



# “The effects of cancer on a family are way beyond the person who’s had it”: The experience and effect of a familial cancer diagnosis on the health behaviours of family members

Beth McKeague<sup>\*</sup>, Rebecca Maguire

Department of Psychology, Maynooth University, Maynooth, County Kildare, Ireland

## ARTICLE INFO

### Keywords:

Cancer survivors  
Health behaviour  
Assessment of healthcare needs  
Patient involvement  
Family member  
Qualitative research

## ABSTRACT

**Purpose:** People who are first-degree relatives of cancer patients are at an increased risk of developing cancer themselves. Despite this, relatives of cancer patients do not always make beneficial changes to their health behaviours. This study aimed to answer the following questions: (1) do the health behaviours of people who are first-degree relatives of cancer survivors change following cancer diagnosis, and if so, how, and why, (2) what motivations/barriers exist for first-degree relatives when seeking to engage with health promoting behaviours, and (3) what do first-degree relatives believe healthcare organisations can do to improve uptake of healthy lifestyle changes.

**Method:** Nine biological first-degree relatives of cancer survivors living in Ireland (6 children, 2 siblings, 1 parent) participated in semi-structured interviews which were later thematically analysed.

**Results:** Findings revealed four superordinate themes: Being Conscious/Aware, Limited Lifestyle Changes, Psychosocial Consequences of Experience, and Unmet Needs, with each of these themes having two to three subordinate themes. Patient and public involvement emphasised Unmet Needs, including needs for information and family support, as the theme that was most reflective of participants’ lived experience.

**Conclusions:** Results suggest that while family members tend not to change their lifestyle behaviours following cancer diagnosis, they do seem to make changes to their medical behaviours. Additionally, they can be negatively impacted by the experience in several other ways. Identifying means of support will allow relatives to cope better post diagnosis.

## 1. Introduction

Every year in Ireland, over 40,000 people are diagnosed with cancer (O’Connor et al., 2019). Thanks to advances in cancer treatments, survival rates have improved significantly, with the number of survivors in Ireland standing at over 200,000 in 2019 (Humpel et al., 2007; O’Connor et al., 2019). However, it is important to recognise that almost all of these cancer survivors will have biological family members, and due to their relation to a cancer patient, may be at an increased risk of developing cancer themselves in their lifetime. Research has demonstrated that cancer types such as breast, endometrial, colorectal, and gastric are all associated with a genetic risk factor (Maddensky et al., 2005; Matsubara et al., 2013; Boonyasiriwat et al., 2014; Li et al., 2016; Whitney et al., 2019). In particular, people who are biological first-degree relatives (FDR) of cancer patients (i.e., parents, siblings,

children) are at a higher risk of getting diagnosed with cancer in comparison to those without a family history of cancer (FHC) (Matsubara et al., 2013; Katz et al., 2017; Haug et al., 2018; Whitney et al., 2019).

Genetic susceptibility is not the only risk to consider. There are also a wide range of behavioural and external factors that can influence the chance of a person getting cancer. These include, but are not limited to, smoking, alcohol consumption, physical activity, diet, weight, and medical preventative behaviours like cancer screenings (Rex et al., 2000; Safaeian et al., 2007; Claassen et al., 2010; Beesley et al., 2011; Department of Health, 2017; Lacombe et al., 2019). Furthermore, evidence suggests that FHC may interact with external risk factors to further increase a person’s overall risk (Wu et al., 2011).

As FDR of cancer patients have a higher chance of getting cancer themselves, it may be in their best interests to change their health behaviours in order to promote their health and reduce their risk of later

<sup>\*</sup> Corresponding author.

E-mail addresses: [bethmckeague@gmail.com](mailto:bethmckeague@gmail.com) (B. McKeague), [rebecca.maguire@mu.ie](mailto:rebecca.maguire@mu.ie) (R. Maguire).

<https://doi.org/10.1016/j.ejon.2021.101905>

Received 14 August 2020; Received in revised form 27 January 2021; Accepted 28 January 2021

Available online 2 February 2021

1462-3889/© 2021 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

developing cancer. While Mazanec et al. (2015) demonstrated that family members of cancer survivors tend to rate their intention to make overall health behaviour changes as high, other studies suggest that this intention may not always translate into actual behavioural changes. For example, while studies looking at those with an FHC found that they were more likely to engage with medical behaviours, such as screenings, they did not engage in lifestyle changes or other health promoting behaviours following diagnosis (Madlensky et al., 2005; Bostean et al., 2013; Matsubara et al., 2013). Furthermore, Haug et al. (2018) showed that people with and without an FHC were equally likely to engage in unfavourable lifestyle behaviours. These studies illustrate how people with an FHC tend to make limited changes in relation to lifestyle behaviours, but they do improve their medical behaviours. However, there is a dearth of research around this topic and, in particular, little is known about why people with an FHC make limited health behaviour changes.

This lack of engagement from FDR of cancer patients in health promoting behaviours begs the question: what can be done to promote health behaviour changes in this group? van Veen et al. (2018) found that providing cancer survivors and their relatives with nutritional information led to positive dietary changes, independently of their reported nutritional information needs. However, several studies have found that relatives of cancer patients have unsatisfied information and education needs in a variety of areas such as supportive care for themselves and for their relative (Adams et al., 2009), medical information about the relative's diagnosis and future personal and familial cancer risk (McCarthy, 2011; Turner et al., 2013), and access to the information and healthcare providers in the first place (McCarthy, 2011; McDonnell et al., 2019). Additionally, Claassen et al. (2010) suggested that personalised and targeted health messages may work better for encouraging health behaviour changes in FDR of cancer patients. However, the effectiveness of this practice has yet to be evidenced. This research highlights that although family members of cancer patients make limited overall health behaviour changes, they also feel unsupported in their informational needs. Addressing this problem may aid FDR in overcoming any limitations that discourage them from engaging in health promoting behaviours.

It is clear that there is a variety of research surrounding people with an FHC, however, much of this research is quantitative and does not look into why FDR of cancer patients may make so few health behaviour changes. Overall, there is limited research on this topic that uses qualitative methods to explore the experience of those with an FHC. In this study, a series of semi-structured interviews with FDR of cancer survivors will explore the following questions: (1) do the health behaviours of FDR change due to the cancer diagnosis, and if so, how, and why, (2) what motivations and barriers exist for FDR when seeking to engage in health promoting behaviours, and (3) what do FDR believe healthcare organisations can do to improve the uptake of healthy lifestyle changes. As this study is inductive in nature, there are no themes that are hypothesised to emerge.

## 2. Method

This study was conducted and is reported in compliance with SRQR guidelines (O'Brien et al., 2014).

### 2.1. Design

This research employed a phenomenological qualitative design in the form of one-to-one semi structured interviews using an inductive thematic approach.

### 2.2. Participants

The sample was acquired using a convenience sampling method. The inclusion criteria for the study were that the participants were 18 or older, they were a biological first-degree relative (i.e., parent, sibling,

child) of a person who had survived cancer, and they had not had a personal cancer diagnosis themselves. The study was advertised using social media platforms such as Facebook and Twitter and specific cancer support groups from around Ireland were approached to ask about sharing the study advertisements with their followers via social media or email. There was no incentive for participation.

### 2.3. Data collection

Data was collected through semi-structured interviews over two weeks in June 2020 where the researcher conducting the interviews was informed by an interview schedule focusing on health behaviour changes, motivations for and barriers to change, and any recommendations for healthcare organisations or people (see Appendix 1). The interviews were designed to enable the participants to talk about their experiences of any health behaviour changes that may or may not have occurred as a result of their relative's cancer diagnosis and how they feel about what the healthcare system is currently doing to encourage health behaviour changes in first-degree relatives of cancer survivors. Audio recordings of the interviews were made. The interviews lasted between 7 and 44 min (M = 18 min). Due to restrictions imposed by the Covid-19 pandemic, all interviews took place individually online using either Facebook Messenger, Skype, or Microsoft Teams. The interview data were transcribed in standard 'playscript' orthography.

### 2.4. Patient public involvement (PPI)

The research questions, sampling methodology, interview schedule, and results interpretation were influenced by the researcher, who has an FHC and is an FDR of a cancer survivor, and through discussions with researchers and staff members of cancer support groups, and the study participants. This was done to ensure that PPI was an integral part of the design and outcomes of the study.

Prior to conducting the study, the proposed research questions, sampling methodology, and interview schedule were discussed with researchers in Arc Cancer Support Ireland to ensure that the appropriate participants were targeted and the relevant experiences and needs of FDR of cancer survivors were reflected in the study. After the completion of the data analysis, the results of the study were shared with staff member of the Gary Kelly Cancer Support Centre, and the study participants, using a graphic describing the themes (see Fig. 1). This was done as part of interpreting the emergent themes and in order to distinguish which were most important to the patients and public that were key to this research.

### 2.5. Ethical considerations

Ethical approval was obtained from the Maynooth University Social Research Ethics Subcommittee (SRESC) prior to the commencement of the study (reference number SRESC-2020-2,402,919). Participants were made aware of their right to withdraw from the interview. Furthermore, they were made aware of their right to withdraw their data from being used and to review and edit the data prior to its anonymisation a week after the interview took place. An ethical protocol was created to address the possibility that a participant may become distressed as a result of the interview process. This protocol included giving participants the ability to pause the interview and take a break, end the interview entirely, or withdraw their data from the study, as well as providing participants contact information for support services such as the Irish Cancer Society and the Crisis Text Line and the contact information for the research supervisor in case the participant did not feel that the research was carried out as described.

Measures were taken to anonymise the data and reduce the risk of participants being identified from the interview transcripts. All audio files of the interviews were destroyed a week after each interview took place. All participants were given code names based on the order the



Fig. 1. Breakdown of results shared for PPI.

interviews were conducted (i.e., first interviewee code name = PA1, second interviewee code name = PA2, etc.). The names of people and specific places such as places of residence, higher education institutions and healthcare facilities were disguised by redacting the names from the transcripts. All deletions for ethical reasons are marked clearly in the transcripts.

## 2.6. Data analysis procedure

The data were analysed using basic thematic analysis. The data analysis followed the six-stage thematic analysis process described in detail by Braun and Clarke (2006). This method was chosen as it is a commonly employed qualitative data analysis technique in psycho-oncology (Douglas et al., 2009; White et al., 2018). The qualitative research software Weft QDA was used to facilitate the analysis of the data through searching and reviewing themes in the text, as well as compiling quotes that supported the themes.

Firstly, the interviews were read and re-read (BMcK) in order to become familiarised with the data and its content. The digital transcripts of the interviews were then coded with initial ideas and meanings from the text (BMcK). Basic recurring themes were noted and relevant quotes were highlighted (BMcK). After the initial coding, emerging themes that were related to the research question were searched for throughout the text using the initial codes (BMcK). After a list of themes was formed from the previous stage, they were reviewed to check that they were appropriate and fit with the data, the research question, and the coding done previously (RM). It is at this stage that some themes became more important than others and therefore some of the initial themes were deleted or edited (BMcK & RM). Certain themes helped to explain others and these were identified as superordinate themes which held other subordinate themes together (BMcK & RM). The finalised master themes

were then defined and named so that they could be explained and justified accurately (BMcK & RM). The final stage involves writing up the analysis of the data to provide a coherent argument as to why the chosen themes were relevant to the data and the research question (BMcK). This style of thematic analysis is a dynamic and cyclical process which involves returning to stages several times to ensure the analytic results are as accurate as possible.

The resulting list of themes was reviewed by the secondary author (RM). A select number of transcripts were analysed by the secondary author and discussions were held between the two authors to ensure there was consensus over the finalised list of themes. This was done to enhance the trustworthiness and credibility of the data analysis and findings of the study.

## 3. Results

### 3.1. Sample characteristics

The sample of nine participants comprised of seven females and two males. The ages of participants ranged from 23 to 56. The majority of the participants had a parent who was a cancer survivor, either a mother ( $n = 4$ ) or a father ( $n = 2$ ). The most common type of cancer that emerged amongst participants' FDR was breast ( $n = 4$ ). The time from which the FDR was declared cancer free varied greatly from eight months to over six years, with variation in regard to those who had multiple diagnoses (see Table 1).

### 3.2. Themes emerging from data

In this section, each of the themes will be defined, described, and illustrated using representative quotations from the transcripts (see

**Table 1**  
Participant characteristics.

Participant ID	Gender	Age	Cancer Survivor Relation	Cancer Type	Time Since Cancer Free
PA1	Female	31	Mother	Breast	Nine Months
PA2	Male	24	Mother	Breast	One Year, Ten Months
PA3	Female	41	Mother	Kidney	Six Years, Eight Months
PA4	Female	41	Daughter	Acute Lymphoblastic Leukaemia (ALL)	Eight Months
PA5	Female	56	Sister	Breast	Three Years, Six Months (approximate)
PA6	Female	56	Brother	Non-Hodgkin Lymphoma (NHL)	One Year
PA7	Male	23	Father	Prostate	One Year, Six Months
PA8	Female	34	Father	Prostate, Bladder, Colon	Fifteen Years since first diagnosis (two all clears, one ongoing, and one recurring diagnosis since)
PA9	Female	33	Mother	Breast	One Year (since most recent all clear, two previous diagnoses)

Table 2). After analysing the transcripts, four main superordinate themes emerged, each with their own subordinate themes (see Fig. 1).

### 3.2.1. T1. Being Conscious/Aware

Participants expressed that the biggest change to their behaviour as a result of their relative's cancer diagnosis was becoming "definitely more conscious (PA1)", or "more aware of what to look for (PA5)" in relation to their overall health, signs of illness, and family history of illness. In regard to why this change occurred, some participants (n = 3) cited the unexpectedness of their relative's diagnosis, "I would have felt as though it was something that wasn't going to happen to me (PA1)".

### 3.2.2. T1.1. Getting medical check-ups

This was the main behavioural change that occurred as a result of becoming more conscious (n = 7). Medical preventative behaviours referred to by participants included actively self-examining themselves more, engaging in and seeking out cancer screenings, "I sort of felt that blood tests and getting doctors involved was the, was the way to keep myself safe in that sense (PA3)", and seeking medical attention more regularly or if they had physical symptoms, "if that doesn't go away, I might need to go, eh, have a look or ask some advice (PA2)".

### 3.2.3. T1.2. Feeling that cancer is unavoidable

Several participants (n = 4) referenced that they felt that there was an element of inevitability to being diagnosed with cancer in their lifetime. Reasons for this were their personal FHC, the outcomes for other family members who had had cancer, the statistics surrounding cancer diagnoses, "one in two (PA5, PA6, PA8)", and not feeling that behavioural changes such as diet would actually make a difference to their risk of getting cancer, "diet's maybe a part of it, but it's not all of it (PA6)".

### 3.2.4. T1.3. Noticing changes to the body with age

This heightened awareness of how the body changes with age was

referred to by nearly all participants (n = 8) as a trigger for their shift in consciousness, and also as a new element that they have noticed as a result of becoming more aware, "I'm probably more aware now that I'm, I'm older that maybe it's something I need to be keeping an eye on for myself (PA8)".

### 3.2.5. T2. Limited lifestyle changes

Only two participants explicitly said that they had made long-term lifestyle changes (i.e., diet, exercise) as a result of their relative's cancer diagnosis. The other participants in the study either did not bring up lifestyle changes, admitted that they only had made further medical changes as opposed to lifestyle ones, "it was a lot harder to kind of like institute those changes (PA3)", or they did not change their behaviour at all.

### 3.2.6. T2.1. Perception of Existing Healthy Behaviours

The majority of participants (n = 5) reasoned that part of why they made limited lifestyle changes was because they believed that their existing behaviours were already healthy. When asked if they had made any lifestyle changes since the diagnosis, these participants talked about how they have always made an effort to be healthy or would discuss their current behaviours to highlight how they actively avoid particular unhealthy actions, "I've never been a massive drinker, I've never been a smoker (PA8)".

### 3.2.7. T2.2. Effort of Making Changes

This theme broadly encompasses the barriers and limitations that participants faced when trying to make changes to their lifestyle behaviours. Their efforts to make changes to their health behaviours were affected by issues such as motivation, time, money, falling out of habit or difficulty keeping up habits, "become a bit complacent (PA6)", and struggling to connect the beneficial outcomes to particular behaviours (e.g., understanding that diet and exercise are linked with overall health and not just weight loss and beauty standards). Participants also brought up the current context of the COVID-19 pandemic as a barrier to engaging in health promoting behaviours as they felt the pandemic affected their motivation, "in this COVID, eh, situation the fact that I'm in the house all the time, I might feel that I'm stuck in a rut and then my motivation might be a wee bit lower (PA2)".

### 3.2.8. T2.3. Not Letting Fear Dictate Life

A portion of the participants (n = 4) expressed their thoughts on the idea that although people should be mindful of their health, they should not let that dictate the choices they make and how they live their lives, "you can't let it rule your life (PA3)". Participants spoke about how they did not want to let the fear of getting cancer in the future affect their life decisions, such as having a family, or affect their enjoyment of life through their mental health or indulging in certain foods or activities (e.g., eating cake, drinking wine, etc.).

### 3.2.9. T3. Psychosocial Consequences of Experience

While speaking about their experiences, participants often referenced the psychological and social consequences or effects that they experienced as a result of being an FDR of a cancer survivor, despite there being no questions in the interview schedule to prompt these topics.

### 3.2.10. T3.1. Impact on family relationships

There were both positive and negative impacts on family relationships experienced by participants. Positive effects included coming together as a family to support one another, "he's made us feel like they're not, it's not the end of the world, and maybe that's him minding us (PA8)", and getting to spend time together as a result. Negative effects included strained family dynamics and relations with other family members, large-scale impact on the relationship of the participant with the cancer survivor, and the stresses of dealing with other people while also trying

**Table 2**  
Themes extracted from experiences of FDR of cancer survivors.

Superordinate Theme	Subordinate Theme	Definition and Summary	Representative Quotes
Being Conscious/ Aware		The most cited change that participants experienced as a result of their relative's cancer diagnosis. Participants referred to becoming more aware of their overall health, health risks, signs of illness, and family history of illness. The unexpectedness of the diagnosis was a reason for this change.	"I wanted to sort of em ... I suppose start, start keeping an eye out for things" (PA3) "the main reason why I got so much, eh, more concerned about my body and the signs it gives me is because this came out of left field just so completely" (PA2) "I'm more conscious that there is a history of cancer in the family" (PA8)
	Getting Medical Check-Ups	A behavioural change that came about as a result of participants change in consciousness. Behaviours most often referred to self-examinations and medical screenings.	"I'm much better at examining myself now, I do it once a month out of habit." (PA1) "when he got the colon diagnosis, em, I went for em a check-up myself, I went for a colonoscopy em just in case" (PA8)
	Feeling That Cancer is Unavoidable	A change in awareness in participants around their own risk of cancer and feeling that lifestyle changes may not make any difference to their risk due to the sense that cancer is unavoidable.	"you always hope it's not gonna be you but obviously statistically it's, is it one in two or something" (PA6) "it seems inevitable that it's going to happen at some point" (PA3)
	Noticing Changes in the Body with Age	A further element of becoming more conscious, including growing older as a reason for becoming more aware or noticing bodily changes with age as a result of having heightened awareness.	"also related to like coming into my thirties and you're like think you need to kinda get yourself together a bit." (PA9) "as you get older you definitely become a bit more aware of your mortality" (PA5)
Limited Lifestyle Changes		The lack of lifestyle changes made by participants.	"lifestyle not so much." (PA2) "I've thought about it, read a bit about it but I haven't really changed my behaviour, no." (PA6)
	Perception of Existing Healthy Behaviours	The feeling from participants that their current lifestyle behaviours were already healthy and as a result, there was no need to make changes in that regard.	"I do have a conscious effort to try and eat right and to workout, I've always kinda had that." (PA2) "I've always been healthy anyway I was a sporty kid ... I've always been diet, like conscious of my diet and different things as well." (PA4)
	Effort of Making Changes	All the different barriers that exist for participants if and when they try and make an effort to change their lifestyle behaviours. These limitations include perception of behavioural outcomes, time, motivation, etc.	"motivation ahaha like, yeah I suppose yeah, yeah laziness and eh, motivation and having a relatively demanding job" (PA9) "it felt like there were too many things that, for me to be able to control ... probably the biggest thing for me is like sort of failing to see that exercise and eating healthier and all of that kind of stuff like has benefits apart from it being about looks." (PA3)
	Not Letting Fear Dictate Life	The participants' belief that you should be mindful of your health but should not let the fear of cancer dictate how you live and enjoy your life.	"kind of just falling out of a habit I guess" (PA7) "if I wanna have the cake, if I wanna have the wine, life's too short I'm gonna, I'm gonna have it and enjoy myself." (PA6) "you can't treat it like a ticking time bomb because it's, you know, it definitely isn't that." (PA9)
Psychosocial Consequences of Experience		The psychological and social consequences and outcomes that came from their lived experience of being an FDR of a cancer survivor. These topics were brought up despite being unprompted by the interview schedule.	"The effects of cancer on a family are way beyond the person who's had it" (PA4)
	Impact on Family Relationships	The positive and negative impact of the lived experience of participants on their family relationships.	"the fact that we're, we kinda kept the channels for talk open, and we were able to, kinda let each other that everything's okay with it." (PA2) "you know there were good aspects of it like, you know, family being together and looking after each other and that sort of stuff but there were also sort of, you know, unexpectedly hard parts ... it can be quite damaging, em, the family dynamic can get very strained" (PA3) "my relationship with my mother definitely changed due to illness because you kind of have that innate fear that they're going to die" (PA9)
	Impact on Mental Health	How the experience affected participants mental health. Participants highlighted the effects as well as their thoughts on how people should manage their mental wellbeing.	"I started taking my mental health more seriously as well ... I sort of felt like I couldn't cope with a lot of things and I needed to start kind of looking out, after myself more in that sense ... if you can take care of that side of things, it'll pay dividends down the line" (PA3) "mental health is a huge part ... like health, you know your diet, your, your body, your all that, that ... Affects your mental health as well and your mental health effects that" (PA4) "I did end up in A&E through anxiety" (PA6)
Unmet Needs		The specific needs of participants that are not being satisfied. These were brought up when speaking about what participants believed healthcare organisations could do to improve the uptake of health behaviour changes in FDR of cancer survivors.	"I don't recall seeing anything, em, directed at the family of, you know, the relatives" (PA1) "I don't know if they do anything at all right now nobody ever made any contact with me or had any, em, reached out in any sort of way" (PA3)
	Need for Information	The need for FDR of cancer survivors to have access to and be provided with accessible, useful, and targeted information.	"sometimes I felt with the nurses there was a bit of a, bit of a barrier they didn't want to actually discuss things with you." (PA6) "I think maybe there's a piece of education they could do around like helping people understand processes or treatments ... I imagine there's huge parts of the population that can't

(continued on next page)



Table 2 (continued)

Superordinate Theme	Subordinate Theme	Definition and Summary	Representative Quotes
	Need for Support	The need for FDR of cancer survivors to be provided the necessary support to make health behaviour changes and to cope with the overall experience.	<p>access information and don't know about these things ... maybe providing information around kind of what's involved, the terminology, the language of it" (PA8)</p> <p>"So, I think if you, there was just some services that were just, a wee bit more out in the open and you wouldn't have to, like dive in the internet and search for them." (PA2)</p> <p>"particularly if it's your person that you go to for help when you're in trouble like ... I didn't have someone that I could really turn to" (PA3)</p> <p>"as a family ... there wasn't much support. I think you're just expected to get on with it." (PA6)</p> <p>"I suppose as, as a daughter I like, I'm kind of, I'm not getting that level of support ... sometimes you see like, and it seems like the entire family get a support whereas it's not been our experience" (PA8)</p>

to be there for the cancer survivor, "everybody's in and out, crazy times, going to the hospital (PA6)".

### 3.2.11. T3.2. Impact on Mental Health

Most participants (n = 7) spoke about how the experience affected their mental health in some way. Some brought up the fear they experienced as a result of the cancer diagnosis and how that was difficult to deal with, "the stress, you know, it's lessened but it's not completely gone if that makes sense (PA4)". Others brought up how their experiences exacerbated existing mental health concerns. In general, most of these participants mentioned the importance of taking care of one's mental health during times of stress such as what they went through, and that both the cancer survivors and FDR should seek professional help to cope with the experience of cancer, "don't oppose going to talk to a professional, like a counsellor (PA2)".

### 3.2.12. T4. Unmet needs

Participants were asked what they believed healthcare organisations could do to improve the uptake of health behaviour changes in FDR of cancer survivors and if they could offer any advice for people like themselves in relation to health behaviours. This resulted in participants (n = 8) speaking about their experiences of unmet needs in the healthcare system and what they would recommend healthcare providers could do to satisfy these needs.

### 3.2.13. T4.1. Need for information

Participants (n = 8) spoke about a distinct lack of accessible, useful, and targeted information that was available to FDR of cancer patients. Issues included no educational materials that were directly for relatives of cancer patients, "there was no kind of em, here's what daughters of someone with cancer should have kind of a thing (PA3)", unwillingness of healthcare professionals to speak to them or explain things more clearly, and the inaccessibility of information due to the use of jargon and/or the overabundance of misinformation available. Ways to combat these issues according to participants could be to create targeted health messages and reaching out to FDR of cancer patients to explain to them what they can do to reduce their own risk, "people who are in remission, you know, to maybe discuss with their families you know around healthy eating and exercise (PA9)".

### 3.2.14. T4.2. Need for support

Another unsatisfied need expressed was that of support. Participants (n = 7) desired a variety of different supports, such as familial group support, "just have a wee side for if you notice that any of your family members are taking this very hard, because, it's kind of a group effort to get over this (PA2)", mental health support, and support in regard to engaging in health promoting behaviours. Furthermore, sometimes participants did not know where they could go to access support if they wanted it or did not know if their situation was serious enough to qualify

for support, "I don't think there was, I mean there was nothing for me (PA3)".

## 4. Discussion

This study aimed to investigate whether or not FDR of cancer survivors change their health behaviours, why they choose to make changes or not, what motivations and limitations exist in relations to making health behaviour changes, and what FDR believe healthcare organisations can do to improve the uptake of health behaviour changes in people like themselves. It was found that, while the majority of participants (n = 8) made changes to their medical behaviours, a minority made changes to lifestyle behaviours (n = 2) or did not make any behavioural changes at all (n = 1). The major motivations for participants to change their health behaviours were the desire to live a long and high-quality life, getting older, and wanting to catch cancer early if they do get it. The major barriers to engaging in health behaviour changes were general motivation, falling out of habits, and struggling to connect the positive outcomes of lifestyle changes to the behaviours. Participants recommended that healthcare organisations should provide greater levels of both information and support to FDR of cancer survivors in order to improve engagement in health promoting behaviours. These findings have important implications for those looking to support families following a cancer diagnosis.

It was unsurprising that the majority of participants only made medical behavioural changes, rather than lifestyle changes, following their relative's diagnosis. This echoes the findings of previous studies looking at health behaviour changes of people with an FHC (Madlensky et al., 2005; Bostean et al., 2013; Matsubara et al., 2013; Haug et al., 2018), and further highlights the fact that people with an FHC do not actively change their diet and exercise habits, despite evidence showing how these factors can influence a person's cancer risk (Department of Health, 2017). The results of the current study expand on existing literature, specifically by highlighting why FDR make such limited lifestyle changes. Specifically, the subordinate themes Perception of Existing Healthy Behaviours, Effort of Making Changes, and Not Letting Fear Dictate Life directly indicate participant's reasoning when making health behaviour decisions and the difficulties they face in both engaging in health promoting behaviours and balancing health management with enjoying life. In addition, it is interesting to consider the theme Effort of Making Changes in the current global context as multiple participants spoke about how they experienced lack of motivation due to the COVID-19 pandemic. This may indicate that the pandemic or issues caused by lockdown were exacerbating the difficulties people face when trying to undertake health promoting behaviours.

There were a number of unexpected findings that emerged from the results. In particular, the theme Impact on Mental Health was touched on by the majority of the interviewees (n = 6). The fact that there were no questions that prompted this topic and that so many participants

brought this up of their own volition instead highlights its centrality in the experience of FDRs. However, there is a depth of research on the psychological effects of a cancer diagnosis on family members, with studies finding that relatives often experience greater psychological stress than the patients themselves (Heins et al., 2013; Turner et al., 2013), and overall negative mental health effects as a result of their experience (Mosher et al., 2013). The results of this study further highlight the considerable psychological impact of a cancer diagnosis on FDRs, suggesting a need to consider the provision of supports for family members dealing with a cancer diagnosis.

Another unexpected finding was many participants' Feeling that Cancer is Unavoidable. This fatalistic view of people's odds of getting cancer may be contributing to a lack of engagement in health behaviour changes. While this theme was surprising in the context of the research, there have been studies demonstrating that having an FHC leads to a greater cancer risk perception (Haber et al., 2012; Katz et al., 2017). In the Irish population specifically, one study found that people do not have a good understanding of cancer risk factors and one in seven participants did not believe that lifetime cancer risk could be changed (Ryan et al., 2015). This is an area that could be addressed by health messages to ensure that the efficacy and worth of health promoting behaviours is understood by people despite the perception that the chances of getting cancer are very high regardless.

As part of the PPI element of this study, the themes of the research were shared with participants and national cancer support groups in order to collect feedback on what they thought of the results and if they felt these were reflective of their own experience. The themes that were highlighted as important and very reflective by PPI were Unmet Needs, Psychosocial Consequences of Experience, and Feeling that Cancer is Unavoidable. For the latter, one participant spoke about how that theme was very relevant to their experience, which is unsurprising as they spoke the most about this sense of inevitability in regard to a personal cancer diagnosis. On the other hand, a different participant (one of the two who had made explicit lifestyle changes) described how they found that theme surprising and struggled to understand why people would feel that way if they were making behavioural changes. This example highlights the considerable individual variability in family members' reactions to diagnosis and may suggest that any supports encouraging health behaviour changes should be tailored to individual needs.

Research has demonstrated how relatives of cancer patients often express needs for information from healthcare providers (Adams et al., 2009; McCarthy, 2011; Turner et al., 2013; McDonnell et al., 2019). Similarly, all the PPI feedback in this study emphasised how the theme Unmet Needs was most reflective of their experiences. This clearly indicates that FDR of cancer survivors do not feel adequately informed or supported by healthcare organisations. Problems that were cited included nobody reaching out to the FDR during or after treatment to discuss their risks, feeling unsupported in their efforts to make health behaviour changes, being unsure of who to go to when they felt scared or upset both individually and as a family, struggling to find trustworthy or relevant information themselves, and more. All of these issues were brought up after participants were asked what they would recommend healthcare organisations to do to improve the uptake of health behaviour changes in family members of cancer survivors. This illustrates that FDR of cancer survivors have a clear idea of their unmet needs and what they would like to see healthcare organisations offering people like themselves. The important step now is for healthcare providers to work on improving the experiences and outcomes for this group.

There were several strengths to this study. The sample of participants had a good balance of FDR of cancer survivors in terms of the varied age range and of different cancer types their relatives had. Furthermore, the PPI element of this study adds value to the findings and their interpretation as it is those who have been directly affected by cancer who have shaped the research outcomes. However, there were also several limitations to this study. There is limited generalisability of the findings given the small sample size of Irish FDR of cancer survivors, and the

recruitment strategy used may not have reached all eligible FDR. The participants' experiences were collected retrospectively and thus it is possible that the reported experiences may have differed if they were gathered during the treatment stage. In addition, the data collection for this study occurred in the context of a national lockdown due to the COVID-19 pandemic, which may have impacted the participants' attitudes and behaviours.

In conclusion, this study shows that FDR of cancer survivors do make medical changes, but limited lifestyle changes. It is clear that the participants faced many difficulties throughout their experiences in relation to how they engage in health behaviour changes, but also on a psychological and social level. These findings imply that healthcare organisations should consider what family members have to say about the lack of support and information made available for them, especially as individuals who are at a higher risk of developing cancer themselves. Taking these recommendations on board may not only lead to reduced cancer cases in FDR of cancer patients but may also lead to peace of mind for those who have already dealt with a great deal.

#### CRediT authorship contribution statement

**Beth McKeague:** Conceptualization, Methodology, Formal analysis, Investigation, Resources, Writing - original draft, Visualization, Funding acquisition. **Rebecca Maguire:** Writing - review & editing, Supervision, Project administration.

#### Declaration of competing interest

There was no conflict of interests for the authors in this study.

#### Acknowledgements

This work was supported by an Irish Cancer Society Summer Studentship SSS20MCK. The authors acknowledge the input and support that was provided by several Irish cancer support groups (i.e., Arc Cancer Support, West Wicklow Cancer Support, Gary Kelly Cancer Support Centre, Éist Cancer Support Centre Carlow, Kerry Cancer Support Group, East Galway and Midlands Cancer Support, and YouCan Ireland Cancer Support Network) and the family members of cancer survivors that took part in this study.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejon.2021.101905>.

#### References

- Adams, E., Boulton, M., Watson, E., 2009. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Educ. Counsel.* 77 (2), 179–186. <https://doi.org/10.1016/j.pec.2009.03.027>.
- Beesley, V.L., Price, M.A., Webb, P.M., 2011. Loss of lifestyle: health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer. *Support. Care Canc.* 19 (12), 1949–1956. <https://doi.org/10.1007/s00520-010-1035-2>. Heidelberg: Springer Nature B.V.
- Boonyasirawat, W., et al., 2014. Intention to undergo colonoscopy screening among relatives of colorectal cancer cases: a theory-based model. *Ann. Behav. Med.* 47 (3), 280–291. <https://doi.org/10.1007/s12160-013-9562-y>.
- Bostean, G., Crespi, C.M., McCarthy, W.J., 2013. Associations among family history of cancer, cancer screening and lifestyle behaviors: a population-based study. *Canc. Causes Contr.* 24 (8), 1491–1503. <https://doi.org/10.1007/s10552-013-0226-9>.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3 (2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>. Routledge.
- Claassen, L., Henneman, L., Janssens, A.C.J.W., Wijdenes-Pijl, M., Qureshi, N., Walter, F. M., et al., 2010. Using family history information to promote healthy lifestyles and prevent diseases; a discussion of the evidence. *BMC Publ. Health* 10 (1), 248. <https://doi.org/10.1186/1471-2458-10-248>.
- Department of Health, 2017. National Cancer Strategy 2017–2026. Available at: <https://assets.gov.ie/9315/6f1592a09583421baa87de3a7e9cb619.pdf>.

- Douglas, H.A., Hamilton, R.J., Grubs, R.E., 2009. The effect of brca gene testing on family relationships: a thematic analysis of qualitative interviews. *J. Genet. Counsel.* 18 (5), 418–435. <https://doi.org/10.1007/s10897-009-9232-1>.
- Haber, G., Ahmed, N.U., Pekovic, V., 2012. Family history of cancer and its association with breast cancer risk perception and repeat mammography. *Am. J. Publ. Health* 102 (12), 2322–2329. <https://doi.org/10.2105/AJPH.2012.300786>.
- Haug, U., Riedel, O., Cholimakow-Bodechtel, C., Olsson, L., et al., 2018. First-degree relatives of cancer patients: a target group for primary prevention? A cross-sectional study. *Br. J. Canc.* 118 (9), 1255–1261. <https://doi.org/10.1038/s41416-018-0057-2>.
- Heins, M., Schellevis, F., Rijken, M., Donker, G., van der Hoek, L., Korevaar, J., et al., 2013. Partners of cancer patients consult their GPs significantly more often with both somatic and psychosocial problems. *Scand. J. Prim. Health Care* 31 (4), 203–208. <https://doi.org/10.3109/02813432.2013.861153>.
- Humpel, N., Magee, C., Jones, S.C., 2007. The impact of a cancer diagnosis on the health behaviors of cancer survivors and their family and friends. *Support. Care Canc.* 15 (6), 621–630. <https://doi.org/10.1007/s00520-006-0207-6>.
- Katz, L.H., Advani, S., Burton-Chase, A.M., Fellman, B., Polivka, K.M., Yuan, Y., et al., 2017. Cancer screening behaviors and risk perceptions among family members of colorectal cancer patients with unexplained mismatch repair deficiency. *Fam. Cancer* 16 (2), 231–237. <https://doi.org/10.1007/s10689-016-9947-8>.
- Lacombe, J., Armstrong, M.E.G., Wright, F.L., Foster, C., et al., 2019. The impact of physical activity and an additional behavioural risk factor on cardiovascular disease, cancer and all-cause mortality: a systematic review. *BMC Publ. Health* 19 (1), 900. <https://doi.org/10.1186/s12889-019-7030-8>.
- Li, J., Hart, T.L., Aronson, M., Crangle, C., Govindarajan, A., et al., 2016. Cancer worry, perceived risk and cancer screening in first-degree relatives of patients with familial gastric cancer. *J. Genet. Counsel.* 25 (3), 520–528. <https://doi.org/10.1007/s10897-015-9903-z>.
- Madlensky, L., Vierkant, R.A., Vachon, C.M., Pankratz, V.S., Cerhan, J.R., Vadaparampil, S.T., et al., 2005. Preventive health behaviors and familial breast cancer. *Cancer Epidemiol. Biomark. Prev.* 14 (10), 2340. <https://doi.org/10.1158/1055-9965.EPI-05-0254>. LP – 2345.
- Matsubara, H., Hayashi, K., Sobue, T., Mizunuma, H., Suzuki, S., et al., 2013. Association between cancer screening behavior and family history among Japanese women. *Prev. Med.* 56 (5), 293–298. <https://doi.org/10.1016/j.ypmed.2013.01.017>.
- Mazanec, S.R., Flocke, S.A., Daly, B.J., 2015. Health behaviors in family members of patients completing cancer treatment. *Oncol. Nurs. Forum* 42 (1), 54–62. <https://doi.org/10.1188/15.ONF.54-62>.
- McCarthy, B., 2011. Family members of patients with cancer: what they know, how they know and what they want to know. *Eur. J. Oncol. Nurs.* 15 (5), 428–441. <https://doi.org/10.1016/j.ejon.2010.10.009>.
- McDonnell, K.K., Owens, O.L., Hilfinger Messias, D.K., Heiney, S.P., Friedman, D.B., Campbell, C., et al., 2019. Health behavior changes in African American family members facing lung cancer: tensions and compromises. *Eur. J. Oncol. Nurs.* 38, 57–64. <https://doi.org/10.1016/j.ejon.2018.12.002>.
- Mosher, C.E., Bakas, T., Champion, V.L., 2013. Physical health, mental health, and life changes among family caregivers of patients with lung cancer. *Oncol. Nurs. Forum* 40 (1), 53–61. <https://doi.org/10.1188/13.ONF.53-61>.
- O'Brien, B.C., Harris, I.B., Beckman, T.J., Reed, D.A., Cook, D.A., et al., 2014. Standards for reporting qualitative research. *Acad. Med.* 89 (9), 1245–1251. <https://doi.org/10.1097/ACM.0000000000000388>.
- O'Connor, M., Drummond, F., O'Donovan, B., Donnelly, C., 2019. *The Unmet Needs Of Cancer Survivors In Ireland: A Scoping Review 2019*. Cork. Available at: [https://www.ncri.ie/sites/ncri/files/pubs/HSE Report 3 - Unmet needs of cancer survivors in Ireland Final Version.pdf](https://www.ncri.ie/sites/ncri/files/pubs/HSE%20Report%203%20-%20Unmet%20needs%20of%20cancer%20survivors%20in%20Ireland%20Final%20Version.pdf).
- Rex, D.K., Johnson, D.A., Lieberman, D.A., Burt, R.W., Sonnenberg, A., 2000. Colorectal cancer prevention 2000: screening recommendations of the American College of Gastroenterology. *Am. J. Gastroenterol.* 95 (4), 868–877. [https://doi.org/10.1016/S0002-9270\(00\)00851-0](https://doi.org/10.1016/S0002-9270(00)00851-0).
- Ryan, A.M., Cusken, S., Schellekens, H., Ni Bhuachalla, E., Burns, L., Kenny, U., et al., 2015. 'Poor awareness of risk factors for cancer in Irish adults: results of a large survey and review of the literature'. *Oncol.* 20 (4), 372–378. <https://doi.org/10.1634/theoncologist.2014-0453>.
- Safaeian, M., Solomon, D., Castle, P.E., 2007. Cervical cancer prevention—cervical screening: science in evolution. *Obstet. Gynecol. Clin. N. Am.* 34 (4), 739–760. <https://doi.org/10.1016/j.jgc.2007.09.004>.
- Turner, D., Adams, E., Boulton, M., Harrison, M., Khan, N., Rose, P., et al., 2013. Partners and close family members of long-term cancer survivors: health status, psychosocial well-being and unmet supportive care needs. *Psycho Oncol.* 22 (1), 12–19. <https://doi.org/10.1002/pon.2050>. John Wiley & Sons, Inc.
- van Veen, M.R., Winkels, R.M., Kampman, E., Beijer, S., van Veen, M.R., 2018. Nutritional information provision to cancer patients and their relatives can promote dietary behavior changes independent of nutritional information needs. *Nutr Cancer* 70 (3), 483–489. <https://doi.org/10.1080/01635581.2018.1446092>.
- White, J., Park, J., Russell, K.B., Reynolds, K.A., Madani, A., Carlson, L.E., et al., 2018. Falling through the cracks. A thematic evaluation of unmet needs of adult survivors of childhood cancers. *Psycho Oncol.* 27 (8), 1979–1986. <https://doi.org/10.1002/pon.4754>.
- Whitney, C.A., Dorfman, C.S., Shelby, R.A., Keefe, F.J., Gandhi, V., Somers, T.J., 2019. Reminders of cancer risk and pain catastrophizing: relationships with cancer worry and perceived risk in women with a first-degree relative with breast cancer. *Fam. Cancer* 18 (1), 9–18. <https://doi.org/10.1007/s10689-018-0082-6>.
- Wu, M., Zhang, Z., Kampman, E., Zhou, J., Han, R., Yang, J., et al., 2011. Does family history of cancer modify the effects of lifestyle risk factors on esophageal cancer? a population-based case-control study in China. *Int. J. Canc.* 128 (9), 2147–2157. <https://doi.org/10.1002/ijc.25532>.