



# Illness Cognitions Among Adolescents and Young Adults Who Have a Parent with Cancer: a Qualitative Exploration Using the Common-Sense Model of Self-regulation as a Framework

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## Abstract

**Background** Individuals construct beliefs about an illness based on their own perceptions, interpretation, and understanding of the illness and its treatment. These beliefs (collectively referred to as “illness cognitions” or “representations”) can have implications for psychological outcomes in family members and carers of an individual with an illness. The aim of this study was to explore young people’s perceptions of their parent’s cancer using the Common-Sense Model of Self-Regulation as a theoretical framework.

**Methods** Semi-structured, one-on-one interviews were conducted with young people who had a parent diagnosed with cancer. Interview transcripts were analysed using deductive thematic analysis techniques.

**Results** Eleven young people aged 15–24 years participated in the study. Major themes aligned with the dimensions of the Common-Sense Model of Self-Regulation. Young people described their experiences with parental cancer with reference to cognitive representations (beliefs about the illness identity, their understanding or coherence of the illness, and consequences, curability or controllability, timeline, and cause of the illness) and emotional representations (emotional beliefs and subjective feelings about the illness).

**Conclusions** Findings indicate that young people’s perceptions of their parent’s cancer can be usefully described within the framework of the Common-Sense Model of Self-Regulation. Future research should investigate the relationships between young people’s illness cognitions, coping strategies, and psychological adjustment following their parent’s cancer diagnosis. This will provide valuable insights for the development of interventions that target specific types of illness cognitions associated with maladaptive coping strategies and poor adjustment.

**Keywords** Adolescent and young adult · Common-sense model of self-regulation · Illness cognitions · Parental cancer · Oncology · Qualitative research

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## Introduction

A parent’s diagnosis of cancer can have a significant impact on the family and can be especially distressing for dependent children. Adolescents and young adults, who are at an age where they have the capacity to understand the potential implications of cancer for themselves and their family [1, 2], have been identified as experiencing higher levels of distress than younger children [3–5]. In Australia, it is estimated that 21,000 young people aged 12–25 years have a parent diagnosed with cancer each year [6], and more than half experience clinically-elevated levels of distress [7].

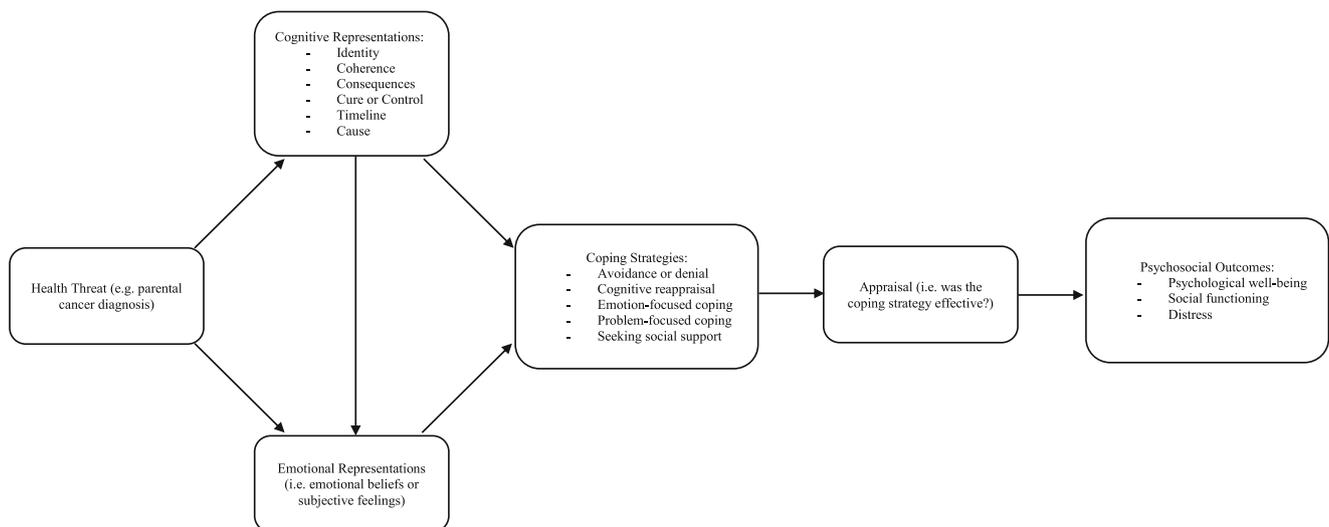
A range of factors are known to moderate young people’s psychological adjustment following a parent’s cancer diagnosis, including their age and gender, their parent’s gender, time since parent’s diagnosis, having unmet needs, and poor family functioning [3, 8–11]. Some findings also

suggest that the way that children think about their parent's cancer is associated with their ability to cope with, and adjust to, the illness. For example, Compas et al. [5] found that children's perception of the stressfulness of their parent's cancer was associated with the development of anxiety and depression, and that this had a more significant impact than the stage of their parent's disease and their prognosis. Furthermore, they found that children generally perceived low levels of personal control over their parent's cancer, which may potentially prevent them from using problem-focused approaches to coping [5]. Despite these important findings, to the best of our knowledge, there has been no recent research exploring the beliefs that young people form about their parent's cancer and the potential impact of these beliefs on their psychological adjustment to the illness.

Leventhal's Common-Sense Model of Self-Regulation proposes an explicit causal link between an individual's beliefs about an illness, the coping strategies that they employ in response to the illness, and their physical health and psychological outcomes (see Fig. 1) [14–16]. An individual constructs beliefs about an illness based on their own perceptions, interpretation, and understanding of the illness and its treatment [15, 17, 18]. These beliefs are collectively defined as “illness cognitions” or “representations”, and are not necessarily scientifically or medically substantiated [19]. They are formulated based on information provided by three broad domains of information: previous social interactions, personal experiences, and cultural knowledge of the illness; external social influences from perceived important others or authoritative figures; and current experiences with the illness [15]. Illness cognitions are complex and dynamic [20], evolving over time in response to internal and external stimuli, for example; emerging side effects of treatment or public opinion about the causes of the illness [19].

The Common-Sense Model of Self-Regulation is conceptualized as a parallel processing framework, whereby an individual simultaneously constructs cognitive and emotional representations of an illness [15]. Cognitive representations are organized around five central themes or dimensions: identity (the label used to describe the illness and perceptions of symptoms associated with the illness), consequences (beliefs about the anticipated or experienced impact of the illness on quality of life or physical, cognitive, or social capacity), cure or control (beliefs about the efficacy of treatment or the extent to which the individual has personal control over the illness), timeline (beliefs about the duration or progression of the illness), and cause (beliefs about the factors responsible for causing the illness). These dimensions are considered to be the “basic building blocks” of investigations into how individuals construct beliefs about illness [15]. The Common-Sense Model of Self-Regulation reflects an ongoing interplay between empirical data and theoretical concepts [21]. As a result, the original model has been extended through the inclusion of an additional cognitive representation dimension of coherence (personal understanding or comprehension of the illness) [22]. Other changes have included incorporating a cyclical timeline dimension, and splitting the cure or control dimension into separate dimensions of treatment control and personal control [22].

In response to an illness or health threat, an individual is thought to employ coping strategies that are consistent with their own representation of the illness or threat. For example, research indicates that perceptions of serious consequences are associated with avoidance and denial coping strategies, such as behavioural disengagement [23]. Furthermore, perceptions that the illness is uncontrollable, chronic, and highly symptomatic have also been associated with avoidance and denial coping strategies [15]. In contrast, perceptions that the illness is controllable have been associated with active coping strategies, including problem-focused coping [24]. This



**Fig. 1** Leventhal's Common-Sense Model of Self-Regulation applied to parental cancer [adapted from 12, 13]

research highlights the importance of understanding these associations; by identifying and modifying beliefs that are associated with maladaptive coping strategies, an individual's distress may be reduced, potentially resulting in better psychological adjustment [15].

Although the model was originally developed to describe “lay” understanding of illness experiences in individuals diagnosed with an illness [25], it has also been used to explore illness cognitions in family members and significant others caring for someone experiencing ill-health [26–33]. Bogosian et al. [29] used the model to describe illness cognitions among adolescents who have a parent with multiple sclerosis. Using a quantitative measure, developed for specific use in this cohort, they found that stronger subjective beliefs about the negative consequences of their parent's illness and a perception that it was chronic and unpredictable were associated with poorer psychological adjustment, independent of parental report of illness severity [29].

Based on these findings, the Common-Sense Model of Self-Regulation is proposed as an appropriate theoretical framework for exploring illness cognitions in young people who have a parent with cancer. The aim of this study was to explore young people's perceptions of their parent's cancer and examine how these perceptions correspond with the dimensions of illness cognitions as understood within the Common-Sense Model of Self-Regulation.

## Methods

### Design

Semi-structured, one-on-one interviews were conducted with young people who had a parent diagnosed with cancer. Interviews explored young people's experiences following their parent's diagnosis and their cognitive and emotional representations of their parent's cancer. Open-ended questions included in the interview schedule (Table 1) were based on the Common-Sense Model of Self-Regulation.

### Participants

Participants were recruited through advertisements distributed online through cancer support and advocacy groups, including CanTeen<sup>1</sup> and Australian-based cancer support groups on social media. All advertisements contained information about the study and interested young people (or their parents) were asked to contact the researcher via telephone or email if they (or their child) were interested in participating in the study.

<sup>1</sup> CanTeen is an Australian support organization for young people affected by cancer, including young people diagnosed with cancer, and young people who have a brother, sister, or parent diagnosed with cancer.

**Table 1** Interview schedule outlining relevant dimension of the Common-Sense Model of Self-Regulation (questions asked in past tense for bereaved participants and participants whose parent had finished active treatment)

1. Could you tell me about your experience with parental cancer? (illness identity, treatment control)
  - a. Which of your parents was diagnosed with cancer?
  - b. What type of cancer were they diagnosed with?
  - c. What type of treatment have they had?
2. What was it like when your parent was first diagnosed with cancer? (emotional representations)
  - a. How did you react when you first found out?
  - b. How did your family deal with your parent's diagnosis?
3. In general, how do you feel when you think about your parent's cancer? (emotional representations)
4. How has your parent's cancer impacted your life? (consequences)
  - a. In what way has your parent's cancer negatively impacted your life?
  - b. Has your parent's cancer had a positive impact on your life in any way?
5. How has cancer affected your parent? (illness identity)
6. What symptoms and side effects has your parent experienced as a result of their cancer? (illness identity)
7. How do you think your parent's cancer might affect them in the long term?<sup>a</sup> (timeline, treatment control)
8. Can you tell me about any changes you have noticed in the way you act around your parent since their diagnosis? (personal control)
  - a. What sort of things do you do that you feel make a difference to their illness or how they are feeling?
9. Can you tell me about the sort of things that you might talk about with your parent or with your family about your parent's cancer? (coherence)
10. Can you tell me about what you think of the information that has been shared with you about your parent's cancer? (coherence)
  - a. Do you feel like you know enough about your parent's cancer?
  - b. Is there anything that you might like to know more about?
11. Do you think there is anything your parent could have done to avoid cancer? (cause)
  - a. Do you have any thoughts on what might have caused your parent's cancer?
12. Is there anything else you would like to add to what has already been said?

<sup>a</sup> Bereaved participants were not asked this question

Young people aged 12–24 years were eligible to participate if they had a parent who had been diagnosed with any type or stage of cancer, were aware of their parent's cancer diagnosis, and were living at home at the time of their parent's diagnosis and treatment. This included young people who had a parent who had been diagnosed with curable, metastatic, or advanced cancer, and young people who had a parent who had died from cancer. Although there are various definitions of ‘youth’ (e.g. 15–24 years as defined by the United Nations [34] and 10–24 years as defined within the scientific literature [35]), the age range of 12–24 years was chosen because it aligns with

definitions provided by the Australian Institute of Health and Welfare [36].

Eleven young people from ten families participated in the interviews (age range = 15–24 years;  $M = 19.1$  years; female = 7). Of those, two participants had both parents who had been diagnosed with cancer, two participants were bereaved, and two had a parent with advanced or metastatic cancer, one had a parent who was still undergoing treatment for a curable form of cancer, and four had a parent who had finished active treatment. One participant's father had been diagnosed with several unrelated types of cancer. Time since initial diagnosis ranged from 6 months to 8 years. Parental cancer diagnoses included non-Hodgkin's lymphoma, lung, bowel, pancreatic, kidney (including collecting duct carcinoma), testicular, ovarian, cervical, and breast cancer. Participants described various household structures; two participants lived alone with a single parent, three participants lived with a single parent and other relatives (two with siblings and one with grandparents), and six participants lived with both parents (four with siblings and one with an aunt). Of those that lived with both parents, two participants lived with parents who were separated but had moved in together in order to fulfil a caregiver role.

## Interviews

Interviews were conducted by the first author (CF). CF is a PhD researcher with a background in social health sciences and previous research experience in cancer support. The researcher had no contact with participants prior to the study commencement. Interviews were conducted either face-to-face, via telephone, or via a web-conferencing programme. Face-to-face interviews were conducted at the CanTeen Division office in Sydney, Australia. Interviews ranged from 9 to 37 min in length ( $M = 23$  min). Interviews were audio-recorded and transcribed verbatim using a professional transcription service. The interview schedule was used flexibly to explore participants' cognitive and emotional representations of their parent's cancer in relation to the dimensions of the Common-Sense Model of Self-Regulation. All participants were asked each of the questions outlined in the interview schedule, with the exception of bereaved participants who were not asked about their thoughts on how their parent's cancer might affect them long term. Probing questions were used to obtain more specific or in-depth information on emerging themes. Similar themes were apparent within all interviews and recruitment was finalized when no new themes emerged in three consecutive interviews.

## Ethical Considerations

The study was reviewed and approved by the Social and Behavioural Research Ethics Committee at Flinders University (project number 7436). All participants received a

research pack containing written information about the study, formal written consent forms, and a questionnaire to collect participant demographic and parent cancer-related medical information. A copy of the interview schedule was also included to enable potential participants to make a fully informed decision about participating in the study. Parental consent was obtained for participants younger than 18 years. Participants returned signed consent forms and completed demographics questionnaires to the researcher prior to the interview. Participants were given assurances regarding the confidentiality and anonymity of the information they shared during the interview. Participants were informed that they were able to withdraw from the study at any time.

## Analysis

Following previous qualitative research exploring illness perceptions using the Common-Sense Model of Self-Regulation as a framework [25, 29, 37], thematic analysis methods were used to analyse the data. Thematic analysis involves identifying themes or patterns of meaning across a qualitative data set [38]. It is a flexible method that does not prescribe methods for data collection, theoretical positions, or epistemological or ontological frameworks [38]. In the present study, a combination of deductive (theory-driven) and inductive (data-driven) approaches were employed to identify and organize themes using the Common-Sense Model of Self-Regulation as a framework, while also allowing themes outside of the framework to be identified to ensure that the data were analysed comprehensively.

Braun and Clarke's [38, 39] steps for coding and analysing qualitative data were followed to conduct the thematic analysis. Interview transcripts were verified for accuracy prior to analysis and were read-through several times for familiarization. Interview transcripts were initially coded by the first author (CF) according to the dimensions of the model and the remaining text was coded according to additional themes derived from the data. Themes were reviewed to ensure that data within themes were coherent, and that there were clear and identifiable distinctions between themes. Following this, a codebook was developed by the first author to outline definitions of codes. A sub-set of transcripts (30%) was coded independently by a second researcher with a background in psychology and qualitative research (see Acknowledgements), who was not part of the research team, through reference to the codebook. Discrepancies in coding were resolved through discussion until consensus on definition of codes and interpretation of data was reached.

This paper describes the themes that related to the Common-Sense Model of Self-Regulation; additional themes that were identified were related to interpersonal aspects of the cancer experience (e.g. social support and communication

about cancer), rather than young people's cognitive and emotional representations of their parent's cancer.

## Results

In general, participants expressed appreciation for the opportunity to share their experience and they hoped that this would, in some way, help other young people in a similar situation. Most young people spoke openly during the interview, with very minimal prompting. Two participants required more direct prompting with probing questions; these interviews were the two shortest in length (9 and 14 min). One of these participants had a parent with terminal cancer, possibly contributing to her difficulty in answering some of the questions. The other participant's parent had a recent diagnosis, and hence was at the beginning of the cancer experience, also potentially contributing to his short responses, as some of the questions asked may not have been relevant to his individual experience. Analyses confirmed that the Common-Sense Model of Self-Regulation could be utilized to describe young people's experience of parental cancer and that these experiences were varied. Definitions and illustrative quotes for themes and sub-themes are presented in Table 2.

### Emotional Representations

Young people described a mixture of initial feelings after learning of their parent's cancer diagnosis: shock (e.g. "it felt like all the breath had been knocked out of me"), confusion (e.g. "I didn't really understand what, the magnitude of what it was, or like, how to feel or what to do"), numbness (e.g. "the immediate reaction, it was for me, it was a bit muted"), a loss of control (e.g. "It felt like I had no control back over my life"), and, in contrast, a level of acceptance (e.g. "I guess I was prepared for it to be cancer"). Participants described their experiences since their parent's diagnosis as "surreal", "a bumpy ride" and "very full on, very confronting". In general, young people felt fear over the possibility of losing their parent and uncertainty about the future, despite whether their parent was in remission, undergoing curative treatment, or receiving palliative care.

### Identity

All participants were able to describe the type of cancer that their parent had been diagnosed with; many were also able to describe the stage of cancer. Participants spoke about the impact of common side effects including fatigue, hair loss, nausea, weight gain, weight loss, and problems with memory or concentration. Some participants spoke about the high cost of symptoms like fatigue or problems with memory or concentration; in particular for participants who had a parent with

terminal cancer. This was noted by one participant as she recounted the last few months spent with her dad: "...we wanted to spend time with him but he just, I don't know, couldn't – didn't have the thinking capacity to do it.". This experience was similar to another participant who described the impact of her mother's fatigue:

"...in the last few months, probably just her being really exhausted all the time – having to not just rest sort of once a day or occasionally but being – becoming, I guess, less ... around and available in some ways and probably ... energy wise, just not being able to sort of talk with people for a longer period of time."

Young people also spoke about the emotional side effects of cancer; cancer did not just impact their parent physically, it was also a "mental game". One participant described the changes in her mother since her diagnosis with ovarian cancer: "...emotionally she's a lot more anxious about things and she cries a lot and gets down a fair bit". Some participants felt that although their parent was likely experiencing a number of physical symptoms, this was not always expressed; for example, two participants described their parent's pain as being something that was not really "complained about" or "overemphasised", despite being ever-present.

### Coherence

Young people described a desire to be informed about their parent's cancer, and they achieved this by accompanying their parent to doctor's appointments, speaking with their parent's treating doctors, researching the disease in their own time, and having open communication with their parent about their cancer. One participant described checking in with his mother to "see how it's all going, how the treatment's going ... [and to] see if she's alright." Another participant commented that he found knowing as much as he could about his mother's cancer beneficial:

"...I just tried to get as much information as possible about it, and I think that helped me to accept that, helped me to really, like reduce the anxiety just knowing this, like percentages of chance of it coming back, and all that, I think, because that was one of the ways I coped by like, information and reading about it, and knowing as much as I could about it."

In contrast, some participants felt that knowing too much would have been overwhelming:

"I wanted to know enough information to get me by, but not enough information to know every detail. ...because

**Table 2** Themes and sub-themes identified from the deductive analysis

Main theme (dimension of Common-Sense Model)	Definition	Sub-theme	Illustrative quotes from young peoples' interviews
1. Identity	Young peoples' perceptions of the side effects and symptoms that their parent experiences due to their cancer		"She did not really eat, she was very nauseous and she spent a lot of time sleeping."
2. Emotional representations	Young peoples' emotional beliefs and subjective feelings about their parent's cancer		"I think, shock and confusion, just because I did not really understand what, the magnitude of what it was, or like, how to feel or what to do."
3. Coherence	Young peoples' understanding or comprehension of their parent's cancer		"I wanted to know enough information to get me by, but not enough information to know every detail."
4. Consequences	Young peoples' perceptions of the impact their parent's cancer has had on their daily life	1. Young person	"I've just become a lot more anxious kind of person, yeah. It's really changed my perspective on things and there's been like actually a bit of role reversal, so because my mum's a single parent, yeah, so it's actually like I am kind of mothering her in a sense."
	Young peoples' perceptions of the impact their parent's cancer has had on their family life	2. Family	"...it's caused a lot of tension in our house as well because this is so much stress all of the time."
	Young peoples' perceptions of the impact their parent's cancer has had on their parent's life	3. Parent	"...she's also figured out who her true friends are, and emotionally that has really helped her, she feels a lot lighter, she even says 'That whole experience, I know who my true friends are, because they were the ones that offered to come to a round of chemo, or offered to take me to radiation' ..."
5. Cure or control	Young peoples' perceptions of the personal control they have over their parent's cancer symptoms, side effects, and distress	1. Personal Control — Relieving Symptoms and Distress	"...you had to sort of have a calming presence, you could not be loud and yelling or anything like that, because if it stressed her out ... she would feel sicker and you did not want to her feel unhappy and unwell."
	Young peoples' perceptions of the personal control they have over maintaining a normal life separate from their parent's cancer	2. Personal Control — Maintaining Normality	"...when they are sick and that sort of idea of someone's helpless, I guess, is kind of pretty prevalent in society in general. So, I think just making sure that you do not replicate that as much as possible at home and treating family members as human..."
	Young peoples' perceptions of the control treatment can have over their parent's cancer	3. Treatment control	"...she's got like medically it's stage 4 breast cancer, secondary breast cancer so it's caused by the production of the hormones but it's coming from her bones, so it's in her bones so it's like it's inoperable. So essentially it's pretty much just keeping it under control but it's not going to go away."
6. Timeline	Young peoples' perceptions of the expected duration and progression of their parent's cancer		"...that's all pretty uncertain, they have sort of said to us, this is incurable and we know that the end is coming soon but they will not give us a time frame ... it's kind of like switched between denial and ... she'll be fine and then thinking that she's going to die like tomorrow."
7. Cause	Young peoples' perceptions of the causes of their parent's cancer	1. Chance	"...to me it just feels like it picks a random person in the world there's no actual reason for it, because there's no history of it going through our family either so."
		2. Environmental or external attributions	"I've heard that people have said that, other bad people in their lives can cause cancer, ..."
		3. Genetic/hereditary attributions	"...cancer has also been a fairly genetic sort of disease going through — I mean her father passed away when she was fifteen or something of cancer and he had a melanoma in the eye or something and she had a few other relatives that've passed away early because of cancer. So whether or not there is some sort of gene in your DNA that has something to do with the likelihood of her developing cancer, ..."
		4. Lifestyle attributions	"...she eats everything I eat, she drinks whereas I do not, but drinking usually is a liver issue not just any random cancer issue. She smokes but it wasn't lung cancer it wasn't anything that could have linked to that. So I worry more now that she's still smoking because well I feel like that might cause it to come back sooner or things like that."
		5. Psychological attributions	"...I think she told me that it was stress."

it almost made it too real, and I kind of wanted to keep this fantasy land that we were all okay.”

A similar sentiment was shared by another participant who commented that “it’s good to be a little bit oblivious”.

## Consequences

Young people described a range of consequences that their parent’s cancer had for them, their family, and their parent. For many, the most prominent consequence for themselves was having to take on extra household responsibilities:

“...I would often come home from school and I’d cook dinner and I’d clean the house and I found myself taking on a lot more responsibilities just because my mum wasn’t able to...”

Many young people also accompanied their parent to treatment and other medical appointments and provided emotional support. Two participants likened this to fulfilling a parental role, with one stating that: “... it’s actually like I am kind of mothering her in a sense.” Taking on extra responsibilities had a flow-on effect on schooling:

“...my results went down the drain, because I didn’t have time to study for exams on top of looking after mum, and looking after my little brother after he got home from school.”

One participant spoke about how she had considered dropping out of school to work full-time and care for her mother. Some described this not necessarily as a negative consequence of their parent’s cancer, but as a shift in their priorities. In particular, many participants spoke about how the experience brought their family closer together and taught them to be more appreciative of the time they had together. One participant described it in this way:

“...we care more about going to things and it’s important to go watch someone in the football grand final, because you don’t know what could happen the next day. So I think everything has become more important to us.”

Young people also spoke about the consequences for their parent. In particular, two participants described how breast cancer had negatively impacted their mothers’ self-esteem. One participant reflected on her mother losing her hair after chemotherapy: “I went from seeing my mum being such a strong, beautiful woman to someone who felt so insecure.” Another participant stated that her mother no longer wore swimsuits because of the visible scars on her breasts.

Young people also highlighted the positive consequences for their parent. One participant stated that his mother was “pretty proud of herself that she’s made it”. Several participants spoke about how cancer had improved their parent’s relationships by helping them to “figure out who [their] true friends are” and had given them “a new fresh start ... a start again, and at a new place, with different people”.

## Cure or Control

Young people were very well-informed about what could be done medically to treat their parent’s cancer. One participant, whose mother was diagnosed with metastatic breast cancer, described the difference between treating to cure and treating to control: “...essentially it’s pretty much just keeping it under control, but it’s not going to go away.” Another participant spoke about how chemotherapy reduced her mother’s risk of cancer recurrence, although she acknowledged that the risk was not completely eliminated. Frustration was expressed by another participant who stated that he had been “stonewalled” by an oncologist who deemed his mother too unwell to try an experimental treatment for her rare form of cancer.

Young people gained a sense of personal control over the cancer experience by doing anything that they could to “make [their parent’s] life easier or less stressful”. One participant said that she felt that this “made it just so much easier for [her mother] because she didn’t have to worry about those things, she could concentrate on the things that she felt were most important to her.” Another participant described how changing the way he behaved around his mother could help to make her feel better:

“...you had to sort of have a calming presence, you couldn’t be loud and yelling or anything like that, because if it stressed her out ... she would feel sicker and you didn’t want to her feel unhappy and unwell.”

For some participants, this meant shielding their parent from their emotional reactions to their cancer. One participant stated that she “hid away [her] feelings because it – she [mother] was really upset and we just needed to get things done...” Another participant stated that she “didn’t want her [mother] to know that it was affecting me in such a great way until I knew she would be able to cope with the fact that, it was obviously affecting me as well as her.”

Personal control over the cancer experience was as much about what could be done to support the parent or relieve their symptoms and distress as it was about preventing cancer from becoming the parent’s identity; one participant stated that it was important to make sure that she did not make her mother feel like she was helpless just because she was sick; as much as possible, she wanted to avoid her mother “becoming the

cancer patient ... in every facet of life”. There was also a desire to maintain a normal life outside of the cancer experience; that although cancer was a big aspect of their family’s lives, “it [didn’t] have to be the focus”.

### Timeline

Young people spoke about cancer as being a “battle”. One participant expressed this through her belief that “my mum’s not going to die, my mum’s going to win this battle.” For others, their parent’s future was much less certain. One participant reflected on the unpredictable timeline of his father’s cancer: “it’s a battle for him, and it’s touch and go, whether or not he lives or dies”. Similarly, other young people who had a parent with terminal cancer expressed a lot of uncertainty over their parent’s future and a desire to know exactly how much time they had left with their parent:

“...that’s all pretty uncertain, they’ve sort of said to us, this is incurable and we know that the end is coming soon but they won’t give us a time frame ... it’s kind of like switched between denial and ... she’ll be fine and then thinking that she’s going to die like tomorrow.”

Although this uncertainty was a continuous stress for those with a parent with terminal cancer, young people showed resilience through their ability to adapt to the situation. One participant commented that she and her family had learned to take it “day by day ... and well we’re kind of figuring out like a pattern now.”

Those who had a parent in remission spoke about their fears that the cancer might come back in the future, although one participant commented that these fears “have slowly dissipated and gone away” over time. Another participant was able to rationalize her fears that her mother’s cancer would return: “...I figured with the amount of chemicals and treatment they gave her, at the moment, for the next couple of years, I know that we’re okay and it’s not going to come back.”

### Cause

Although they were able to offer a range of potential causes for their parent’s cancer, including biological, environmental, lifestyle, or psychological causes, many participants felt that cancer was something that “just happens”. One participant felt that in her mother’s case “[cancer] picks a random person in the world, there’s no actual reason for it, because there’s no history of it going through our family”.

Young people also talked about their fears about their own risk of developing cancer in the future (e.g. “I get worried of it going to be me in five years or ten years or however long...”) and how their attitude towards cancer prevention

behaviours has changed in response to their parent’s cancer (e.g. “Even things like putting sun block on, I’m so crazy, obsessive about putting it on now...”).

### Discussion

These findings extend previous research examining young people’s experiences with parental cancer by providing an insight into young people’s perceptions of, and emotional reactions to, their parent’s cancer. Results confirmed the relevance of the dimensions of the Common-Sense Model of Self-Regulation for describing illness cognitions in young people following their parent’s diagnosis with cancer.

The 11 young people who participated in interviews were a diverse sample; but despite this, there were common themes in the experiences they reported. Participants described negative emotional reactions, such as feelings of fear, uncertainty, and a loss of control, in response to their parent’s cancer. These feelings were not just limited to participants who had a parent with terminal cancer or who were reflecting on the time before their parent had died; they were shared by participants who had a parent in remission. Many still feared that the cancer could return.

Participants described having an active involvement in helping their parent during their cancer experience; through attending their parent’s appointments, researching their parent’s cancer in their own time, or talking with their parent about treatment options. They had a coherent understanding of their parent’s cancer, their treatment, and what could be expected in terms of the progression of the disease, and indicated that knowing as much information as possible about their parent’s cancer was beneficial. This is consistent with findings reported by Maynard et al. [40], where adolescent participants described that having information about their parent’s cancer and its treatment was important in helping them cope. Using a problem-focused coping strategy, whereby young people play an active role in supporting their parent through their illness, may improve their sense of control over the situation. This sentiment was not shared by all participants however; one participant felt that knowing too much about her parent’s cancer would erase the illusion that everything was okay, suggesting a personal preference for a more emotion-focused coping strategy, such as denial or avoidance.

Participants described taking on extra responsibilities that would have otherwise been fulfilled by their parent, following their parent’s diagnosis. These included preparing meals, cleaning the house, looking after pets, and babysitting younger siblings. Although almost all participants spoke about taking on these extra responsibilities, this was particularly notable for those with a single parent. Many participants described how having these responsibilities impacted their schooling. For some, this meant considering whether or not to drop out

of school to find full-time work and care for their parent. Others felt that this shift in their priorities was a positive experience, because it made them focus on what was important in their lives — their family. Benefit finding, defined as “the process of deriving positive growth from adversity” [41], has been shown to lead to positive outcomes among family caregivers [42, 43], and may be an important aspect of coping for young people following a parent’s cancer diagnosis.

Several participants described their parent’s cancer as a “battle”. The use of violence-related metaphors for the cancer experience has been described previously both in peer-reviewed literature [44, 45] and in the media [46–49] as potentially detrimental for people diagnosed with cancer. These kinds of metaphors position cancer as an opponent — an enemy to defeat — and may contribute to feelings of helplessness and anxiety. In particular for people with terminal cancer, this can cause feelings of failure or guilt for losing the “fight” against cancer [49]. For young people who have a parent with terminal cancer, this may generate feelings of resentment towards their parent for not “fighting hard enough” and lead to difficulties accepting their parent’s diagnosis and eventual death. Instead it may be more helpful to view cancer as a natural process — as something that “just happens” — as several participants described when reflecting on possible causes of their parent’s cancer. This belief is substantiated by research showing that two-thirds of all cancers are caused by unavoidable random errors that occur during DNA replication [50]. Changing the rhetoric around the cancer experience by avoiding the use of violence-related metaphors that place blame on the person with the diagnosis and emphasizing the random nature of the disease may be helpful for young people to reach an acceptance of their parent’s cancer and prognosis.

Facing the potential death of a parent is not an experience that is normal in adolescence or young adulthood [51]. Despite their difficult and unusual circumstances, many participants did what they could to maintain a sense of normality in their life. For some, this involved ensuring that family life did not revolve around their parent’s cancer, by drawing a distinction between their parent as a mother or father versus a “cancer patient”. This attempt to separate the disease from the family has been previously described as adaptive. In particular, a family identity that revolves around the parent with cancer for an extended period of time may negatively affect the family’s ability to meet the developmental needs of all family members, particularly dependent children [2]. Although taking ownership of the disease appears to be an important aspect of perceived control for the person with cancer [52], maintaining a sense of normality — an identity separate from the cancer — may be an important coping strategy for young people when their parent has cancer.

The findings of this study should be considered in light of some potential limitations. Participants were recruited primarily through an organization aimed at supporting young people through a cancer experience. Furthermore, participants were self-selected. As a result, the findings may not be representative of the experiences of young people outside of the organization. The sample size was quite small, however, this is a small and difficult-to-recruit population. Talking about parental cancer can be uncomfortable and potentially distressing, and it is possible that many young people may have not wanted to participate in the study for this reason. The young people who participated in the study had varied experiences with parental cancer and varied in the length of time since their parent’s initial diagnosis. Despite this, there were common themes among the experiences that young people reported and they were easily able to recall and recount their experiences in great detail.

The findings of this research indicate that young people’s perceptions of their parent’s cancer can be usefully described within the framework of the Common-Sense Model of Self-Regulation. It should be noted that it was not the aim of this research to make conclusions about the relationships between specific types of illness cognitions, coping strategies, and psychological morbidity, but instead to examine how young people’s perceptions of their parent’s cancer correspond with the dimensions of the Common-Sense Model of Self-Regulation. The present study extends previous research by exploring young people’s perceptions of their parent’s cancer in the context of a theoretical framework. This enables the opportunity for measures based on the model to be developed and used in further research, and potentially clinical practice, to identify those at risk of poor psychological adjustment following a parent’s cancer diagnosis. Hence, this work may provide a basis for the development of quantitative measures of illness cognitions in young people who have a parent with cancer.

Future quantitative research should expand on these findings by determining the relationships between young people’s illness cognitions, coping strategies, and psychological adjustment following their parent’s cancer diagnosis. Quantitative research should be conducted, using a larger sample size, to examine differences in illness cognitions among young people of different ages, and to ensure that the findings may be generalized and replicated within the wider cancer population. Future research may also explore how young people’s perceptions of their parent’s cancer impact their own coping with personal cancer symptoms as an adult, using a longitudinal design. This research may provide valuable insight for the development of interventions that target harmful beliefs and promote positive coping strategies to support young people through the cancer experience.

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## Compliance with Ethical Standards

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

**Conflict of Interest** The authors declare that they have no conflict of interest.

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