Exploring the Experience of Recurrence with Advanced Cancer for People Who Perceived Themselves to Be Cancer Free: A Grounded Theory Study

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Statements:

The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

Abstract

Exploring the Experience of Advanced Cancer Recurrence in People Who Perceived Themselves to be Cancer Free: A Grounded Theory Study

Purpose: Advances in cancer treatment have led to longer cancer-free periods and overall survival. This study aimed to understand patients' experiences of transitioning out of a state of believing to be cancer free into incurable recurrence with advanced disease.

Methods: Using constructivist grounded theory with in-depth interviews patients (n=15) with solid tumors from a major US cancer center participated. Theoretical sampling enabled concepts to be developed until theme saturation. Constant comparative analysis used initial and focused coding to develop themes and concepts to describe this specific period from extended time cancer free and transition to advanced incurable disease.

Results: Three interrelated concepts were identified: Reluctant Acceptance, Seeking Survival through Continuous Treatment, and Hope in the Face of an Uncertain Future. A conceptual model of the experience was developed encompassing anger and sadness, at initial recurrence, to reluctant acceptance, and, finally, a cycle of seeking continuous treatment to prolong life leading to a sense of hope in the face of an uncertain future.

Conclusion: The cycle between treatment and hope creates a state of personal equilibrium, which provides insights into the importance of treatment for this population. This study provides direction for future research to understand the expectations of people experiencing advanced cancer recurrence.

Implications for Cancer Survivors: Many cancer survivors live with advanced cancer. Assessing their needs as they transition from survivor with no disease to survivor with advanced disease requires a new conceptualization of the experience which recognizes expectations and priorities for care of this patient group.

Key Words
advanced cancer; advanced recurrence; continuous treatment; hope; uncertainty; survival; reluctant acceptance;

Introduction

Public and patient perceptions of cancer and its treatability have changed over time as the numbers of those living with and beyond cancer rise, and new therapeutic options are developed. Cancer incidence is increasing, especially in ageing societies, and the lifetime risk of developing cancer has increased, such that around half of those born since 1960 may develop cancer[1]. For many, improvements in cancer therapeutic options mean that they are more likely to survive post-diagnosis than ever before, with 67% alive five or more years after diagnosis [2]. The number of cancer survivors is estimated to grow by 3% per annum, with almost a quarter of the population of those over 65 estimated to be cancer survivors by 2040 [3]. The number of people who have survived five or more years since diagnosis increased by 21% between 2010 and 2015 [3]. This trend is likely to continue as novel treatments transform durable survival for disease such as melanoma[4]. With trials underway of these novel agents for other cancer types [5], there is perhaps an increasing public expectation that being ‘cured’ from their cancer is a realistic expectation.

Whilst there may be hope for long-term survival from cancer for many, the reality for others is that their cancer will either be diagnosed at an advanced stage III or IV, or else they will experience metastatic or advanced disease at some point after initial diagnosis and treatment. Recurrence rates vary, with cancer type being a major factor in the likelihood of recurrence. For example, those diagnosed with glioblastoma, ovarian cancer and soft tissue sarcomas have higher risks of recurrent disease, whereas those with breast cancer, kidney cancer, or lymphoma have lower risks of recurrent disease [6-10]. It has been estimated that 1 in 6 cancer survivors will experience a recurrence of their disease [11].

For some, fear of recurrence becomes a major, pervasive concern [12], with the worry of living with uncertainty [13]. Fear of cancer recurrence is thought to be a distinct phenomenon related to cancer survivorship [14]. For others, hope and a positive outlook, even in the face of adverse indications, is a feature [15, 16]. People can engage in activities that are distractions from their past experiences, with a desire to ‘leave the disease behind’ [17]. Such positive narratives are not surprising, perhaps, given a dominant discourse of treatment and cure in both the media and policy domains [18]. People adapt to a new identity of being a cancer survivor, incorporating this into their concept of self [19].

Given these discourses of cure, hope, and novel treatments, being diagnosed with recurrent disease, especially of advanced cancer, may be unexpected for some, especially when their initial diagnosis was of a cancer with a lower rate of recurrence. There is little existing research into the experiences and perceptions of this group of cancer survivors whose years since their initial diagnosis may have led them to a perception of ‘cure’, yet who are then faced with a diagnosis of recurrent, advanced, cancer that may challenge the concept of self that they have come to believe for themselves. Understanding the expectations that people with advanced recurrent cancer have, and their priorities for care, is needed to help health care providers provide appropriate care that maintains quality of life and assists them with treatment decisions in light of their uncertain prognosis.

Methods

Aims and Research Question

This study aims to capture a specific moment in the disease trajectory of people who were treated for cancer and who were living in an extended phase during which they perceived themselves to be cancer free, and subsequently experienced an advanced cancer recurrence. The experience of living in this phase is evolving as new treatment options become available and living with advanced cancer for a longer time period is achievable. This study provides meaning and insight into this changing paradigm of time marked by evolving treatment options. This study fills a gap in knowledge and asks the question, what is this experience of transitioning out of a state of believing to be cancer free into incurable recurrence of advanced cancer?

Ethics Approval

This research was undertaken following compliance with ethical standards in line with the Principles of the Declaration of Helsinki. Institutional Review Board (IRB) approval was received from City of Hope, Duarte, California as well as the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University in Lancaster, England.

Design

Working in the area of cancer survivorship and observing cancer recurrence in this population, who had believed themselves to be cured there was a need to explore this phenomena and guided the development of this study. Charmaz [20] constructivist grounded theory (CGT) was the methodology followed for this research. It allows meaning to develop as theoretical sampling and constant comparative analysis takes place and specifically does not start with a theoretical framework but seeks to inductively develop one from the data. CGT seeks to provide a description of a situation that conceptualizes the participants' perspectives through the inductive organization of the data provided and developed through co-construction with participants as equal with the researcher [21, 22, 20]. This method provides a framework that allows both the methodology and methods of the research study to work together. The newly developed conceptual model will allow others to understand the experience and provide a framework to guide future research in this population of cancer survivors [23].

Participants and Setting

Participants in this study were people diagnosed with an advanced cancer Stage III or IV recurrence after living two years or more where they had perceived themselves to be cancer free. Participants had a history of primary breast, ovarian, lung or colorectal cancer that had been treated initially with curative intent. Cancer free status was verified in their medical records prior to experiencing this recurrence. Participants also verified their perception of being cancer free or cured from their initial diagnosis in their interviews.

The setting for this study was a free-standing NCI designated cancer center in Southern California. Due to the prestige that comes with NCI-designation and the available cancer research at this center, the patient population could be more highly motivated and have the resources to seek out, and receive, state-of the-science cancer treatment.

Recruitment and sampling:

Oncologists for solid tumor diseases, primarily breast, lung and colorectal, agreed to identify their patients who met the inclusion criteria; presenting with an advanced cancer after two or more years of perceiving themselves to be cancer-free. Therefore, using purposeful sampling these potential participants who had experienced the phenomenon being studied were approached by the researcher. The study was introduced to the participant with a description of the requirements and answering all of their questions. If they were interested in participating, they completed an informed consent per IRB requirements and a time and place for the one-time interview was agreed upon. Potential participants were excluded if they were unable to complete an in-depth interview or did not speak fluent English.

Data collection

In CGT, in-depth interviewing facilitates the gathering of information to explore the desired phenomenon in an unrestricted manner [20]. In-depth interviews allow the researcher to focus on the research phenomena from the context of the participants perspective. Semi-structured interviews were used to allow participants to describe their experience of advanced cancer recurrence after two or more years where they considered themselves to be cancer free [20, 24]. The in-depth interviews were undertaken with the researcher and lasted between 60 – 90 minutes. As dictated by a CGT approach, purposive to theoretical sampling occurred. Interviews were transcribed and coded line by line by the researcher and reviewed by the co-authors. As concepts were inductively developing from the previous interviews and coding, the next interview allowed theoretical sampling of the previous developing concepts to be further understood by focusing the interview questions for the next participant to gather more information and perspectives to examine the concepts more deeply. The Interview Guide is provided in Table 1. Transcripts of the interviews were reviewed in depth between the researcher and co-authors. Interpretations and coding was compared and contrasted together. Differences in coding to concepts were discussed between the researcher and co-authors. until agreement was achieved.

Data Analysis

The median time from recurrence to interview was two months, with a range from two days to 15 months. Initial coding using action terms from the participants own words, as is consistent with CGT methodology, led to themes as focused coding then allowed the development of theoretical concepts. Theoretical concepts were compared through constant comparative analysis, new themes were developed and defined until saturation of themes occurred [25, 26, 20, 27]. Saturation of themes occurs as the characteristics of the phenomena are the same and no new concepts were introduced [28]. This process of concurrent data collection and continuous analysis involved moving from participant codes to detailed subcategories which then were inductively developed into distinct categories; using theoretical sampling and refining of the interview questions to co-construct and support the categories and development of the final concepts between the researcher and participant.

For example, one initial code was *recognizing cancer not curable-uncertain future,* the focused codes were *realization incurable cancer* and *reluctantly accept.* This led to the Category of *Behavior/attitude toward recurrence* and to the final concept of *Reluctant Acceptance.*

> *"I'm considered in remission, however, I have to continue my therapy indefinitely because of the kind of cancer I do have."* (P7:23)

A detailed description (Table 2) illustrates how the categories developed from a descriptive explanation to theoretical development and allowed verification of the developing concepts to be co-constructed by the researcher, as is congruent with CGT, until saturation of themes. Participant confidentiality is protected by using a "P" and participant number followed by transcript line number/s to identify participant quotes in text.

Findings

The final sample size was 15 participants; demographics are described in Table 3. The mean age was 65.4 years and the median age was 66 years, with a range from 44 years to 77 years of age. The overall time from initial diagnosis of cancer to diagnosis of advanced recurrence of Stage III or IV disease ranged from two years to 17 years with a mean of 8.7 years and median time of 10 years. The mean and median were provided as the data had large extremes with more than one participant experiencing the same number of years between diagnosis to advanced disease.

The categories and subcategories with conceptual headings are illustrated in Figure 1. The categories underlying the study's concept were: Reluctant Acceptance, Seeking Survival through Continuous Treatment, and Hope in the Face of an Uncertain Future. There were multiple shared sub-categories included in the three concepts: coping, behavior and attitude towards recurrence and treatment focused.

Through continued analysis of the data the final concepts described the experience of advanced cancer recurrence in this population and a conceptual model was developed. Figure 2 illustrates the final conceptual model of *Seeking Survival in Advanced Cancer Recurrence*. In this period of recurrence participants continued to seek treatment in hope of living with advanced cancer. They recognized that a cure was not possible but maintaining their cancer as stable disease meant they could continue to live for as long as possible.

Reluctant Acceptance

Initial acceptance of the recurrence of advanced disease, and the impact on their perception of their future acted as the springboard to move from feeling vulnerable or uncertain about their future to redefine this towards a positive outcome. Participants described their initial response as causing sadness but moved immediately to seeking treatment:

> *"I had my 2 or 3 days of like, you know sadness and like, you know, not feeling good about it, but that was it really. To be honest with you that was it. Then it was like ok now what are we going to do?" (P10:49)*

This concept of reluctant acceptance included the initial anger and sadness at the realization that their cancer was now incurable, and this was impacted by participant age both temporal and developmental. Participant age may have influenced acceptance of the reality of death being closer due to the sense of lifespan and position within that span. The mean age of the participants was 65.4 years. These participants were all retired and many with adult aged children or grandchildren. Research has shown that older adults willingness to participate in research or not, is dependent on the impact the current diagnosis has on their lives [29]. There was a recognition that time had passed since their initial diagnosis and might impact their ability to tolerate treatment. As one participant put it:

> *"you are a little tireder. It took a little longer to get back to fighting mode as far as we're going to still beat this thing." (P2:110-111)*

Their choice was to accept and move forward. The faith in their physicians and their willingness to seek treatment to live was described in their interviews and will be discussed further.

Seeking Survival through Continuous Treatment

Participants immediately sought treatment as a means to survive. They understood that their cancer had returned, that it was advanced, and that it might end their lives. They believed, however, that resuming treatment might allow them to live longer. This focus on the liminality of life demonstrated their recognition that this time their cancer could take their life. As liminality means a life transition [30] although they were ambiguous about the uncertainty of their future they believed that the ability to receive treatments with advanced cancer could allow them to live longer.

> *"It's like, you know what have I done that I'm going through this again? And this time it won't be cured. I just have to live with it." (P13:90)*

The consideration that their original treatment with the intent to cure did not cure them the first time, was not described by participants. They described the positive side that they had been cancer free for several years so they believed they could have that much time again.

> *"Hey this is not too bad you know, I wasn't too bad. I have been through this before. I figure if I did it once I could do it again." (P3:026)*

This concept of seeking treatment to continue survival was increased with the concept of Hope in the Face of an Uncertain Future. They worked together to reinforce treatment and hope. Having a treatment plan was important.

> *"When she was giving me the results, she told me, I would probably never be cancer-free at this point….it would be like a fire. And it would be the medications that would keep it down like a little ember burning, so they could keep it under control." (P11:81-84)*

Hope in the Face of an Uncertain Future

The use of hope related to hope as a motivator for living longer. Hope and spirituality and hope for treatment were necessary to move forward [31]. Hope was seen as a buffer against challenges and maintaining hope supported them to keep going. *"I have hope. I just make the best of it. Do what you have to do. You know, and that's how I feel, I'm doing what I need to do" (P5:207) "I'm always looking at that positive part of it, it's not curable, ok that's a bummer, …You can continue to feel sorry for yourself .. or you can put your big girl panties on and you move forward…I feel you still have an option. (P10:20-23)*

Discussion

This study has explored the experience of a specific population that believed themselves to be cured then recurred with Stage III or IV disease that was now incurable. As participants learned that their cancer had returned, they experienced an initial sense of loss---the loss of having been cancer-free and the loss of certainty as to their future. Despite this, their outlook remained positive, bolstered by underlying hope. A patient put it clearly *"and even though I've had the recurrence I still feel positive about it. It's not a great result. But it's you know, it's treatable*." (P.10:6-10)

The conceptual model developed from this research provides a deeper understanding of the period of time along the cancer survivor continuum from the period of extended survivorship-cancer free and beyond the recurrence with advanced disease. [32]. The emerging core theme during analysis were focused on living even with the realization that their cancer was not curable. As participants dealt with the diagnosis of advanced recurrence their anger and sadness led to reluctantly accepting their disease and acted as a catalyst to seeking survival through continuous treatment. This process of hope for treatment and treatment providing hope encompassed this phase of seeking survival in advanced cancer recurrence.

Other studies have also described a sense of energy related to hope [33-36]. The relationship between spirituality and spiritual well-being to family and self has been shown to provide a sense of quality of life and a feeling of wholeness [37-39].The concept of hope and treatment prolonging life have been described in other studies where the acceptance of incurable disease led to transitioning to hoping for a good quality of life until death [40, 41]. Hope remains a complex and dynamic concept that changes over the course of disease, it is measurable and transcends cultures [42-44]. Other studies have described feeling hopeless, isolated or 'unendurable' suffering and the impact those feelings had on maintaining hope [45, 46]. These were not descriptions seen in this research study and may have been due to current treatment modalities and options that are available now for people with advanced disease.

Limitations of this study were related to the population being primarily women with advanced breast cancer recurrence. This population has benefited with current treatment opportunities with median survival in metastatic breast cancer between 1985-2016 rising from 13 to 33 months [47, 48]. Future studies must include males and females equally to evaluate meaning and desires more thoroughly. The broad range of time from diagnosis to interviews may also have impacted the findings. It must be noted that no people with colorectal cancer were identified for this study. Purposeful sampling and CGT meant saturation of themes occurred but studying people with other tumor types in the future would be necessary. Ethnicity data was not collected. Ethnicity, socioeconomic status, and insurance status would be important variables to evaluate the impact on treatment decisions in future studies. Finally, the study setting for this research was a single free-standing cancer research center. It must be acknowledged that participants may have been biased to seek treatment and therefore not willing to consider no treatment or hospice care. This population desired to maintain survival for as long as possible. They were not in a state of denial; they understood that their cancer had not only recurred but was advanced and no longer curable. Seeking to live with cancer through access to continuous treatment in this population was their goal, despite the reality that their initial treatment did not cure them. And although the belief at the beginning of this research was that this population would be considering hospice care and end of life discussions it is not what they wanted. Additionally, access to low cost or no cost treatment through clinical trials may have impacted their decision to seek treatment. Treatment had provided them with additional years the first time and they believed it would provide them with years again.

Conclusion

The CGT approach allowed the participants voices to be included, informing the creation of a newly developed conceptual model that provides a framework for future conceptual analysis. As the opportunities for treatment in this period of advanced recurrence has rapidly changed this conceptual model provides insight into the current context of treatment opportunities and the changing paradigm experienced for this population [49, 50]. The recent years have identified immunotherapy discoveries that have led to many new cancer therapies, that initiate the individuals own immune system to fight their cancer [51]. Breakthroughs in the treatment of melanoma, kidney cancer and lung cancer have encouraged more trials and brought about improved responses [51]

Implications for Cancer Survivors

Today’s changing paradigm of treatment opportunities for people with advanced cancer recurrence no longer limits treatment to those newly diagnosed with early stage disease [52]. People with advanced cancer recurrence have access to clinical trials and newly developed focused treatment that has shown response in Stage IV disease which in the past meant referral to hospice and end of life care. How these realizations will impact advanced stage disease management remains an unknown at this time. Current trends to establish early palliative care referrals fits well into this changing paradigm that includes multiple unknowns related to prognosis and symptom concerns [52, 53]. People experiencing advanced cancer recurrence are generally older aged and experiencing multiple co-morbidities along with their cancer diagnosis [54, 55, 53]. Access to a multidisciplinary team of experts to provide the physical, psychological, social and spiritual care needed and will be essential to provide quality cancer care to improve outcomes for this developing population. For this population planning for the future of living with advanced cancer is essential and yet these conversations are not taking place [56, 57]. As these patients are focused on treatment, leading them to conversations about advanced care planning has not been a priority. Efforts to improve communication that honors not only the physical but also the psychological, social and spiritual needs of this population is needed. Policymakers in the U.S. and around the world need information regarding the expectations of people with advanced cancer recurrence, including defining what palliative chemotherapy means, available treatment options and prognosis. These efforts will support an understanding of the patients own meaning of life and priorities for their care and how ethical health care decisions will be sustained in the future [58, 59] .

Knowledge Translation

- In today's changing paradigm of treatment options for people with advanced cancer, seeking treatment is a priority for many.
- The concept of reluctant acceptance motivates the action of seeking treatment and increasing hope in an uncertain future.
- For people with advanced cancer recurrence the current treatment environment does not limit treatment options or imply end of life care as the only option.

This conceptual model requires additional research testing within different ethnicities, different cancer populations and different ages, in community and academic settings. There are important implications for future health needs of this population as they receive multiple treatments and risk multiple co-morbidities associated with continued treatment and their unknown long-term effects. Cancer risk increases with age and as this population includes a significant number of older adults, co-morbidities of aging and extensive cancer treatments reinforces the importance of early palliative care referrals for all cancer patients. Further studies comparing older adults with advanced recurrence seeking treatment to younger adults with advanced recurrence seeking treatment would help identify differences in treatment planning needs, or not. This study has broad clinical and policy implications and should serve as a guide to advancing practice and the focus for future research.

Declarations

The authors did not receive support from any organization for submitted work.

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The study was performed in line with the Principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of the City of Hope, Duarte, California as well as the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University in Lancaster, England. (also listed in the manuscript pg. 4).

Informed written consent was obstained from all individual participants included in this study. (manuscript pg. 4).

All data is available by reasonable request from the lead author-Denice Economou.

Atlas TI was used to help organize the line by line coding data.

Authors Contributions:
Conceptualization of this study was by Denice Economou as this was her Dissertation work for her PhD. Her supervisors and co-authors are Dr. Catherine Walshe and Dr. Sarah Brearley from Lancaster University in Lancaster, England. Formal analysis began with Denice Economou and was reviewed, discussed and modified as appropriate under the supervision of Catherine Walshe and Sarah Brearley.

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Table 1 Interview Guide

Interview Guide-Areas to be Examined	**Rational for Inclusion**	**Example Questions**
Introduction	General discussion about original diagnosis	Please tell me briefly about your initial diagnosis and what that entailed?
Concept of Cure or living with "no disease"	Attempt to verify their perception of being cured	1. How did you end your initial treatment? 2. What did you understand about your prognosis? 3. What was this time of "no disease" like for you?
Understanding what this recurrence means	Aim of study is to understand what recurrence means after perceiving self to be cured. Need to explore those feelings and what recurrence means for them	1. What do you understand about your recurrence? 2. Did you expect to have your cancer return? 3. What does this recurrence mean to you?
Exploring what the participants wishes are now that they have recurred	Opportunity to hear what the participant's plans are and what is important to them now. Using strategies to verify meaning and build theoretical confirmation of newly evolving theory	1. What are your concerns now? 2. What is most important to you now?
Further Explore Developing Concepts	Explore the developing concepts from previous participants to verify developing thoughts related to the concept.	1. Explore in depth beliefs around theory constructs to further clarify evolving theory.
Wrap Up	Explore any additional thoughts the participant might like to discuss Thank them for their participation and provide the researchers contact information should they have any further questions.	1. Are there any other thoughts or concerns you have about this advanced recurrence? 2. Thank you for participating

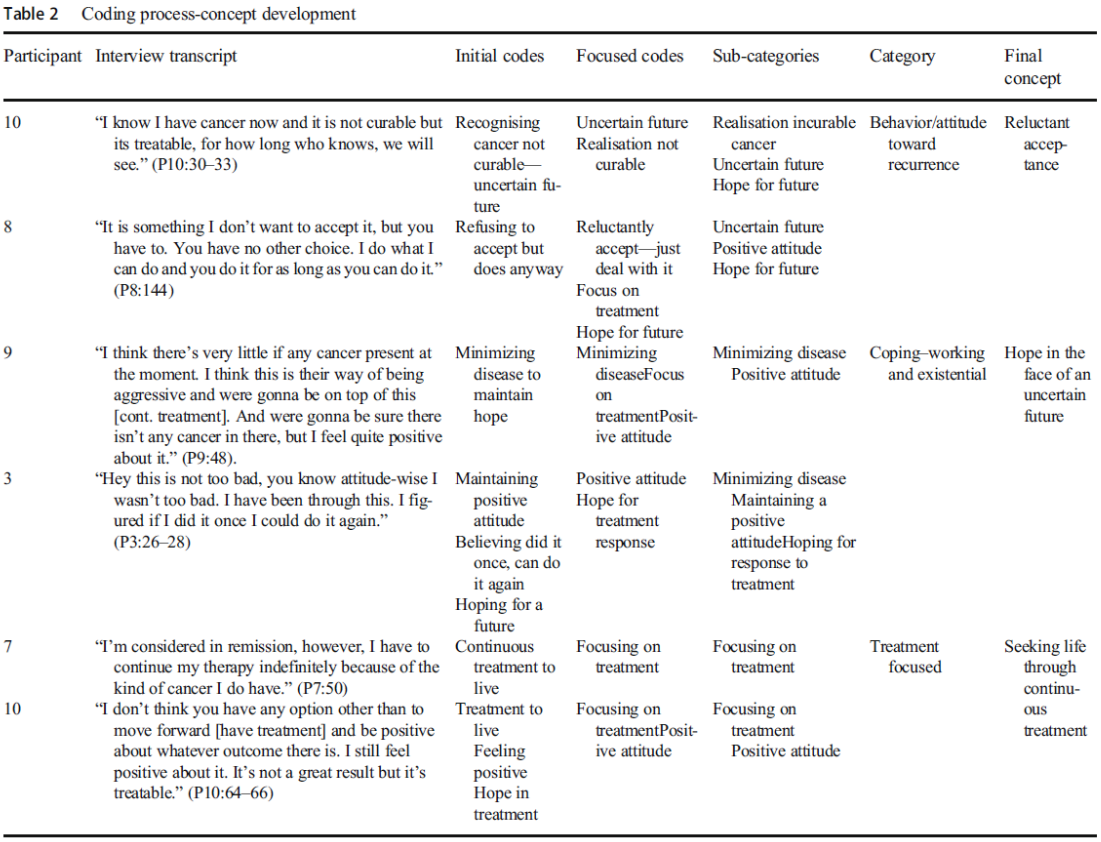


Table 2 Coding process-concept development

Participant	Interview transcript	Initial codes	Focused codes	Sub-categories	Category	Final concept
10	"I know I have cancer now and it is not curable but its treatable, for how long who knows, we will see." (P10:30–33)	Recognising cancer not curable—uncertain future	Uncertain future Realisation not curable	Realisation incurable cancer Uncertain future Hope for future	Behavior/attitude toward recurrence	Reluctant acceptance
8	"It is something I don't want to accept it, but you have to. You have no other choice. I do what I can do and you do it for as long as you can do it." (P8:144)	Refusing to accept but does anyway	Reluctantly accept—just deal with it Focus on treatment Hope for future	Uncertain future Positive attitude Hope for future		
9	"I think there's very little if any cancer present at the moment. I think this is their way of being aggressive and were gonna be on top of this [cont. treatment]. And were gonna be sure there isn't any cancer in there, but I feel quite positive about it." (P9:48).	Minimizing disease to maintain hope	Minimizing diseaseFocus on treatmentPositive attitude	Minimizing disease Positive attitude	Coping–working and existential	Hope in the face of an uncertain future
3	"Hey this is not too bad, you know attitude-wise I wasn't too bad. I have been through this. I figured if I did it once I could do it again." (P3:26–28)	Maintaining positive attitude Believing did it once, can do it again Hoping for a future	Positive attitude Hope for treatment response	Minimizing disease Maintaining a positive attitudeHoping for response to treatment		
7	"I'm considered in remission, however, I have to continue my therapy indefinitely because of the kind of cancer I do have." (P7:50)	Continuous treatment to live	Focusing on treatment	Focusing on treatment	Treatment focused	Seeking life through continuous treatment
10	"I don't think you have any option other than to move forward [have treatment] and be positive about whatever outcome there is. I still feel positive about it. It's not a great result but it's treatable." (P10:64–66)	Treatment to live Feeling positive Hope in treatment	Focusing on treatmentPositive attitude	Focusing on treatment Positive attitude		

Table 3 Participant demographics (N=15)

Characteristic	***n***
Gender	
Female	13
Male	2
Age Range (Years)	**Mean/Median age in Years**
44 yrs. – 77 yrs.	65.4yrs. /66 yrs.
Cancer diagnosis	
Breast cancer	12
Ovarian cancer	1
Lung cancer	1
Breast and ovarian cancer	1

Characteristic	***n***
Time since initial diagnosis to identification of advanced disease **Range (Years)**	**Mean/Median time to recurrence in Years**
2 years – 17years	8.7yrs./10yrs.
Time between Dx. & Interview **Range (Weeks)**	**Mean/Median time between Diagnosis with adv. Disease to interview in Weeks**
0.3 weeks-60 weeks	17.6weeks/8 weeks

Fig. 1 Relationship and intersections between the three concepts of the experience of advanced cancer recurrence

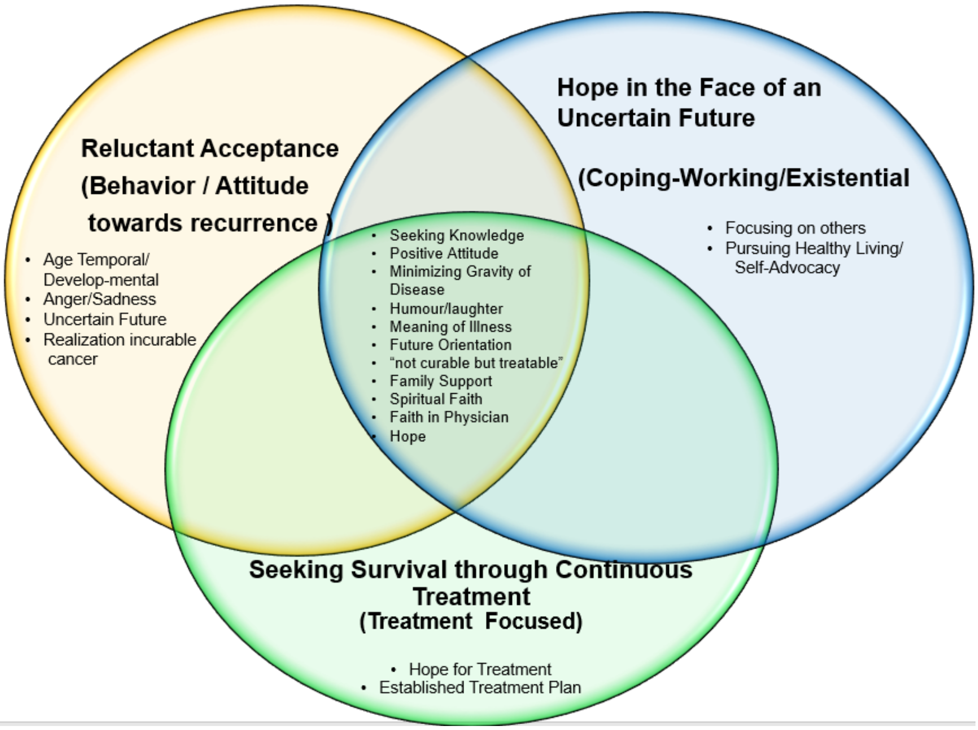
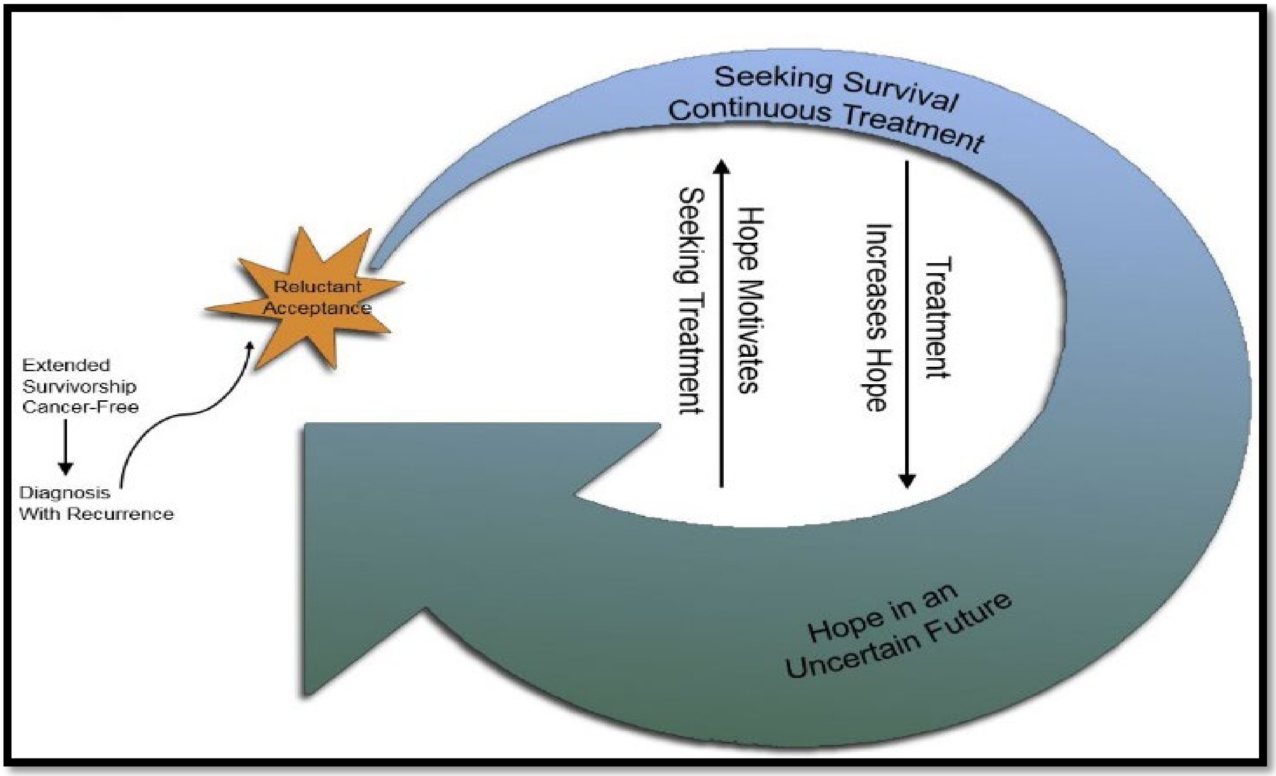


Fig. 2 The conceptual model of seeking survival in advanced cancer recurrence


Seeking Survival
Continuous Treatment
Treatment
Increases Hope
Hope Motivates
Seeking Treatment
Reluctant
Acceptance
Extended
Survivorship
Cancer-Free
Diagnosis
With Recurrence
Hope in an
Uncertain Future