furthermore, these discussions reduced the risk of implicit bias. Aspects of the transcripts that were determined as irrelevant to the research aim were omitted from the transcripts. The transcripts were coded using Microsoft Word, and each step of analysis was undertaken independently in order to gain a variety of perspectives and allow the research team to meet regularly to discuss the data and achieve a consensus.

Ethics

This project received full ethical approval from a university institutional review board. When undertaking qualitative interviews, a researcher can expect an intense, emotional response [38]. In order to deal with the implications of discussing sensitive topics such as the experience of a family member with cancer, the first author took time to develop rapport with the participants [39]. The research team drafted a risk management protocol pertaining to participant distress, online safety precautions and safety of both parties.² The first author gave participants potential questions in preparation as by having prior exposure to the questions being asked, participants could make an informed decision about partaking in the interview. The first author established rapport by introducing herself prior to the recording and asking conversational questions. In times where the first author experienced an emotional response during the interview, they paused the interview and engaged with the participant to ensure that they were comfortable and emotionally prepared to continue with the interview.

² Risk management protocol available upon request.

Reflexivity

As the first author has personal experience with a family cancer diagnosis, she took steps to mitigate the risk of biases. The principal investigator undertook an interview skills session with the first author in order to reduce the risk of question-asking bias. In addition to this, the second author oversaw the list of potential questions that were distributed to participants in advance of the interview. In terms of the data analysis, the principal investigator oversaw each stage of data analysis including the initial transcription, initial coding, subsequent coding and final theme generation.

Results

The first author conducted 10 interviews. Of these participants, their ages ranged from 25 to 60, and the sample was composed of two male and eight female participants. For further details regarding demographic characteristics of these participants, see Table 1. Participants have been given pseudonyms in order to protect confidentiality and anonymity. Two participants had been diagnosed with cancer previously, one of whom had undergone chemotherapy; however, both participants considered themselves to have recovered.

The present study identified five themes relating to the impacts of cancer including bereavement on siblings and how they are supported: *changes in family relationships, sibling's grief is forgotten, benefits of social support networks, supporting their sibling and caregiving and self-support*.

In what follows, where quotations have been contracted, ellipses have been put in square brackets, and where context was needed for the quotations, further contextual information has been placed in square brackets.

"It definitely brought us closer together": changes in family relationships.

Participants described the changes that occurred in the relationships with both their siblings and other family

members. In terms of the changes in sibling relationships, participants primarily identified an increased closeness with their sibling who was diagnosed with cancer. For instance, Amy (sister, bereaved) expressed how her bond with her sister grew due to her sister's cancer:

I think, if anything, it actually made us closer together. 'cause I remember, like, I think in the beginning... she was a kid, she got to miss school, she was fine with it. And then I think, when it hit her, I think she started opening [up] more. She was scared. I remember she wasn't really comfortable telling my parents, so I was the one she would talk to, you know?

In terms of changes in the amount of time spent together in the relationship, participants felt that the relationship changed in that they chose to spend more quality time with their sibling who had cancer. Amanda (brother, bereaved) felt that:

I would have visited him a lot more and we would have chatted. Chatted about everything and anything; music, rugby and... Everything that's just day-to-day stuff. [...] So, I suppose that's where I would have called to see him a lot more than I would have previously and chatted more.

Participants also acknowledged their other family relationships changed because of their sibling's cancer. For instance, participants identified positive changes in their wider family relationships resulting from their sibling's cancer. Orla (sister, alive) identified positive changes in her relationship with her father:

But I've always been close to my dad, I think, honestly, and I talked about this a few times, since I think her illness actually made us closer. And because we were both going through something so horrible.

In terms of other relationships within the family unit and the family unit, participants also identified that the dynamic within the family and the individual relationships within the family unit were no longer the same after the cancer diagnosis and bereavement. Overall, participants identified struggles in adjusting to their new family roles and navigating their family relationships during their sibling's cancer and following their sibling's death. Paul (brother, bereaved) described the changes in his family unit:

[Our family] dramatically changed. I mean, it's not the same at all anymore [...] The dynamics in our relationships... Well, it does have some resemblance to what it was before but, I mean, it just so dramatically changes everything.

Similarly, Anne (brother, bereaved) identified changes across her own siblings in the aftermath of her brother's cancer and death:

I think people struggled to find their position after [my brother's] death because of his role in the family [as the eldest child]. [...] And, so, when [my brother] passed away, the goalposts, things changed [for the rest of us]. Who does what? Our parents are elderly, our parents need care, [so we needed to figure out how to navigate that]. And our relationship with [others in] the family all kind of changed a little bit.

"It felt like my parents lost a child, but it wasn't as if we lost a sibling": sibling's grief is forgotten or overlooked.

Participants confirmed that their grief was not acknowledged in the same way as the grief of their parents. Amy (sister, bereaved) recounts that "It felt like my parents lost a child, but it wasn't as if we lost a sibling. I don't know if that makes sense".

Speakers also felt that as adults, their grief was less important than the grief of other family members and that their role meant that they could not grieve. Anne (brother, bereaved) felt that:

I remember thinking as a sibling, you do feel less justification [compared to other family members]. You can't wallow. You can't grieve in that way. You don't feel justified. Adult sibling grief is about supporting others [...] But my grief is valid and you nearly feel a little bit like you've less right to grieve [than the parents or wife]".

This feeling that siblings' grief is overlooked or forgotten was also reflected in participants' perceptions that the support organizations and psychological support services that were available for family members of cancer patients were not designed for siblings or applicable to them. Orla (sister, alive) recounted the following in this regard:

This is gonna sound so stupid... I didn't know there was [any support available]. [...] One day, [I saw] a big sign for support for relatives of people with cancer. I can't remember exactly what I think it was in anyway, I saw a big sign. And I think this just goes to show how preoccupied I was, I was like, 'Oh, that's not for me. That's for people who are related to somebody with cancer.'

Relatedly, participants did not know where to look for support and identified a clear lack of signposting of services for siblings. Amanda (brother, bereaved) recalled that:

It honestly never occurred to me that I should look for any help or even support group. I don't even know if there are any support groups. If you've cancer yourself,

there actually is very little and you really have to go looking for it yourself.

“I would say definitely find someone to confide in”: benefits of social support networks.

Participants noted an overwhelming sense of kindness from their social network throughout their sibling’s cancer trajectory. Orla (sister, alive) recalls the way in which her social network offered her kindness during her sister’s cancer:

There’s lots of little memories... all I remember really is the kindness. The constancy of them all, you know, that they were always there to kind of check in on me and help and offer [support]. They made so many offers of help, offers to do things, to drop food up to the hospital, whatever. But really, it was just that I knew they were there.

Participants also disclosed the importance of having somebody to talk to whilst dealing with a sibling’s cancer. Amy (sister, bereaved) states: *“I would say definitely find someone to confide in. Because it does get heavy. Yeah, just find someone you trust”*.

There were also indicators among participants that everyone in the family unit copes differently and that it is important for wider social support networks to identify and acknowledge that they must adjust their support to suit the needs of each respective person. Anne (brother, bereaved) confirms that social networks need to ensure they are not neglecting to talk about the cancer:

Some people [family members] will want to talk about it. And one of the worst things you can probably do is ignore it. Like, you know, [pretend] that it’s not happening. And so be receptive to what the person wants to talk about.

Participants recalled specific individuals or scenarios that stood out for them and that functioned in a way to provide support or alleviate the pressure that came with being a sibling of a cancer patient. Paul (brother, bereaved) recalled that:

There’s lots of small, innocuous things that seem innocuous that are actually in hindsight, they’re huge. You don’t need to have these big sort of displays of comprehension or understanding or, you know, insight or something like that. [...] I’ll tell you one story. I was heading out [to visit his brother with cancer abroad] and I left my phone in the house but, my dad’s best friend, we’d given him keys to the house and he’d spotted my phone and then, during the workday, he drove it out to the airport and, I mean that was just so extraordinarily selfless and helpful. And so, that was definitely just on his part, it was just understanding,

like real empathy. I wish it had been more essentially what [his dad’s friend] did, which was empathize with the situation. And, you know, in that circumstance, there was a clear line of action.

As part of the importance of their social network, participants acknowledged the importance of communication. For instance, participants identified that communication across a variety of avenues was necessary. Many participants felt that communicating with a friend, family member or a professional through socializing or talking about their experiences was a vital aspect of feeling supported as they navigated their sibling’s cancer. Amanda (brother, bereaved) disclosed:

I do think talk, communication is key. As I say, it doesn’t have to be part of a group. It’s kind of, it’s the one person. Yeah. You know you’d hope everyone would have one good friend and they don’t. Not everybody does. I think if everybody did, that would be, that would make these things much easier.

“You become a lot more caring towards them”: supporting and caring for their sibling.

Participants acknowledged that there was shift in their roles within their sibling relationships during their sibling’s cancer treatment. For example, Anne had an increased sense of protectiveness and desire to support her brother who had previously acted in a caregiving manner within the family dynamic but which ultimately switched when he was diagnosed with cancer: *“I think that that changed, I suppose maybe the dynamic of him being the carer... I suppose in that sense we became kind of protective of him”*.

Similarly, Charlotte (brother, bereaved) indicated that she felt a greater duty to look after her sick brother: *“you become a lot more caring towards them, not that we weren’t [before] but, you’ve kind of gone, ‘okay, he’s the person who needs to be looked after here”*.

Some participants also reported that they adopted a caregiving role or took on a supportive role in order to provide support to their sibling during the cancer process. Maria (sister, alive) identified:

I mean, to have somebody as sick as [my sister] in your home. And yet,, we were absolutely, you know, mind-ing her. I mean, they were telling us we just would not think that she was ever going to make it.

Paul (brother, bereaved) also felt that he was trying to find his role within the family in order to be able to offer support to his brother:

I definitely switched into a kind of a caregiver role, I suppose. But, I mean, we were we were all just sort of trying to find our roles and to take care of ourselves as best as possible and then enable each other to take care of themselves as well.

In some cases, where the severity of the siblings' needs precluded the possibility of caregiving, participants acknowledged the emotional support that they provided to their siblings with cancer. Isabel (sisters × 2, bereaved) described how she went about supporting her sister with cancer:

[The support was] more complicated, say, than caregiving because she was in hospital all of the time. So, she had the care. So I wouldn't be bold enough to say that I was doing the caregiving, but I certainly do support the role of handholding.

"I got out and I put on my walking boots and I walked those hills": self-care strategies to support oneself.

Participants also identified a variety of ways in which they engaged in self-care practices to support themselves. Overall, most participants acknowledged the significance of exercise and supporting oneself through physical activity. Isabel (sisters × 2, bereaved) maintains that:

One of the things that was really good for me mentally was I got out and I put on my walking boots and I walked those hills on my own, I wouldn't go with anybody for the first few months and I put on my headphones. And I walked and walked and walked and a certain song would come on. And I'd realize there were tears running down my face, I didn't I wasn't conscious of it, you know.

Other participants recalled that staying positive helped them the emotions associated with having a sibling going through cancer. In particular, some participants adopted a positive attitude when they observed others around them using such an approach. Amanda (brother, bereaved) used positivity as a way to cope when she witnessed the way it allowed her brother who had cancer to cope with his illness:

I suppose there's a saying you've got to live until you die, you know, and that's what he [her brother] had chosen. And that's why he didn't take the clinical trial. He wanted to try to live. And do things on his own terms without being controlled by appointments. You know, so he made it. He was very. He was very strong [...] But he faced it all with, you know, incredible bravery [...] Yes, I would say positive attitudes.

Ken (sister, bereaved) noted that journaling was a useful self-care strategy that he used in order to process his sister's cancer.

Another thing that I did was journal. I journaled quite a lot, I still find it quite useful. And I find it very useful for going to bed that, if you just get everything out on paper, at least then you don't have to think about it when you're lying down. And that works really well.

[...] I think it's just even if it's only like, you know, two or three lines, just go ahead [and do it], right? Because I often think your brain is like a computer. [...] You have limited amounts of space, you need to get it out, you can't always keep it in there. Otherwise, it's just going to melt.

Discussion

To the authors' knowledge, the present study is the first to examine the impact of cancer in a dedicated sample of adult siblings of cancer patients. The findings of the present study indicate that adult siblings of cancer patients are impacted in both positive and negative ways by their sibling's cancer. The study identified five themes: *changes in family relationships, sibling's grief is forgotten and overlooked, benefits in social support networks, supporting and caring for their sibling and self-care strategies to support oneself*.

A significant finding of the present study is that participants identified a sense of feeling forgotten in terms of addressing their grief and psychological struggles. This relates to the findings of Bowman et al. [40] who determined that bereaved siblings were often forgotten or left out of interventions. Bowman et al. [40] noted that parents of bereaved siblings noticed that siblings were neglected in the days following their sibling's death. In the present study, participants of siblings of cancer patients identified that their parents were struggling with the cancer diagnosis and in many cases, the bereavement of their child. Consequently, siblings felt that their grief was minimized as parents were coping with the loss of a child. A novel finding was that the siblings also felt that there was a lack of signposting of support services for siblings affected by cancer. This is similar to the theme "we are only siblings" in a study by Dyregrov [41] on siblings affected by suicide. Dyregrov [41] determined that siblings were primarily supported through the family support network and, in some instances, they were supported professionally; however, this was less frequent; however, the present study is the first study to our knowledge to identify the lack of services for siblings and sense of invisibility in the case of cancer.

Similarly, in the present study, siblings recalled that, in instances where support services were advertised for family members of cancer patients, they perceived that the services were not directed at them, nor did they tailor their advertisements towards siblings. This is also reflected in the findings of Lund et al. [42] who found that caregivers need more information from support services in order to identify when they should access support and what psychological symptoms they may experience. In terms of psychological support agencies, participants also felt that these were not tailored towards the sibling's experience of cancer and instead aimed

to provide generalized psychological based interventions. In addition to this, participants perceived that their grief was less important and less acknowledged than the grief of other family members (e.g. such as the spouse or parent). Consequently, they did not feel that the available supports were applicable to them nor that they were entitled to access available supports due to their perception that their grief was less important.

As siblings in this present study did not feel there was professional support suitable for, or applicable to them, they placed a significant focus on self-care strategies to support themselves. In particular, mindfulness-based strategies were used by participants such as journaling or meditation. Ushley and Garza [43] determined that journaling can be used as a healing agent as it allows individuals to put pen to paper and clarify the feelings associated with their journey. This is also evidenced in a study conducted by Mosher et al. [44] who found that caregivers utilized breathing exercises. Furthermore, maintaining a sense of positivity was a key strategy used by siblings. In a similar manner, Akpan-Idiok et al. [45] identified that caregivers also upheld positive views in order to navigate the cancer. Overall, the participants used self-support strategies as their primary mode for navigating the burden of their sibling's cancer diagnosis and the burden of support.

Another key finding of the present study is the importance of a social support network for the siblings. Participants recalled anecdotes of times when friends, family or colleagues did something that made them feel supported. Family members and carers of patients with cancer who lack a social support network are more at risk psychologically [46]. Therefore, there is a clear importance of having a social support network for siblings of cancer patients. The importance of the social support network is reflected in the findings of Northouse et al. [47] who determined that higher quality of life among family members of cancer patients was associated with higher levels of social support. Participants in the present study also acknowledged the communication benefits that social support networks provided for them during their sibling's cancer and afterwards. Social networks allowed siblings to express how they were feeling and voice their thoughts by maintaining a communication line with their social network. The notion of cancer as a social experience is reflected by Head and Iannarino [48] who also argue that communication and assistance from the social support network varies from individual to individual and who they have in their social support network.

Another important finding of the present study is the changes in family relationships resulting from a sibling's cancer trajectory. Furthermore, attachment theory may underpin the resulting closer bonds that siblings of cancer patients experienced between siblings of cancer patients and other family members. In particular, the closer sibling

relationships may be attributed to the theory's proposition that siblings function to help one another and function in a supportive role [8]. In all cases, these were positive changes that were brought about as a result of their sibling's cancer such as bringing the siblings closer together. This finding can be understood in the context of benefits reported by family members affected by cancer. In the context of cancer patients and spouses, Thornton [49] has a framework for the benefits of cancer for cancer patients themselves and their spouses. As part of this framework, individuals benefitted from the improvements in their interpersonal relationships as a result of the cancer. These findings are similar to the findings of the present study where sibling relationships and family relationships as a whole improved and, thereby benefitted, from the cancer. Furthermore, in the case of paediatric cancer, prior research [14; 5150] has identified that cancer sometimes has "silver linings" which include better family relationships. The findings relating to changes in sibling relationships due to cancer may also have relevance to the context of family systems theory, which attempts to account for the variance of positive and negative family adaptation and the way behaviours and relationships are intertwined in family units [51]. As such, further purposeful research that explicitly examines changes in family relationships arising from a sibling's cancer through a family systems theory approach may be useful.

In the current study, siblings of cancer patients also felt an enhanced responsibility to support their ill sibling and often adopted a caregiving role. Despite the challenges that come with caregiving and the intense emotional responses that are elicited from siblings who are caregivers, caregiving can have positive impacts. Some positive impacts of caregiving are that siblings can spend more quality time and grow a closer bond with their sibling [52]. This is reflected in the findings of the current study in which siblings felt that their role as a caregiver or as a primary supporter facilitated them with spending more quality time with their sibling and allowed them to provide greater levels of support to them [53]. Overall, in the present study, siblings identified more benefits with being in a caregiving or supportive role to their siblings; however, they also identified times when the responsibility burdened them. In contrast to the positive impacts, participants identified the challenges that come with being a caregiver or supporter to their sibling. Siblings in the present study also identified challenges of providing emotional support during the cancer trajectory whilst simultaneously struggling emotionally themselves. This is reflected in the findings of Ullgren et al. [54] from the cancer caregiver literature, who determined that offering emotional support during the cancer trajectory to the cancer patient can take its toll on the caregiver. Moreover, this may be attributed to attachment theory as the bond that adult siblings have stems from their ability to identify with one

another [7]. This may create challenges for siblings who are caring for their sibling with cancer due to their close emotional ties and shared emotional bond. It also may mean that siblings can function to provide psychological support and companionship to their siblings with cancer as they know the best way to provide assistance to them due to their close emotional bond.

Implications

There are a number of implications of the current findings for cancer organizations and interventions. The findings demonstrate that there is a need for better signposting of supportive resources for siblings. There is a need for both health services and cancer support services to take an approach that highlights these resources and communicates the way in which they can be accessed. Overall, there is a need for greater visibility of these services. In addition to this, where supports are available and where services do exist for siblings, these services need to be more coordinated and address the challenges faced specifically by siblings such as well-being, psychological challenges, caregiver burden and emotional challenges. Overall, as siblings engaged in self-care strategies, it may be helpful to use such approaches (e.g. physical exercise, positive reframing and/or journaling) in targeted interventions tailored to the individual needs of siblings affected by cancer [52]. Siblings can also be better supported by the establishment of focus groups or support groups where siblings of cancer patients come together to discuss how they are feeling and seek support from others who had been in a similar situation. Cancer support organizations could also update their support advertisements and leaflets to highlight the way in which they can support siblings. There is a need for future research with siblings of cancer patients to assess their awareness of supports that are available to them and to get their perspectives on support needs for siblings of cancer patients.

Due to the lack of prior research on siblings' experiences of cancer, the impact of the cancer on siblings and the modes of support available to these siblings, there is a clear need for further research in the area. There is a need to take a more in-depth look at support and strategies that facilitate or act as barriers to siblings obtaining support. Furthermore, future research with psycho-oncology professionals would be useful to develop targeted interventions for siblings to support their psychosocial needs. Future research should also aim to develop support strategies that are directed specifically at siblings of cancer patients in order to ensure their niche needs are met such as catering to their emotional needs due to their emotional involvement in their sibling's cancer and their supportive role in order to assist them throughout their sibling's cancer and in cases where their sibling is bereaved.

The present study also has implications for cancer survivors. Supporting siblings who are cancer caregivers is important to ensure that they do not get burnt out and that they provide adequate care or emotional support for their sibling who has cancer, such as a sense of hope [55]. In addition to this, where the burden of caregiving has taken a toll on siblings, the current research points towards specific steps that can be taken to support them (e.g. seeking emotional support or engaging in relevant self-care strategies) and thereby allow them to provide their siblings with a good quality of life throughout their cancer trajectory.

Strengths and limitations

There are a number of strengths and limitations that should be considered when interpreting the findings of the present study. In terms of the strengths, the novelty of this research should be acknowledged as it is the first study of its kind to investigate the impact of cancer on adult siblings. Another strength of the study was that a variety of cancers were found across the siblings (leukaemia, lung cancer, breast cancer, testicular cancer and brain tumours). This is a benefit as a variety of perspectives and cancer experiences were explored. In terms of the limitations, while it should be acknowledged that caregivers and siblings are a hard to access population, the sample of 10 participants may be regarded as relatively small for a study of this nature. Of the ten participants, eight of their siblings were bereaved. Consequently, bereavement and grief may have been primary findings of the study rather than solely the cancer. The current research was also conducted partially online with eight interviews taking place remotely over Zoom. The online nature of the interviews may have been an issue due to a less personal nature of the interview and non-verbal communication may have been reduced. Despite this, interviews were rich in data, which suggests that the online mode and small sample did not impact the quality of the data. Moreover, some participants reported that their sibling was living abroad at the time of their diagnosis and treatment. Consequently, the geographical proximity meant that the impacts were not the same as the impacts of siblings in closer proximity. As identified in the recruitment and participants section of the methodology, some siblings themselves had previously been diagnosed with cancer and had been cured. This may have impacted the findings from these interviews as these individuals may have subconsciously or explicitly drawn from their own cancer experience.

Conclusion

In conclusion, the present study identified five main themes relating to the impact of cancer on adult siblings: *changes in family relationships, sibling's grief is forgotten, benefits of social support networks, supporting their sibling and*

caregiving and self-support. The novel findings of the present study highlight the substantial impact that cancer can have on adult siblings, yet siblings may often feel overlooked or forgotten in favour of other family members. Furthermore, there is evident positive and negative impacts of a sibling's cancer; positive impacts include the way in which sibling and family relationships may change for the better following cancer diagnosis, while negative impacts for siblings of cancer patients include the burden associated with caring for their sick sibling. Social support networks were also available to siblings in the present study, and they made use of self-care strategies to reduce the psychosocial impact of their sibling's cancer; however, siblings also perceived a lack of signposting, or tailoring, of support services towards them. In light of this, there is a clear need for organizations and support services to improve their signposting of services for siblings. Future research should focus on gaining the perspectives of siblings of cancer patients in relation to what supports they feel are available or where they feel support is lacking.

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Author contribution Hazel Burke, conceptualization, data curation and design, data analysis and interpretation, original manuscript preparation and writing, review and editing. Simon Dunne, conceptualization, data curation and design, supervision, interpretation and manuscript review and editing.

Data availability Microsoft Word documents representing the thematic analysis process at different stages of coding may be requested from the first author.

Declarations

Competing interests The authors declare no competing interests.

Ethics approval Procedures and practices carried out as part of the present research were at all times in line with the ethical standards of the pertinent institutional research ethics committees and the 1964 Helsinki Declaration and its later amendments. The authors received from the Psychology Research Ethics Committee, Dublin City University (DCUPEC_DCUPEC_2021_152).

Consent to participate Informed consent for participation was obtained from all participants prior to participation in this research.

Consent for publication Informed consent regarding the potential publication of pseudonymized data in an academic journal or conference was obtained from participations prior to participation in this research.

Conflict of interest The authors declare no competing interests.

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