



“I am not a statistic” ovarian cancer survivors’ views of factors that influenced their long-term survival

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HIGHLIGHTS

- For survivors, the presence of strong support systems was extremely important.
- Survivors identified modifying lifestyle, such as fitness and diet, as beneficial.
- Survivors believe having a strong life purpose contributed to their survival.

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ABSTRACT

Objective: Although a high proportion of women with advanced stage ovarian cancer die within five years, approximately 30% will survive longer than this. The factors contributing to exceptional survival are currently poorly understood. The viewpoints of ovarian cancer survivors were qualitatively explored to determine the factors they felt have influenced their exceptional ovarian cancer survival.

Methods: Four focus groups, one each in Los Angeles (California), Ann Arbor (Michigan), New York (New York) and Edmonton (Alberta, Canada), were conducted with women who had survived at least five years. Physical activity, diet, meditation, prayer, treatment, complementary medicine, and side effects were explored in semi-structured discussions. The audiotaped sessions were transcribed and coded and then analyzed using Dedoose Version 8.0.35, a qualitative analysis software.

Results: Of the 26 women who participated, 23 had advanced stage disease. Three overarching themes emerged: (a) survivors had improved their ‘lifestyles’, including but not limited to fitness and diet; (b) survivors were able to draw on strong support systems, which included family, friends, support groups, faith communities, and healthcare workers; and (c) survivors had a strong life purpose, which manifested as positivity, taking charge of their lives, and advocating for themselves.

Conclusions: Long-term survivors have varying experiences with their cancer, but identified lifestyle modification, motivation and persistence, strong life purpose, and strong support systems as key elements in their better survival. These preliminary findings indicate the need for further prospective studies to determine whether meaningful differences exist between short term and long term survivors on these characteristics.

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1. Introduction

Ovarian carcinoma (cancer) has a particularly high fatality rate among women diagnosed with stage III or IV disease (advanced-stage), however a subset of women experience an exceptional

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survival. Among women diagnosed with advanced stage ovarian cancer, approximately 30% survive five or more years and 15% survive more than 10 years [1]. Several clinical/pathological factors have emerged as associated with this exceptional survival include age at diagnosis, grade, stage, and cancer histotype [1]. Broadly, the factors contributing to survival of five or more years with advanced-stage ovarian cancer are thought to be a complex interaction between clinical, genetic, immunologic, and lifestyle exposures [2].

Studies of the role of personal experiences, including behaviors, attitudes, and beliefs of patients, and resources available to patients, that may contribute to ovarian cancer survival have suggested several themes. Several studies have identified the importance of social support, either in the form of emotional support, social attachment [3–10] or support from the health team [11,12] among cancer patients. Being positive and maintaining a sense of normalcy has also been identified as contributing to cancer patient's survival [4,7,13,14].

Studies of women with exceptional ovarian cancer survival have not been done. Considering this underexplored research area, we completed four focus groups with women with primarily advanced-stage ovarian cancer who have lived five or more years since their diagnosis. Our goal was to identify the personal care, behavior, and lifestyle factors that they felt may have contributed to their survival and that should be investigated further. This is particularly important as these factors present an opportunity for interventions which may benefit patients.

2. Methods

The focus groups were conducted as part of the Exceptional Survival, Lifestyle, and Behaviors study in ovarian cancer initiated by Drs. Leigh Pearce and Jean Richardson. This study was approved by the University of Michigan Institutional Review Board and the Department of Defense Human Research Protections Office (HRPO) Administrative Review. All focus group participants provided written informed consent prior to completing any study procedures. All study materials other than the consent form contained no identifying information and individual responses cannot be linked back to the consent forms.

2.1. Study design

The purpose of this study was to gather information on the lifestyle, behaviors, and personal care factors that women think influenced their exceptional survival with ovarian cancer. Focus groups were conducted between January and May 2018. One focus group was conducted in each of the following cities: Edmonton, Alberta, Canada; Los Angeles, California, USA; Ann Arbor, Michigan, USA; and New York, New York, USA. The U.S. locations were selected to represent different geographic regions. The Canadian location was selected to also understand whether a different healthcare system might influence responses, however this was not observed. This Canadian focus group was held during an ovarian cancer meeting and the participants came from all over Canada.

Women who were diagnosed with high-grade, advanced stage serous ovarian cancer and had lived for at least five years were invited to participate. The goal was to recruit 5–8 women for each focus group. Participants were identified through local, regional and national advocacy organizations and survivor groups. Local advocacy groups were contacted and asked to forward along a description of the study, pertinent fliers, and contact information to ovarian cancer survivors who met the inclusion criteria. Individuals who were interested then contacted a member of the study team, or their information was provided for us to reach out to them. Despite being clear during recruitment that the study was for

women with high-grade serous ovarian cancer, four participants did not have high-grade serous cancer and five could not remember their type; these women were not asked to leave the focus group.

The focus group guide, anchoring survey, and introduction script were developed by Dr. Richardson. The focus group guide served to provide an overall structure and areas covered included physical activity, diet, meditation, prayer, relaxation, complementary medicine, emotional status, cancer treatment, side effects of chemotherapy, and surgery, however women were encouraged to raise additional topics as well. The anchoring survey collected demographic and cancer stage and diagnosis information. We did not collect information on whether participants were experiencing a recurrence at the time of the focus group. Each focus group was audio-recorded and transcribed. Any identifying information was removed from the transcripts.

2.2. Data processing and analysis

Focus groups were transcribed and uploaded to the qualitative software platform, Dedoose Version 8.0.35 [15]. One focus group was coded by the members of the research group in a collaborative open coding process using descriptive codes. A discussion was carried out to determine suitable codes and definitions. The agreed-upon codes were then used to create a codebook. The codebook was revised by the research group following the coding of the second focus group. Following the first revision, Dedoose was used to determine intercoder reliability, a measure that indicates the level of agreement between different coders.

Code reports were then prepared. The code reports allowed for selective coding to be used to identify concepts and categories [16] that were further defined and developed as themes.

The codebook that was developed included 22 primary codes, with 37 sub-codes that served to further categorize the primary codes. The codes that were used for data analysis were perceptions and health beliefs, persistence, group support, diet after treatment, physical activity after treatment, family support, physical activity during treatment, health worker (physician or nurse) support, supplements, advice received, life purpose, friends support, and alternative medicine.

3. Results

Across the four focus group sites, 26 women who had lived at least five years after diagnosis were included (Table 1). All participants were non-Hispanic white and the average age at diagnosis was 52 years. Sixty-six percent of the women had high-grade serous ovarian cancer and the majority (88%) were diagnosed with Stage III or IV disease. Three major themes emerged from the analysis: (a) undertaking long term behavioral and lifestyle changes, (b) relying on strong support systems, and (c) being persistent and believing in a life purpose; these themes are discussed below.

3.1. Behavioral & lifestyle changes

Participants stressed the impact that the changes they made to their lifestyles had on them after diagnosis, and during and after treatment. These changes included new diets, physical activity and exercise regimens, the use of complementary medicine, the use of complementary and alternative therapy in conjunction with conventional medical treatment and supplement use. For the majority of the participants, these changes were long-term, initiated during treatment and continue to this day. "I forced myself to walk outside, all the time I could. And that helped me get stronger ...," one participant explained. Additional specific quotes from participants related to this theme are provided in Table 2.

Table 1
Descriptive characteristics focus group participants.

Measure	N (26)	Mean(SD)/%
Focus Group		
Los Angeles	8	31%
Michigan	5	19%
New York	6	23%
Canada	7	27%
Age at diagnosed	26	52±74
Type of ovarian cancer		
High grade serous	17	66%
Other type of ovarian cancer	4	15%
Not sure	5	19%
Stage		
Stage 1–2	1	12%
Stage 3–4	19	88%
Years since been diagnosed?		
5 to 7 years	5	19%
8 to 9 years	2	8%
10 years or more	19	73%
Surgery		
Yes	26	100%
No	0	0%
Chemotherapy		
Yes	25	96%
No	1	4%
Recurrence		
Yes	13	50%
No	13	50%
Race/ethnicity		
Non-Hispanic White	26	100%

Diet. For most of the participants, there was a deeply held belief that the changes in their diet contributed to their recovery. Participants discussed the elimination of certain foods in their diet, almost always following their own reading of available materials. Dairy, meat, and sugar were mentioned as foods that were eliminated. These eliminations are still practiced by these women. Notably, the participants expressed beliefs that controlling their diet was empowering and gave them license over their healing process. Participants felt that understanding their diets and implementing these lasting changes had an extraordinary impact on their ability to heal their bodies and remain disease free.

Physical Activity. While some participants were unable to exercise or engage in physical activity due to their surgery or side effects of chemotherapy, those that could, believed that exercise played a major role in their recovery. Those that could exercise during treatment described it as making them physically and mentally more resilient. Exercising, which included walking, playing tennis, doing yoga, running, lifting weights, and being active were all mentioned by the participants as activities that they now incorporate into their lives. For some of the participants, exercise was a new habit, but for others it was simply a continuation of how they lived their lives pre-diagnosis:

Complementary Medicine. The majority of the participants had also incorporated some form of complementary medicine, including medicines, therapies, and supplements. Some participants reported using treatments such as acupuncture to address

Table 2
Subthemes and descriptive quotations from theme 1: Behavioral and lifestyle factors.

Subtheme	Descriptive Quotes	Site
Diet	Once I was diagnosed, I changed my whole diet. I used to be a huge red meat eater, every day I would have red meat. I probably ate a lot more fried foods, I ate potatoes, and macaroni and pasta and I just decided this has to all go because it's not good for us.	Canada
	I tried to, as I became more educated about that sugar is not a friend of cancer, at all, I tried to take out excessive sugar. I mean I wasn't a big sugar person. But you know everything has sugar, muffins cakes, cookies. Bread. So I became more conscious. I felt very frustrated that there wasn't more advice, nutritionally.	Los Angeles
	So there's a lot of things that you can learn about how to heal your body and how to bring it back to health.	Los Angeles
	Making sure I have lots of vegetables, moderate intake of fruits. Once again, making sure as those – this is what I believe – as the cells are dying I need the good food and nutrition for the new cells to come back and be healthy. So that's my focus, so I make sure I have greens every day.	Canada
Exercise and Physical Activity	Physical activity has always been a priority to me. In terms of being able to work through the symptoms and you know, I had the neuropathy, but not enough that I couldn't move through it. And then it got better. And I felt like if I didn't move it wouldn't get better, so I was determined to keep moving.	Los Angeles
	This is what I did the minute I came home from chemo, before I even went in to the house I went for a walk and she said that will help your body ... She said get rid of the chemo. I don't think it did, but I think it did give me strength. And that's whatever I could do for walking, the distance, it's what I continued to do.	Canada
	I pretty much could walk. That was my form of exercise. And it felt good when I did it, so I continued to do that.	Michigan
	I forced myself to walk outside, all the time I could. And that helped me get stronger, I think faster.	Los Angeles
	I don't know I've always felt that was the activity that just getting back up there and doing something that I loved made a big difference for, me. And uh here I am. Still here.	New York
	So walking just allowed me to just kind of... I didn't go for the sake of exercise, but it was more of a release.	Canada
	And I have gotten much more active in going to the gym. I always tried to go to the gym, but I never had time between working and family life. So now I have more time.	New York
Complementary Medicine	I try to take the stairs all the time and not use elevators, but if I take the stairs too much I get a little bursitis in my hip. [...] But so it's just walking I try to get out. I don't like going to gyms.	Los Angeles
	Somebody told me that a Japanese sensei, that he was able to throw people with his energy, his chi, and that he was helping people with cancer because his daughter had had brain cancer and supposedly he had saved his daughter. And I was such a skeptic but I went and ... amazing. I really think he got me through the lung cancer and a lot of the ovarian. So that was very helpful.	Michigan
	I did what I guess is chasing supplements too– like silver water, so I do silver water because I'd heard you know [...] Kind of chasing what people were saying?	Canada
	Participant 1: So the first thing I did was rishi mushrooms. I was on rishi mushrooms until my first recurrence.	New York
	Participant 2: What is that?	
	Participant 1: A pill and someone told me that it was going to cure me. When I recurred I figured it wasn't workin' right. Anyway, I said to him, can you help me out with you know, should I be taking this vitamin, more vitamin d, a multi-vitamin. You know? [...] What can I do? You want to try to gain some control.	Los Angeles
	I think I'm happy with the supplements I'm taking, I think they're good for what my body needs while I'm going through chemo.	Canada
A family member that told me to try some kind of a tea and I did some research on it, and it was antioxidant, and to this day I still order, I still pay for it. I take it four to five days a week. I told her I can't stop it, I think it's keeping me alive, I don't know. So I take [curcumin] and cranberry juice because ever since surgeries I've had bladder—UTIs, many of them and vitamin D, and calcium. Pretty basic things. But I, same thing, don't want to quit because maybe that's the thing keeping me alive.	Canada	

side-effects. While some women approached these treatments and supplements with some skepticism, ultimately, they came to believe that they helped. Those who took supplements seemed to make a concerted effort to discover supplements that might be helpful. Some women reported seeing naturopathic doctors who prescribed supplement regimens, while others relied on word of mouth. Similarly to diet, participants described supplements as a means of regaining control over their lives and health. Some participants have continued to take supplements years later.

3.2. Strong support systems

Support systems played a crucial role in the women's experience with the illness after diagnosis, during treatment, and after treatment. These support systems took the form of not just traditional support groups and the support one receives from family, but also included medical workers and support from places of worship. One participant said, "...You know what I think? I take any religious prayer, doesn't matter - doesn't matter what you are. I'll take all prayers from everybody." Additional quotes are provided in [Table 3](#).

Family and Friend Support. The majority of the participants had support from their immediate and extended families, which was not limited by geographic distance. The most important form of support that families and friends provided was emotional, not material, support. Participants described feeling supported by those who set aside time for them, however over-bearing approaches to support were not helpful. They also reported that some people made statements that expressed negative expectations and these were broadly regarded as unhelpful.

Community Support. Support from religious institutions and organizations was also mentioned by the participants, even by those who self-described as not being religious. Support from religious institutions came in the form of food deliveries and prayer. This support, though perhaps religious in foundation, could broadly be thought of and described as an expression of community. Participants mentioned attending support groups on the encouragement of friends and family. Despite initial skepticism, the support groups proved helpful and their experience was positive.

Health Worker Support. A number of participants also mentioned the support they received from their health care workers, both physicians and nurses, as being a crucial part of their support system. Participants spoke highly of care teams that provided competent and sympathetic care and those who advocated for and listened to them.

3.3. Life purpose

Participants mentioned feelings of life purpose as contributing to their recovery. This life purpose took several forms that created a feeling of persistence and positivity in the face of adversity. For some, this life purpose was derived from a sense of serving others, including their community or their families. Others drew a sense of life purpose from their spiritual beliefs or religion. Participants credited their faith with not only helping them get through treatment, but on their survival. Almost all participants described determination to overcome the disease. This ranged from refusing to become just another statistic, to generally just having positive thoughts. These persistent, positive approaches were manifested in their lifestyle and in their interactions with others. Participants also approached their medical care teams with this persistence, at times seeking care from different physicians if their doctors were not responsive. For example, one participant exclaimed, "I'm going to kick cancer's ass." Additional illustrative quotes are provided in [Table 4](#).

4. Discussion

Although clinical, pathological and molecular features associated with exceptional ovarian cancer survival among those with advanced-stage disease have been described, there is limited information on the role personal experiences and actions play in recovery and long-term survival. In this qualitative study, women with advanced stage ovarian cancer shared their experiences which resulted in the identification of three major themes that they felt had contributed to their exceptional survival. Survivors reported being highly motivated to achieve success with changing lifestyle factors, including but not limited to fitness and diet. The women were able to draw on strong support systems, which included family, friends, support groups, faith communities, and healthcare workers. They also expressed a strong life purpose, which manifested as positivity, taking charge of their lives, and advocating for themselves.

Several previous studies have considered the needs of ovarian cancer patients. Similar qualitative studies on ovarian cancer survivors and their experiences suggest that a team approach by the health professionals [3,12], effective communication [3,9,11,12], and efficient connection to resources [3,12] can improve patients' experiences [3,9,11,12]. One recent qualitative study identified major themes of optimistic tenacity, lifestyle adjustments relating to behavior and activity, and the importance of support systems as important factors influencing ovarian cancer patients' experiences with chemotherapy [9]. The participants emphasized the importance of developing strategies for completing primary treatment as prescribed, although there is no standard approach [9]. Another analysis of social concerns of women with ovarian cancer found that there is a need for support from family, friends, and other women with ovarian cancer [17]. In addition, Lutgendorf and colleagues suggested an association between high social attachment and better survival [10]. Also, there are data to suggest that ovarian cancer survivors are involved in self-advocacy and negotiation with their healthcare providers and further that they rely on social support to meet their needs [18]. These observations are in line with our findings among ovarian cancer long-term survivors.

Interestingly, a qualitative study on breast cancer long-term survival found gratitude for life and strength and confidence in their ability to manage life crises were important [19]. This is similar to our finding of strong life purpose playing an important role for long-term survivors, with our participants mentioning feelings of purpose as contributing to their recovery. This life purpose revealed itself for them as determination in the face of adversity and a reliance on spirituality and religion. Strong life purpose has reproducibly been associated with better survival in healthy populations [20] and it may be that this is also the case among cancer survivors.

Our findings also have important implications with respect to the services available to ovarian cancer survivors and for interactions with their support network, including their care team. While we cannot from this study, say whether any of these three areas, behavior and life style choices, social support, and life purpose, were associated with long-term survival, ovarian cancer survivors believed they were important. An interesting study from the Cancer Research Network found that among women with high-grade serous ovarian cancer, those with depression were less likely to survive seven or more years. This provides some evidence that mental health status may influence survival [21]. In addition, data from the Gynecologic Oncology Group suggests that quality of life is associated with survival [22] and therefore even if these factors only affect quality of life they may still play a role in outcomes for the women [22]. Thus, enhancing focus on these areas is important. For example, many health insurance providers do not cover

Table 3
Subthemes and descriptive quotations from theme 2: Having strong support systems.

Subtheme	Descriptive Quotes	Site
Support from Friends and Family	I got through it because I had a tremendous amount of support and love.	Los Angeles
	I felt very fortunate that I had so many people in my life to give me the support.	New York
	I do have tremendous support from family. From my daughter who lives in California and my older son's wife, his wife is just fabulous, my daughter in law. And I have four grandchildren and that's a very big part of my life.	New York
	Family was more important, friends were more important. Just you know, spending time, not "can you help with..." and "I was busy, I gotta do this this", but you phone me for coffee? I'm there. I will meet you there.	Canada
	My sister, three times a day, if I wanted to call she just was at the other end of the phone. And that was just a tremendous, tremendous help to me	New York
	I have to say that my husband really is my rock. Everything, he's just by my side every moment. So that was fantastic. I had a lot of support, so that's what I attribute it to.	New York
	My sister did something I thought was brilliant. That made a, I think, huge difference for me which was that she created a tape. A visualization tapes for me, and she would send them to me. And that was, my whole family was in Boston and I was in California. So part of my morning ritual in that getting up and doing things thing, was putting on the tape and hearing my sisters words talk me out of bed. And it was amazing. And it um, and it was very rejuvenative.	Los Angeles
Burdensome Support	With regard to support, [...] I had to be so careful to protect myself from people who meant well that didn't know how to support.	Michigan
	One of my best friends, [...] wanted to come. And she kind of annoyed me. And "I said you know, I'm really not up for it." And I never tell anybody no, ever, and I said, "It's really not a good day for me." And she goes, "I promise I won't talk or anything I just need to sit with you because I don't I don't think we have much more time." [...] I mean it really upset me.	Michigan
Community Support	And after, when I finished my last chemo, I wrote in the church bulletin, thank you to the church family for all the support and the support they gave us. I know without their prayers, it wouldn't have happened. And I believe that, right to this day.	Canada
	That also brought me closer to my community, through my synagogue. They had a caring committee that reached out to me, they started with the food thing and um no one had ever shown me any kind of, I mean I had never experienced that kind of outpouring. And we were living in California for four years, and yet I had been part of this community to the extent to which, until people were arriving at my door. And so I attribute all of that to that prayer category of the religious connotation. So I didn't necessarily seek God, or a greater power, but the outpouring of my community, to me was religious. And it was very profound.	Los Angeles
	I didn't pray that much, but I had a lot of people praying for me. From my temple, they were praying for me. And then I have friends that they- I still have the card from Words of France and I know they say a prayer every day for me. And then one of my friends says, we need your picture because her sister was actually going to France and they put me on the prayer line and I says 'You know what I think I take any religious prayer, doesn't matter- doesn't matter what you are'. I'll take all prayers from everybody.	Los Angeles
	I wasn't allowed out of the house [...] when I was allowed to go to church and everyone would come and talk to me, they all came and talked to me. I enjoyed that.	Canada
Support Groups	I was one of those people. I did not want to go. I was like I don't want to talk about it. [...] I ended up loving being in a support group. I learned so much.	Los Angeles
	I think the support group helped me because I was the new kid on the block. [...] My husband read a lot about cancer, but he filtered it for me. And that's my personality. He knew what to share. He said, "Women do better in support groups, you know people do better." And I said, "You mean they survive?" He said, "They're able to handle things a little bit more reasonably." And all that helps.	Michigan
	I really think that the support groups were phenomenal. I started in [support group] after a couple of weeks and [...] I really felt I learned a great deal.	New York
Support from Health Workers	But you know in the group, everybody understood. So the groups were really important.	Los Angeles
	I would say if you have confidence in your treatment team, surrender yourselves to them and let them guide you and that was my doctor and the main nurse who was there at every appointment. And I saw her every appointment before every infusion kept telling me, "You're doing great X. You're doing great." And that- it just got me, it helped get me through [...] I would tell other women, if you don't have a treatment team who can be reinforcing that way and encouraging that way, you may want to stay with your treatment team because you trust the treatment but get someone else in your life who will keep telling you how great you're doing and that you can make it.	Los Angeles
	Yeah. You want to hear that. You want a doctor fightin' for you. And is gonna' back you no matter what.	Michigan
	I definitely credit my doctors for my being here. I had great surgery, incredible care afterwards, Great surgery again, incredible care afterwards. No question. I don't think I'd be here without them.	New York
	He was a skilled surgeon. And he gave me hope. So those two things. Did he use drugs that he'd created or any kind of creative way? No [...] Did he have a nurse in his office that was always available? Absolutely. I think that should be a credit for creating an environment, for being a skilled surgeon, for answering my questions, for connecting with me. [...] I think it's really critical that your doctor, that you feel that your doctor cares about you.	Michigan

complementary medicine services such as acupuncture or mind-body therapies, but these were identified as important by the women in our study and several other studies [23–25]. Policy-makers could work with insurance companies to expand the insurance coverage to cover some key areas of the complementary medicine, and make it more accessible to ovarian cancer patients. Moreover, a number of studies have identified the importance of social support, either in the form of emotional support, social attachment [3–10] among cancer patients. Thus, avenues for support should be made available for patients, including providing tips to family, friends and the patients' larger community on how to best to show their support to someone who has ovarian cancer.

This study has several notable strengths. First, to our best knowledge, this is the first qualitative study to explore the personal

care, behavior, and lifestyle factors that patients feel contributed to their exceptional survival with advanced-stage ovarian cancer. Considering this relatively underexplored research area, we utilized the advantages of qualitative study design to complete focus groups, to identify common factors and synthesize the major themes from ovarian cancer patients' perspective. Second, focus groups were conducted in four sites across the U.S. and Canada. This intracontinental study design provided us the opportunity to explore our research questions in different geographic regions with varying health system settings. Third, a semi-structured interview method was implemented during the focus group interviews. This allowed us to focus on our research questions, but at the same time enabled us to explore new topics that came up in the conversations, such as life purpose and resilience.

Table 4
Subthemes and descriptive quotations from theme 3: Persistence and life purpose.

Subtheme	Descriptive Quotes	Site
Life Purpose	Fortunately, the lady who was going to take care of my granddaughter, who was one of my charges, uh couldn't do it anymore, so I got [granddaughter] back. That was like the best thing that could've happened to me. So that was great to have her every day. And it was just enough not to -, so I didn't have to dwell on my own sad story	Michigan
Spirituality and Religion	I think having faith ... I don't know you'd get through cancer treatment without faith. When I came home from the doctor my first thoughts were, "oh I just pray that God chooses that I continue to walk down here." Then my second thought was, "thank God it was me and not my kids." So my faith was very strong and it became stronger than it ever was. [Priest] said "Keep your faith. Keep your faith in God. Keep good people around you. And just keep going." He said "You're going to be ok". And I felt literally, I had about a half a block left to get to the restaurant to meet my friend, I felt like I was floating.	Canada Canada Los Angeles
Positivity and Persistence	Faith has always been a huge part of my life. So when I was first diagnosed with cancer, my first reaction when my doctor told me, I thought, "oh cancer? Oh death. I'm probably going to die." Oh. This, it changed my outlook at church and stuff. And you know, people would be up there singing and it was all serious and I'm thinking, "You're singing about heaven, you should have a big smile on your face! I have my ticket, I'm going soon." Like wow, this is amazing you know, you're taught about it, you read about in the scriptures, you... You believe it, you sing about, and... Well, I'm going. I started to get excited, like a kid on Christmas morning. It sounds crazy but I think, wow. That's what it's all about. And then, I went through chemo and all that and I survived. Woops. And it's been 10 years. Okay, then I've got more to do here. But I'm a very positive person. More so than I used to be. I am so positive now. Well, nobody can really tell you, he said, but I can only say percentage wise, 85% of women who have it to the degree that you do will not be here in 5 years. So I was lying in bed, "but that means 15% will." The things that I have done to help me psychologically or mentally, is plan ahead. What has kept me going is a positive and a very passionate, forceful mindset; I'm not buying into the statistics because if I look at the statistics and I look at the numbers, and I look at the years of who's living, what time, stage this stage that, I might as well just, whatever little money I have, go to the Amalfi coast and just wait it out.	Michigan New York New York Los Angeles
Persistence & Self-Advocacy	[Doctor] said "Have you ever thought of just not doing anything?" And, I mean, I was really ok, I just had this thing going on. And I said "No." And he didn't know what to do with me. And he said, "Well, do you know the statistics?" and I said "no" even though I did. And he was really befuddled with the whole thing. And he's dead silence for a while, "Would you like to hear it, what the statistics are?" And I took a really deep breath, and I said "You know what, I'm not a statistic. I'm me. And I don't wanna hear it." I knew it. But I didn't want to hear it. I was telling one of my doctors that I thought I was doing well because I am positive. Y'know. We all have days that we were crying about something, news and stuff. And this guy said to me, "Then are you saying that only positive feeling-people with positive things survive and other ones-" Y'know he- he was negating it so much that I never went to him again. I said, "This is about me. It's not about you. If I need you on the weekend, I expect you to be there." I was pissed and I left [doctor] and he said, "I guess you're firing me, huh?" And I said, "I guess so."	Michigan Michigan Michigan

However, study limitations include the lack of racial/ethnic diversity; all participants were non-Hispanic white women, thus our findings may not be generalizable beyond this group. In our recruitment, participants were identified through local, regional or national advocacy organizations and survivor groups. This may represent a select group of women. Also, findings from this study only reflect what factors participants thought contributed to their exceptional survival, but as this was not a prospective study of all women with ovarian cancer we do not know the experience of short-term survivors. It seems reasonable that the factors identified here may be necessary to achieve exceptional survival, but are in no way sufficient. It is not clear if short term survivors approached the disease in the same way but were faced with characteristics of the tumor that are resistant to treatment despite best efforts on the part of the individual and those who care for them. The study of Staneva and colleagues [9] interviewed women who were two to three years from their diagnosis and were doing well, but we do not know if these are women destined to experience exceptional survival. Ovarian cancer is a complex disease in terms of genetic, immunologic, and clinical factors that have a definite impact on long-term survival and these factors are not well understood either. However, ovarian cancer places huge demands on the body and mind of the patient who must get through a threatening diagnosis and grueling treatment. This study suggests that the three factors identified are important in meeting that challenge although they cannot guarantee a result. Yet without those characteristics, it may be that women are less likely to survive. Furthermore, there are ways in which those factors can be enhanced for those who are confronted with this challenging diagnosis and treatment.

The results of this study of the factors ovarian cancer patients feel contributed to their exceptional survival provide future directions for research. A prospective cohort study of ovarian cancer survivors is needed to establish the associations between the identified themes and exceptional survival. The associations could be further studied in a randomized-controlled setting. Such interventions carried out during and after treatment could include physical activity, diet, complementary medicine, such as supplements, yoga, meditation, acupuncture; and life purpose interventions. Some of these can be delivered in person by trained professionals as well as through eHealth applications developed to improve life style choices as well as components of life purpose. This will provide important information on modifiable factors that may influence survival and as a result to help women meet the diagnosis, treatment, and recovery in the most effective manner.

Declaration of Competing interest

The authors declare no conflicts of interest.

Author contributions

CLP and JR contributed to the design of the study. LK and AW contributed to data transcription. CLP, JR, AA, and LK contributed to data analysis. All authors participated in the drafting of this manuscript, and have read and approved the final version submitted.

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