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Support Needs of Young Ovarian Cancer Survivors: A Pilot Study

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SUPPORT NEEDS OF YOUNG OVARIAN CANCER SURVIVORS: A PILOT STUDY

For the degree of Master of Public Health

Is approved by the final examining committee:

Dr. Gerald C. Hyner

Chair

Dr. Frank J. Snyder

Dr. D. Randy Black

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SUPPORT NEEDS OF YOUNG OVARIAN CANCER SURVIVORS:
A PILOT STUDY

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ABSTRACT

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Purpose. Young ovarian cancer survivor (18 years old or older but diagnosed before the age of 34 years old) support needs (i.e., physical and daily living, psychological, sexual, patient care and support, health system and information) were examined to guide the design and implementation of future young adult and adolescent cancer support groups and interventions.

Method. This cross-sectional pilot study included 11 young ovarian cancer survivors. The Supportive Care Needs Survey Short Form 34 (SCNS-SF34) was used and open-ended questions were added.

Results. The calculated standardized scores for the SCNS-SF34 survey results showed that sexuality needs were ranked highest (41.7 on a scale 100), followed by physical and daily living needs (25 on a scale of 100), psychological needs (16.9 on a scale of 100, and health system and information needs (5.5 on a scale of 100). Open-ended responses indicated young ovarian cancer survivors' need to address: (a) sexual concerns, (b) psychological support through interacting with other ovarian cancer survivors and professional counseling during and after cancer treatment, and (c) financial support.

Conclusion. Sexuality, professional counseling, and interaction with other survivors were found to be the greatest needs for this sample.

INTRODUCTION

Background and Epidemiology of Ovarian Cancer

Ovarian cancer is defined as “[c]ancer that forms in tissues of the ovary (one of a pair of female reproductive glands in which the ova, or eggs, are formed)” and is classified as a “germ cell” cancer [1]. According to the Centers for Disease Control and Prevention (CDC), ovarian cancer was the fifth leading cause of cancer death in 2013 among women [2]. Despite being considered “rare” [3], ovarian cancer was responsible for more deaths than any other cancer of the reproductive system (e.g., vulvar, uterine, vaginal, ovarian, and cervical) although it only accounted for about 3% of all women’s cancers [2]. Additionally, the lifetime risk for ovarian cancer was 1.8% and that risk increased from 16-45%, if a BRCA1/2 mutation was found [4].

In 2014, there were 21,980 new cases of ovarian cancer in the US, of which 2,660 or 12.1% affected pre-menopausal women, defined as ≤ 45 years old [5]. Out of the 21,980 new cases, 1,077 of them, or 4.9%, affected women ≤ 34 years old [5]. Also in 2014, there were 14,270 deaths due to ovarian cancer in the US, of which 457 deaths, or 3.2%, affected premenopausal women, where women ≤ 34 years old accounted for 114 of these deaths, or 0.8% [5]. The prevalence of ovarian cancer in 2011 was estimated to be 188,867 cases [5]. Therefore the case fatality rate was calculated to be 7.6/100, meaning that 7.6% of the women diagnosed died due to ovarian cancer.

Early diagnosis of ovarian cancer is crucial for survivorship as the 5-year survival rates quickly decrease as the disease progresses. If detected early, the 5-year survival rate was 92.3% if proximal (i.e., Stage I cancer, where the cancerous cells are confined to the ovary) [5-7]. This number falls to 71.7% if the disease has spread regionally (i.e., Stage II cancer, where the cancerous cells have spread to other pelvic tissues) and to 27.4% if the disease has metastasized to other organs and tissues (i.e., Stages III and IV cancer, where cancerous cells can be found in abdominal tissues and regional lymph nodes and where cancerous cells have spread to tissues beyond the abdominal cavity such as the lungs and the liver, respectively) [5-7]. Unfortunately, as of 2015, there is still no screening test available for ovarian cancer.

Adolescent and Young Adult Cancer Survivorship

A cancer survivor, as defined by the National Coalition for Cancer Survivorship, is anyone “living with, through, and beyond a cancer diagnosis” [8]. The population of interest for this study was adolescents and young adults (AYA) ovarian cancer survivors because about 5% of new ovarian cancer cases affect women ≤ 34 years old and 97% of these new cases survive [5]. AYA has been referred to as “invisible” because in the literature, (a) AYA were typically not differentiated from children or adults, (b) medical treatment was delivered in pediatric or adult settings, and (c) there was misunderstanding of AYA feelings towards treatment and disease, all of which led to miscommunication from healthcare providers [9]. Other barriers the AYA population faced were limited finances, high rates of uninsured individuals, and the absence of educational support (e.g. tutoring, counseling) when transitioning back to “normal” life [10]. Also, a previous

survey study reported that AYA cancer survivors' desired age-appropriate information, guidance, and counseling [11].

The literature specific to ovarian cancer survivorship was very limited and was even more scarce when the AYA population was taken into account, as the median age for a diagnosis of ovarian cancer is 63 years old [5]. Related literature focusing on the broad AYA cancer survivor population reported "an unmet need for professional mental health services [which] increased as AYAs reported more treatment-related symptoms" [12]. In Latino young survivors of other cancers such as lymphoma, leukemia, and brain tumors, AYA reported a desire for mental health support, the minimization of the use of the word "cancer," and social support to address stigmatization due to the disease [13].

A closely related disease is breast cancer. With young breast cancer survivors, a survey study reported elevated depressive symptoms and reproductive concerns [14], which are likely magnified in young ovarian cancer survivors since the tumor originated in one of their reproductive organs. Another breast cancer survivor study reported "evidence of differing psychosocial needs between younger and older survivors," especially "age-appropriate support services and age-appropriate information during and after treatment" [15], and it is likely that the same needs apply to young ovarian cancer survivors.

The Executive Director of Ovar'coming Together, an Indiana ovarian cancer non-profit organization, received requests from young survivors (adolescents) of the disease to have an age-appropriate support group (R. Jackson, personal communication, March 2013). Due to the lack of personnel, Ms. Jackson suggested they attend young breast cancer survivor support groups; however, their feedback was mainly negative, as the

young ovarian cancer survivors could not relate to young breast cancer survivors, having faced different health challenges and wanting to address dissimilar concerns (R. Jackson, personal communication, March 2013).

Significance and Study Purpose

The purpose of this study was to examine young (diagnosed at 34 years old or younger) ovarian cancer survivors' self-identified support needs (i.e., physical and daily living, psychological, sexual, patient care and support, health system and information) and the factors involved (i.e., treatment type, stage at diagnosis, etc.) to guide the design and implementation of future young adult and adolescent cancer support groups and interventions. This pilot study was significant as it was the first study focusing on this population and ovarian cancer care.

METHOD

Ethics Approval and Informed Consent

The Institutional Review Board of Purdue University approved the research protocol (IRB Protocol #1502015724). All participants completed an online consent form before taking the survey.

Participant Inclusion and Recruitment

The public Facebook group “Young Ovarian Cancer Survivors Unite!” was created by A. Chuong created in the Fall of 2014. Young ovarian cancer survivors were made aware of the Facebook group via a post on the Ovarian Cancer National Alliance support website Inspire (www.inspire.com) and local non-profit organizations such as Ovar’coming Together of Indiana, Ovarian Cancer 101 of Massachusetts, Lilies of the Valley of Alabama, TEAL Tender Hearts for Ovarian Cancer Awareness of New Jersey, Wisconsin Ovarian Cancer Alliance, Michigan Ovarian Cancer Alliance, and Colorado Ovarian Cancer Alliance. Admittance to the Facebook group required approval from the group administrator with the only requirement that members were female. Participants younger than 18 years old and those diagnosed with ovarian cancer when they were older than 34 years old were excluded from the study. As of February 2015, there were 28 members in the Facebook group. The response rate was 46.4%, with 13 survey

participants; however, data from 2 respondents was excluded from data analysis as they did not provide consent or confirm their status as an ovarian cancer survivor.

Supportive Care Needs Survey Short Form 34 (SCNS-SF34)

Support needs of young ovarian cancer survivors were identified using the Supportive Care Needs Survey Short Form 34 (SCNS-SF34), a previously developed survey by the Centre for Health Research & Psycho-Oncology (CHERP), now renamed the Priority Research Centre for Health Behavior (PRCHB), at the University of Newcastle in Australia [16, 17]. The 34-item survey assessed the perceived needs of cancer survivors, specifically the following measures: psychological needs, system and information needs, physical and daily living needs, patient care and support needs, and issues with sexuality [17]. Survey scores were calculated by summing the items within each domain with a Likert summated scale to yield a crude score [17]. Answers summated as follows: Not applicable = 1, Satisfied = 2, Low need = 3, Moderate need = 4, and High need = 5 [17]. Likert summated scores were standardized using the formula $a \times 100 / (m \times (k - 1))$, where m is the number of items in a domain; a is the adjusted Likert score (crude score $- m$); and k is the maximum score value for each item, as previously described [17]. The five assessed factors accounted for 72.1% of the total variance and the Cronbach alpha coefficient for each domain exceeded 0.8 in previous studies [16, 17]. The Patient Care & Support category was omitted due to an error in the IRB-approved survey. Missing values (no responses) were excluded from score calculations since the sample size was so small.

Survey Administration

Qualtrics, LLC (Purdue University license) was used to administer the survey to the participants through the “Young Ovarian Cancer Survivors Unite!” Facebook page, on a voluntary basis. The survey was open for 4 weeks with the posting of weekly reminders on the group page.

Data Analyses

Descriptive analyses were performed using Stata/SE, Release 12 [18]. The principal investigator and an independent coder identified the major recurring themes from collected open-ended responses. Disagreements in coding were resolved through discussion. Inter-observer agreement was calculated to be 82.14% using the formula

$$\% \text{ agreement} = \frac{\text{agreements}}{\text{agreements} + \text{disagreements}} \times 100 \text{ as previously described [19].}$$

RESULTS

Description of the Sample

Sample characteristics are in Table 1. A total of 13 women participated in the survey but 2 observations were excluded from the analysis, as participants did not provide consent or confirm their status as an ovarian cancer survivor.

Table 1. Sample Characteristics

<i>Characteristic</i>	<i>n</i>	<i>%</i>
Age at time of survey		
23-27 years old	2	18.2
28-34 years old	8	72.7
Older than 34 years old	1	9.1
Race		
White	8	72.7
Asian/Pacific Islander	2	18.2
Hispanic	1	9.1
Education		
High School Graduate	1	9.1
Some College	1	9.1
Associate's Degree / College Graduate	4	36.3
Some Graduate Work	2	18.2
Post-graduate Degree	3	27.3
Occupation		
Employed	8	72.7
Unemployed	3	27.3
Marital Status		
Single	5	45.4
Committed Relationship / Engaged	2	18.2
Married	4	36.4

Table 1. Sample Characteristics (continued)

<i>Characteristic</i>	<i>n</i>	<i>%</i>
Parity		
Yes	2	18.2
No	9	81.8
Age at Diagnosis		
18-22 years old	2	18.2
23-27 years old	3	27.3
28-34 years old	6	54.5
Stage at Diagnosis		
Stage I	4	36.4
Stage II	1	9.1
Stage III	6	54.5
Treatment Received		
Surgery		
Yes	11	100
No	0	0
Chemotherapy		
Yes	9	81.8
No	2	18.2
Current Stage		
Stage III	1	9.1
No Evidence of Disease / In Remission	10	90.9
Geographic location of residence		
Asia	2	18.2
Eastern Europe	1	9.1
US / Canada	8	72.7
Local support group or organization		
Yes	5	45.4
No	6	55.6

The majority of the women in this study were aged 28-34 years old at the time of the survey (72.7%), white (72.7%), college-educated (associate or college degree, 81.8%), employed (72.7%), and resided in North America (72.7%, Table 1). Relating to their ovarian cancer diagnosis, 54.5% of the women were diagnosed between the ages of 28 and 34 years old compared to 45.5% between 18 and 27 years old (Table 1). All women underwent surgery (100%, Table 1) and 81.8% of respondents received chemotherapy

(Table 1). The majority of the young survivors reported being in remission or showing no evidence of disease (90.9%, Table 1). Approximately half of the women reached out to a local group or organization for support (45.4%, Table 1).

Perceived Support Needs: SCNS-SF34 Survey

The scores from the SCNS-SF34 survey measures and missing values can be found in Table 2.

Table 2. SCNS-SF34 Survey Results

<i>Need Category</i>	<i>Crude Scores</i>					<i>Standardized Scores*</i> (Scale of 100)
	<i>Min</i>	<i>Max</i>	<i>Missing Values</i>	<i>M</i>	<i>SD</i>	
Physical & Daily Living	5	25	1	10.0	5.6	25
Psychological	10	50	11	25.2	12.4	16.9
Sexuality	3	15	3	5.5	3.3	41.7
Health System and Information	11	55	30	17.1	15.5	5.5

**Note.* Calculated from the mean crude score as described previously [16].

The calculated standardized scores for the SCNS-SF34 survey results showed that sexuality needs were ranked highest (41.7 on a scale 100), followed by physical and daily living needs (25 on a scale of 100), psychological needs (16.9 on a scale of 100, and health system and information needs (5.5 on a scale of 100) (Table 2).

Perceived Support Needs: Open-Ended Responses

The young ovarian cancer survivors who responded “Yes” to having access to a local support group or organization (45.4%, Table 1) mentioned participating or working with non-profit organizations such as the Wisconsin Ovarian Cancer Alliance (WOCA), Ovar’coming Together (Indiana), the Ovarian Cancer National Alliance (OCNA), the Colorado Ovarian Cancer Alliance (COCA), or various programs “offered through local nonprofits, some of which had hospital affiliations.” Survivor #11, who is involved with COCA, wrote “[the organization] is a great group, but I am by far the youngest member. I often choose not to participate in their events because I feel quite out of place and bitter [that] I am 30 years younger than the rest of the members.” Similarly, survivor #6 indicated a need to talk to and make a connection with other ovarian cancer survivors because of the “understanding of what [she went through].”

Regarding their physical symptoms, three survivors indicated a need for support in managing side effects of cancer treatment. Menopause was brought up multiple times. Specific to surgery and medication or chemotherapy, survivor #10 wrote,

I need to make small adaptations to my life to live comfortably. I suffer from severe hot flashes that cause nausea from my medication and surgical menopause, so I have to have a fan at my desk at work. I have been allowed to alter my work schedule so that I arrive slightly later in the day so that I can get more rest in the morning before work. I also suffer from back pain and muscle spasms as a results [*sic*] of many surgeries.

Survivor #5 mentioned “[h]aving to deal with chemo brain mainly the memory loss, loss of specific words when talking and focusing.”

Having others involved was helpful to survivors for psychological support. Being able to interact with other survivors and needing professional counseling were mentioned multiple times. Survivor #4, who now works with (WOCA), expressed feelings of depression and anxiety due to hormonal changes, her inability to have children and bringing it up to men while dating, and survivor's guilt as she recently lost 2 of her closest "fellow teal sisters." She also indicated "a great need [for] professional counseling" but with no insurance and limited finances, she has been trying to cope on her own. Survivor #10 asked help from family members for "practical things, like help around the house; however, "for emotional support, [she] reach[ed] out most often to fellow survivors for help and advice." Even though she completed her chemotherapy a couple years ago, survivor #9 wrote that it "has been helpful to have people who will still let [her] talk through some of [her] anxieties." Survivors #1 and #5 expressed concern about cancer recurrence.

Survivors indicated needing support with their sexual life. Survivor #1, despite being single currently, expressed concern for future relationships, her feeling insecure now that she has gone through menopause, and how to approach her inability to become pregnant or bear children while dating. Survivors #4 and #6 indicated being both in committed relationships. Survivor #4 mentioned having a very understanding and accommodating sexual partner but she also got frustrated as "intercourse can be very painful at times and makes [her] feel unattractive!" On the other hand, survivor #6 wanted outside support so that her partner could "understand how [she feels] low sex drive due to menopause." Survivor #2, who wrote that even though she was comfortable with her male physician, she found it difficult to talk about her sexual life and wished she

could have the funds to see a sexuality expert, such as the one who went to the annual OCNA conference.

Regarding their most recent experience with a hospital or physician visit, survivor #6 felt her medical team “treated [her] like a queen” and survivor #10 appreciated not being rushed during her appointments. Survivor #1 found her female oncologist to be extremely helpful, giving her resources and addressing her questions and concerns.

DISCUSSION

The purpose of this pilot study was to obtain preliminary data regarding the support needs of young ovarian cancer survivors and identify factors (e.g. treatment type, support group accessibility, etc.) that may contribute to a desire for support. Due to the small sample size, statistical analyses were not plausible and were not performed; however, standardized scores from the SCNS-SF34 indicated that sexuality needs were ranked highest (41.7 on a scale 100), followed by physical and daily living needs (25 on a scale of 100), psychological needs (16.9 on a scale of 100, and health system and information needs (5.5 on a scale of 100) (Table 2). There were many missing values, the majority of which were in the health system and information measure, which may have contributed to its low score. Questions for the latter were located at the end of the survey and participants may have gotten tired of completing the survey. Future studies may have to randomize the order of the measures to decrease the number of missing values. Additionally, the patient care and support SCNS-SF34 standardized score was not calculated due to an error in the IRB-approved administered survey; however information related to the topic was gathered in the qualitative part of this study.

Young ovarian cancer survivors who indicated having access to local support shared descriptions of their experience and/or named the organizations, some of which collaborated with local hospitals, demonstrating that much of the support originated from

the non-profit sector. For one survivor, the large age difference and the lack of common concerns demonstrated the importance of tailoring activities to the various stages of life (i.e. adolescence, young adulthood, late adulthood, etc.). Some young ovarian cancer survivors were very open to share their experiences, citing their sexuality needs most frequently, agreeing with the SCNS-SF34 scores above. Others chose not to share more than just what was asked in the SCNS-SF34 survey.

Survivors' physical support needs mainly revolved around the side effects from cancer treatment such as chemotherapy and surgery, bringing up the topic of surgical menopause. One survivor had to make accommodations at work due to her hot flashes while another mentioned having family members helping her with practical tasks such as around the home. However, much of the young survivors' psychological support came from fellow survivors especially being able to talk to other women who went through a similar experience, but there was mention of survivor's guilt, especially when close friends succumbed to ovarian cancer. One survivor wrote that she still talked about her cancer experience despite no longer receiving chemotherapy, indicating that post-cancer psychological support is needed just as much as while in treatment. Professional psychological counseling seemed difficult to obtain for one young survivor due to her lack of insurance and limited financial resources.

The greatest support need was in regards to sexuality. Their greatest need was how to approach the subject of not being able to become pregnant or bear children while dating, fearing that men will shy away from or leave their relationship. One survivor knew of a resource which was made available at a national conference; however, similar to the survivor wanting professional psychological support, limited finances prevented

her from seeing a sexuality expert. Survivors in committed relationships, on the other hand, seemed to want support to address their own and their partners' expectations and frustrations, as reported previously [20]. Understandably, a concern that younger women (i.e., young ovarian cancer survivors) have was family planning, which for older women (i.e., 63 years old), was no longer an issue since they may have naturally gone through menopause. Angelina Jolie Pitt, an American celebrity in an effort to be proactive about her own health due to her family history of breast and ovarian cancers and carrying a BRCA1 mutation, defended her choice to remove her ovaries and fallopian tubes (laparoscopic bilateral salpingo-oophorectomy) as she will undergo surgical menopause [20]. She showed empathy to cancer survivors as she wrote in the New York Times "I feel deeply for women for whom this moment comes very early in life, before they have had their children. Their situation is far harder than mine" [21].

On the subject of medical cancer care, young ovarian cancer survivors were very satisfied, as they did not feel rushed during appointments, had their questions and concerns addressed, were given resources when needed and requested, and were treated respectfully. Although one survivor felt comfortable with her male physician, the difference in gender may have attributed to her inability to bring up her sexual concerns to him like another survivor was able to with her female oncologist.

Finances seemed to be a concern for two survivors, preventing them from seeking professional psychological or sexual support, supporting the findings of previous studies [10]. Young survivors are likely still in school or just starting out in their careers; therefore a cancer diagnosis followed by treatment and monitoring can be costly and unexpected. These young ovarian cancer survivors and other young cancer survivors

could benefit from having a database of resources such as the Surviving And Moving Forward Fund (The SAMFund, <http://www.thesamfund.org/>), a Boston-based non-profit organization whose mission is to help young cancer survivors financially. Future studies may need to add financial assistance to the SCNS-SF34 measures to gain a more complete picture of young cancer survivor support needs.

As was reported previously, young breast cancer survivors sought “age-appropriate support services and age-appropriate information during and after treatment” [15]. This study demonstrates that the same needs may apply to young ovarian cancer survivors as well.

Limitations

The sample size for this study was very small and with ovarian cancer being considered a rare disease [3] and women ≤ 34 years old account for less than 5% of new cases annually [5], this study focused on a very specific population. Additionally, statistical analysis on such a small sample was not plausible. A second limitation was the study was cross-sectional and did not account for how cancer survivor support needs may change with their health status over time. Longitudinal study participants could be recruited in a clinical setting as cancer survivors are likely going to a physician or hospital for treatment and/or monitoring of their cancer’s progress. Access to their medical records could provide additional data and clarification of any misinformation about their medical condition and treatment. A third limitation was participants in this sample all had Internet and Facebook access, excluding individuals without computers or Internet from responding. The response rate was 46.4% and could be improved if

information about respondents and non-respondents could be obtained, which was not plausible in this study. Survivors not wanting to relive their cancer experience or let ovarian cancer define them could be 2 of the reasons why some young survivors chose not to respond. To increase response rates, future studies on this topic may be conducted in person and in a clinical as mentioned previously. Face-to-face interaction and randomization of the measures could also decrease the number of missing values (Table 2). Another limitation was that needs of young and older cancer survivors could not be compared. A 2013 literature review attempted to differentiate ovarian cancer survivors needs; however, their definition of a young survivor was a woman aged 45 years old or younger [20]. Last, with more time and better planning, training of the coders for the open-ended responses could increase future inter-observer agreement percentage.

CONCLUSION

This study was a preliminary investigation of young (≤ 34 years old) ovarian cancer survivors' self-identified support needs. Although further studies are needed, future interventions addressing the support needs of young ovarian cancer survivors should focus on (a) sexuality, how to address the inability to become pregnant or bear children when dating or starting a relationship and the sexual life changes for survivors and their partners following surgery or surgical menopause; (b) psychological support, while in and after treatment, and interaction with other survivors; and (c) financial support, to be able to seek professional counseling at any time.

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