



1 Article

## 2 Information and Support Needs of Mothers At-Risk for and 3 Surviving with Breast/Ovarian Cancer: The Role of Patient 4 Navigation in Health Outcomes

5 Talia Zamir<sup>1\*</sup>, Muriel Statman<sup>1</sup>, Marcelo M. Sleiman, Jr.<sup>1</sup>, Dheeraj Oruganty<sup>1</sup>, Adina Flaischmann<sup>2</sup>, Elana Silber<sup>2</sup>,  
6 and Kenneth P. Tercyak<sup>1</sup>.

7 <sup>1</sup> Lombardi Comprehensive Cancer Center, Washington, DC, USA.

8 <sup>2</sup> Sharsheret, Teaneck, NJ, USA.

9 \* Correspondence: tz218@georgetown.edu; Address: Lombardi Comprehensive Cancer Center, Georgetown  
10 University Medical Center, 2115 Wisconsin Avenue, NW, Suite 300, Washington DC 20007.

### 11 Abstract:

12 Over 1.5M US cancer survivors are raising children, and many are mothers affected by  
13 breast/ovarian cancer. The average woman has a 1:8 chance of developing breast cancer and a 1:87  
14 chance of developing ovarian cancer. Mothers, especially those with minor children, may experience  
15 worsening quality of life (QoL) compared to their counterparts without children. That is because  
16 mothers with cancer face the dual challenge of parenting and managing their illness, often while  
17 maintaining primary caregiving roles. Community-based organizations (CBOs) offer critical patient  
18 navigation services to women at-risk for and surviving with breast/ovarian cancer. Yet, little is  
19 known about how CBO engagement supports mothers' cancer experience and QoL. We conducted  
20 a secondary analysis of a national CBO's cancer control program evaluation data (2021-2023) to  
21 address this gap. Among all women who contacted the CBO (N=1,758), a majority were mothers  
22 (N=1217, 69.2%): 56% identified as mothers of adult children, 31% were mothers of minor-age (<18)  
23 children, and 13% were mothers of both minor and adult children ( $\chi^2=341.46$ ,  $p<0.001$ ). Among the  
24 mothers with children aged <18, 82% were non-Hispanic White, 6% were African American, about  
25 4% were not diagnosed with breast or ovarian cancer, 8% were not diagnosed with breast and/or  
26 ovarian cancer but were high risk due to BRCA mutation carriage, 28% were diagnosed with breast  
27 and/or ovarian cancer and were high-risk due to BRCA mutation carriage, 68% were diagnosed with  
28 breast and/or ovarian cancer and were not high risk BRCA mutation carriers, and 20% were both  
29 diagnosed with breast and/or ovarian cancer and carried a BRCA mutation. Regarding QoL of  
30 mothers with younger children, 47% were in fair/poor health and 20% experienced frequent mental  
31 distress (M=6.8 physically unhealthy days, M=7.4 mentally unhealthy days, and M=5.5 activity-  
32 limited days within the prior 30 days). Importantly, 54% of these mothers reported participation in  
33 a CBO-led service focused on psychoeducation for children and families about cancer, and 39%  
34 engaged with cancer survivorship resources. In the evaluation sample, mothers with young children  
35 reported high satisfaction with the CBO's cancer control services, and with well-developed  
36 psychosocial empowerment ( $r=0.47$ ,  $p<0.001$ ). CBO patient navigation programming for mothers  
37 surviving breast/ovarian cancer strongly supports them throughout the survivorship journey, and  
38 especially when these programs attend to their parenting role.

39  
40 **Keywords:** breast cancer, mothers, quality of life  
41

## 1. Introduction

The average woman in the US has a 1:8 chance of developing breast cancer (BC) and a 1:87 chance of developing ovarian cancer (OC) in her lifetime [1]. A BC or OC diagnosis interferes with all aspects of a woman's well-being, including employment, social and familial relationships, and childrearing. It is estimated that 12% of BC survivors and 5% of OC survivors live with minor children, and their mothering role while undergoing cancer treatment can be doubly burdensome [2].

Mothers with cancer often face unique challenges given their responsibilities as both a mother and a patient. These mothers may struggle to strike a balance between everyday childrearing and addressing their children's fears and concerns about cancer [3–5]. Reports from patients and survivors, both while undergoing treatment and afterward, underscore how challenging it is to navigate their own health priorities with the needs and well-being of their children. Research suggests that these mothers often reaffirm their commitment first and foremost to their children [6,7]. Additionally, survivors often bear a reduced sense of parental efficacy (i.e., a caregiver's confidence in their ability to raise children) and experience feelings of sadness and guilt since a cancer diagnosis can disrupt how a parent feels they can meet the needs of their children [5,8]. Thus, it is incumbent on healthcare providers to consider how motherhood may influence patient decision-making, feelings of empowerment (e.g., their perceived control over their health decisions), and overall quality of life (QoL) [9,10].

Cancer can have a profound and adverse impact on the QoL of both mothers and their children. Compared to young BC survivors (those diagnosed before age 30) without children, young mothers surviving BC who have children report higher levels of fear of recurrence and report that BC disrupts their family dynamics to a greater extent [9,11]. Similarly, young survivors with children report greater distress and lower QoL compared to older survivors, and they frequently report higher levels of depression, difficulty sleeping, and anxiety [12–15]. Mothers often communicate that they feel their survivorship journey is interwoven with the functioning of their family; thus, it is important to consider how motherhood (and the ages of children) influences a survivor's ability to maintain a high QoL.

Research suggests the ages of mothers' dependent children heavily impact survivors' decision-making and psychosocial support needs. Compared to mothers who have adult children (above age 18), mothers surviving cancer who have dependent children often struggle to explain their disease to their children [16]. These mothers see their disease as a significant stressor and burden for both them and their youngsters, and many report seeing affective and behavioral changes in their children throughout the cancer treatment journey. Many BC and OC survivors report the need for additional resources to navigate effectively discussing their disease with youth [17,18]. For example, although mothers surviving cancer who have adolescent-aged children note that they do not want conversations about cancer to dominate their relationships with their children, they seek guidance about engaging in conversations with their children about cancer in a nonthreatening way to help reduce their own uncertainty and psychological distress [19].

Community-based organizations (CBOs) have increasingly recognized and helped address the information and support needs of families affected by cancer. CBOs are integral in connecting BC and OC survivors with psychosocial and other resources, including financial support and childcare [20,21]. For mothers surviving with BC or OC, collaboration with a CBO usually begins when a patient or family member contacts the CBO for assistance. The CBO then provides patient navigation (PN) to help connect mothers to resources and services available from within the CBO itself or allied organizations [10,22]. Research suggests that PN to these support networks offer by and through CBOs promotes the formation of strong social ties among patients with cancer, which have been shown to be associated with survival advantages [23,24]. For example, when OC patients who reported high levels of depression and low levels of social support (high-risk) were compared to those with low depression risk and high levels of social

96 support (low-risk), higher-risk patients demonstrated an upregulation in ovarian tumor  
97 progression [24]. For mothers surviving or at-risk for cancer, peer support networks  
98 provided by CBOs give survivors an opportunity to ask questions about treatment and  
99 share challenges, including those associated with raising children while receiving  
100 treatment [25,26]. Post-treatment support administered by and through CBOs could also  
101 be beneficial; one study found that following OC surgery, women can engage in  
102 community-based occupational therapy to reduce post-surgery distress and manage  
103 concerns [27]. However, raising awareness about these services to the populations they  
104 aim to assist (including historically marginalized groups with low prevalence of cancer  
105 screening) may influence their overall utilization [28,29].

106 These findings suggest that cancer-focused CBOs fill gaps in cancer prevention,  
107 control, and PN that are left unaddressed by the clinical services offered through hospitals  
108 and similar settings. Mothers who belong to high-risk and vulnerable populations  
109 traditionally face systemic barriers to comprehensive cancer care in the US: CBOs PN can  
110 be vital in educating patients and survivors from these populations about cancer  
111 screening, and help them schedule appointments and provide opportunities for  
112 psychosocial support [22,30] Yet, there has been little research evaluating the efficacy of  
113 CBOs in supporting mothers at-risk for, diagnosed with, and surviving BC and OC in this  
114 context.

115 In order to optimize the impact of CBOs service lines, it is important to understand  
116 the overall needs and outcomes of the services offered, including mothers' experience with  
117 PN and how CBOs empower mothers to make informed health decisions about BC and  
118 OC [10,31]. This would include information and support that is applicable to mothers as  
119 well as their children (both young and older), and particularly in the case of adult-onset  
120 inherited cancer syndromes that may be passed from generation to generation. This is of  
121 particular importance to the Ashkenazi Jewish population who, due to founder mutations,  
122 possess unique biological risks. It is estimated that 1:40 Jewish women are *BRCA*  
123 pathogenic variant carriers compared to the general population where the prevalence is  
124 1:400 [32,33]. For Jewish mothers with identified *BRCA* mutation carriage, CBOs may help  
125 them explore options for preventative care and empower them to make the more informed  
126 choices for themselves and their families, including increased cancer screening, surgical  
127 intervention through mastectomies and/or oophorectomies, and talking with their  
128 children about hereditary BC and OC [34]. To the extent that the information and support  
129 needs of these and other mothers at-risk for and surviving with BC and OC are met by  
130 CBOs, mothers' QoL may improve.

131 This study examines the utilization and care needs among a large cohort of mothers  
132 who engaged with a CBO [35]. Using a secondary data analysis, we sought to examine the  
133 impact of child age on mothers' utilization of CBO programs and their associated  
134 outcomes. Our analysis consists of both a between-group comparison and within-group  
135 investigation; first by comparing the outcomes of mothers according to their child's age,  
136 and next by examining mothers with young children only to identify their specific needs.

## 137 2. Materials and Methods

### 138 2.1. Methodology

139 This study involves a secondary analysis of self-report surveys collected in 2022 and  
140 2023 by a national not-for-profit CBO that provides no-cost cancer prevention and control  
141 PN services to the community. This CBO is headquartered in a northeastern state, has  
142 regional offices in four other states, and maintains a toll-free telephone line, has a website,  
143 an active online presence to help support women across their journey with BC and OC  
144 (from risk screening to diagnosis, to treatment and survivorship). Their confidential,  
145 annual evaluations assess women's empowerment, satisfaction with the organization and  
146 delivery of PN, QoL, and related outcomes. For the purpose of this analysis,  
147 "participation" in PN was defined as at least one completed encounter between mothers

148 and the CBO, including with its trained peer supporters. Encounters include PN delivered  
149 over the telephone, as well as two-way correspondences by email and text, hosted  
150 webinars, moderated social media groups, and other educational and information-  
151 oriented PN programming. Annual surveys were administered beginning in January each  
152 year. Surveys were distributed by email to all community members who engaged with  
153 the organization, including women at-risk for, diagnosed with, and surviving with BC  
154 and OC. Those with incomplete surveys were prompted +7, +14, and +21 days after the  
155 initial survey invitation following an established protocol [10,35]. The study was reviewed  
156 and approved by the host university's Institutional Review Board.

## 157 2.2. *Participants and Measures*

### 158 2.2.1. Sociodemographic and clinical characteristics

159 Mothers provided self-reported medical histories, including information on cancer  
160 survivorship (e.g., familial and/or genetic risks) and survivorship status related to BC, OC,  
161 or other cancers. Demographic details, such as marital status, race, ethnicity, Jewish  
162 descent, education, employment, household income, number of children, and age of  
163 children, were also gathered [36].

### 164 2.2.2. Program utilization

165 Program utilization was determined by women responding to Yes/No items about  
166 whether they did or did not participate in one of six core programs or services offered by  
167 the CBO, as described below. These services are: (1) Busy Box; (2) Best Face Forward; (3)  
168 Thriving Again; (4) Peer Support Network; (5) Genetics for Life; and (6) Embrace [35].

- 169 1. Busy Box: Busy Box offers support for survivors facing BC while simultaneously  
170 raising young pre-teens. The program takes into account the age and gender of the  
171 children, and the survivor's expressed needs and concerns when curating a Busy  
172 Box. Participants in the program receive pamphlets related to coping with a cancer  
173 diagnosis and how to engage in family communication about this topic, including  
174 speaking with children about cancer in a parent. Age-appropriate toys and games  
175 are also provided to help occupy children of survivors undergoing treatment.
- 176 2. Best Face Forward: Best Face Forward provides resources and materials  
177 addressing the cosmetic side effects of radiation and chemotherapy treatment for  
178 women with BC and OC. Informational materials about managing hair loss,  
179 changes in skin tones, and body image are included. All participants also receive a  
180 kit in the mail that includes make-up products for all skin tones and makeup  
181 application instructions.
- 182 3. Thriving Again: Thriving again is a BC and OC survivorship support program  
183 specifically tailored to the needs of these populations. Participants receive a  
184 survivorship kit, which is a customized booklet with advice about how to live a  
185 physically and mentally healthy life as a survivor.
- 186 4. Peer Support Network: The Peer Support Network connects women newly  
187 diagnosed with or at high risk of developing BC or OC, with one-on-one trained  
188 volunteer peer supporters who share similar diagnoses and experiences.  
189 Participants complete interest form based on their cancer status and preferred  
190 modes of communication and are connected with a peer supporter.
- 191 5. Genetics for Life: Genetics for Life addresses the concerns of women at higher risk  
192 of developing hereditary BC and/or OC. This program provides women with  
193 cancer or at risk for cancer with genetic education and information related to  
194  
195  
196  
197  
198  
199  
200

deleterious mutations in *BRCA* and other cancer predisposition genes which impact the community that the CBO serves.

6. Embrace: Embrace is designed to meet the needs of women who are living with metastatic BC or OC. The program offers one-on-one support, and primarily includes a trained mental health professional who coordinates and facilitates telephone-based support group calls. Embrace participants are also connected with resources specific to women surviving with advanced cancer.

### 2.2.3. Patient navigation quality

PN quality was measured by a study-specific seven-item scale consisting of five-point Likert ratings (1 = strongly disagree; 5 = strongly agree) to assess if the services received were: 1) helpful, 2) informative, 3) timely, 4) effective, 5) supportive, 6) reliable, and 7) recommendable to others. These items were summed together to form a continuous PN quality score and then averaged: higher scores indicate a more high quality PN experience. The internal consistency of the PN quality measure was high (Cronbach's alpha = 0.97).

### 2.2.4. CBO care satisfaction

Satisfaction with the CBO was determined through a summary score from a four-item scale consisting of five-point Likert ratings (1 = strongly disagree; 5 = strongly agree) to assess participant opinions about if the programs and services offered by the CBO were: 1) valuable to them, 2) valuable to their families, 3) helpful, and 4) relevant. These items together assessed the CBO's ability to understand the needs of and provide valuable support, services, and help to women facing cancer. The measure demonstrated high reliability (Cronbach's alpha = 0.98) in assessing the extent to which women's needs were met and felt supported by the CBO [37].

### 2.2.5. Health-related quality of life

Following guidance by the Centers for Disease Control and Prevention for assessing health-related QoL [38], women reported on their overall health (1 = poor, 5 = excellent), the total number of physically and mentally unhealthy days in the 30 days preceding the survey, and the number of days during which poor physical/mental health adversely affected their usual activities (i.e., self-care, work, recreation).

### 2.2.6. Empowerment

The CBO assessed women's empowerment with conceptually derived five-point Likert scales (1 = strongly disagree; 5 = strongly agree). The two empowerment items evaluated the extent to which CBO services: 1) facilitated more informed choices about medical treatment and 2) increased confidence in managing health care, as based on the extant research literature [39]. These items were interrelated ( $r = 0.87$ ,  $p < .001$ ) and combined to form an empowerment score. A higher empowerment score was indicative of women feeling more confident in their abilities to make informed decisions for their health.

## 2.3. Data Analysis

Secondary data analyses consisted of both between-group and within-group comparisons. For the purposes of this comparative analysis, mothers were divided into three groups based on the age of their child: mothers of young children only (Group A), mothers of adult children only (Group B), and mothers of both adult and young children (Group C). First, descriptive statistics were generated to describe and compare the characteristics and prevalence of mothers from groups A, B, and C within the CBO using  $\chi^2$  tests. Next, program utilization was compared between mothers with minor children only (Group A) and mothers with at least one adult child (Groups B and C). Mothers in

255 Group A were compared to those in Group B on dimensions of PN quality, CBO care  
256 satisfaction, empowerment, and QoL using Students' t-test. Next, within-group analysis  
257 was conducted to further investigate the PN experiences and outcomes of Group A. In  
258 this sub-analysis, we assessed Group A mothers' PN experiences as well as their QoL and  
259 its associations with mothers' sociodemographic and clinical characteristics.

### 260 3. Results

#### 261 3.1. Prevalence of Motherhood and Demographics of Participants

262 As shown in Table 1, and among all women who contacted the CBO and completed  
263 annual evaluations during the years of inquiry (N=1,758), a majority were mothers  
264 raising one or more children (N=1,217, 69.2%). Among those women, 31% (N=377)  
265 identified as mothers of younger children (Group A; < age 18), 56% (N=682) identified  
266 as mothers of older children (Group B; ≥ age 18), and 13% (N=158) identified as mothers  
267 of both older and younger children (Group C; < and ≥ age 18). These proportions were  
268 all statistically different from chance, and from one another ( $\chi^2=341.46$ ,  $p<0.001$ ; Group A  
269 vs. Group B  $p<0.001$ ; Group A vs. Group C  $p<0.001$ ; Group C vs. Group B  $p<0.001$ ).

270 Among the subset of N=377 mothers in Group A, the sociodemographic and  
271 clinical characteristics were as follows. The mean age of these mothers was 41.5 years  
272 (SD = 6.1) and most reported being partnered (78.8%). A significant proportion of these  
273 women (84.9%), identified as BC survivors based on the following definition: "In cancer,  
274 a person is considered to be a survivor from the time of diagnosis until the end of life"  
275 [36]. An additional 3.7% self-identified as not diagnosed with BC or OC, 7.7% were not  
276 diagnosed with BC or OC but were high risk due to *BRCA* mutation carriage, 68.4%  
277 were diagnosed with BC or OC but were not high risk *BRCA* mutation carriers, and  
278 20.2% were diagnosed with BC or OC and carried a *BRCA* mutation.

279

280

**Table 1. Characteristics of mothers all mothers (N=1,217) and mothers of young children (N=377)**

	Groups A+B+C				Group A			
	N=1,217				N=377			
	M	SD	n	%	M	SD	n	%
Age	53.7	12.3			41.4	6.06		
Race								
White			1011	84.3			309	82
Non-White			189	15.7			63	16.7
Marital Status								
Partnered			856	70.3			297	78.8
Not partnered			361	29.7			80	21.2
Education								
< College			745	61.2			218	57.8
≥ College			472	38.8			159	42.2
Employment								
Employed			767	63			188	49.9
Not employed or retired			450	37			189	50.1
At-risk ( <i>BRCA</i> mutation cancer predisposition)								
No predisposition/ No cancer diagnosis			63	5.2			14	3.7
Yes predisposition/ No cancer diagnosis			60	4.9			29	7.7
No predisposition/ Yes cancer diagnosis			884	72.6			258	68.4
Yes predisposition/ Yes cancer diagnosis			210	17.3			76	20.2
Health-related quality of life								
General Health								
Excellent/very good			267	22.2			76	20.3
Good			434	36			124	33.2
Fair/poor			503	41.8			174	46.5
Frequent mental distress								
No			979	80.4			303	80.4
Yes			238	19.6			74	19.6

281

282

283

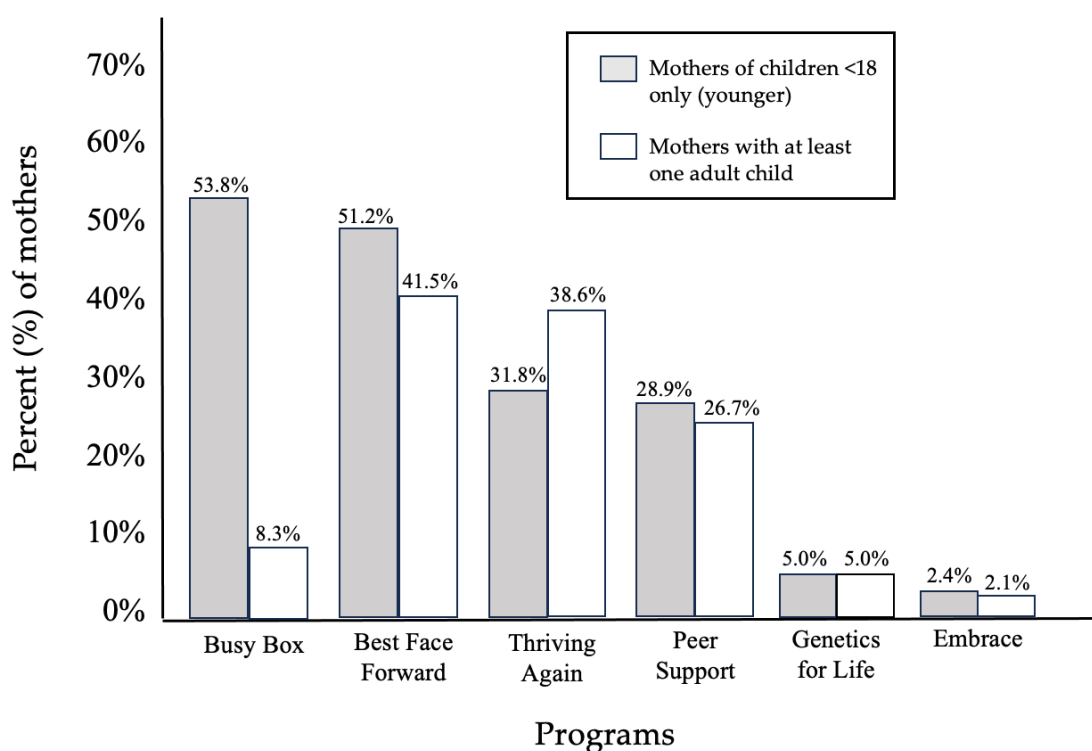
284

285

### 3.2. Program Utilization

Figure 1 presents a comparison of CBO core program utilization between Groups A and Groups B+C. The highest level of engagement for mothers with young children (Group A) was with two main components: Busy Box was utilized by 53.8% and Best Face Forward was utilized by 51.2%. More than one-third (38.7%) of these mothers indicated that they participated in both Busy Box and Best Face Forward concurrently. The Busy Box program (the program specifically designed for mothers with younger children) accounted for the largest discrepancy between Group A and Groups B+C; with over half of Group A mothers utilizing Busy Box, while only 8.3% of Groups B+C mothers reported using it.

For the other services, the utilization by mothers in these two groups is similar. Nearly one-third of Group A mothers reported participation in Thriving Again (31.8%) and Peer Support (28.9), with similar rates of utilization for mothers with at least one adult child (38.6% and 26.7%, respectively). Although 22.2% of the sample was an identified carrier of a cancer predisposition gene, less than 10% of mothers in total reported participating in Genetics for Life (a program devoted to genetic education).



**Figure 1.** Participation in programs by mothers of young children only (N= 377) compared to mothers with at least one adult child in the sample (N=840).

\* Observations do not total to 100% due to multiple responses.

### 3.3. Observed differences in maternal CBO outcomes and quality of life based on children's ages

We next compared indices of CBO outcome measures (PN quality, care satisfaction, empowerment) and QoL between mothers in Group A and mothers in Group B. There, differences in QoL were observed. Mothers with only adult children experienced decreased QoL compared to mothers with only young children—both for physically unhealthy days ( $t = -2.7$ ,  $df = 1,037$ ,  $p < 0.05$ ) and activity limiting days ( $t = -2.1$ ,  $df = 1,009$ ,  $p < 0.05$ ). Otherwise, no between group differences were identified. To better

313 understand the QoL of mothers with younger children (Group A), we next examined  
314 within-group associations among the CBO outcomes of interest and clinical  
315 characteristics with QoL.

### 3.3.1. Patient navigation quality in Mothers with Young Children

318 The average score for PN quality of mothers with young children was 4.6 out of 5  
319 (SD = 0.71), indicating an overall positive and favorable view of the CBO's PN efforts. A  
320 majority of these mothers (73.9%) strongly agreed that they found their interactions with  
321 the CBO to be meaningful and helpful. Mothers of young children also agreed they  
322 would contact the CBO again in the future for themselves (73.7%) or recommend the  
323 services to their friends in need of similar assistance (78.1%). These mothers endorsed  
324 that the PN experience connected them with valuable services and resources (75.5%) and  
325 that the information provided was given in a timely manner (74.3%). Lastly, mothers of  
326 young children felt supported and that PN helped them deal more effectively with their  
327 concerns (68.5%).

### 3.3.2. Associations between Care Satisfaction and Empowerment in Mothers with Young Children

331 CBO care satisfaction among mothers of young children was 4.7 out of 5 (SD =  
332 0.83), suggesting that the CBO effectively supported and provided resources for mothers  
333 and their families facing BC and OC. Many of these mothers agreed that the CBO  
334 provides valuable programs (77.7%) and resources (81.1%) for survivors and their  
335 families. These mothers also strongly agreed that the CBO understood their needs and  
336 those of their families (78.9%). Regarding mothers of young children's sense of  
337 empowerment, it averaged 4.02 out of 5 (SD = 0.93). A substantial proportion of these  
338 mothers strongly agreed that they felt confident in managing their health care (72.0%)  
339 and were well-equipped to make informed healthcare decisions regarding their disease  
340 management (68.2%). At the bivariate level, mothers with young children who reported  
341 high satisfaction with the CBO's programs and services also reported well-developed  
342 psychosocial empowerment after engaging in these services ( $r = 0.48, p < 0.001$ ).

### 3.3.3 Health-Related Quality of Life in Mothers with Young Children

345 The self-reported assessment of health status within the sample revealed that 46.6%  
346 of mothers with young children reported being in fair or poor health (Table 1). About  
347 20% of these mothers reported frequent mental distress (i.e., those reporting greater than  
348 13 days of mentally unhealthy days in the past month). On average, mothers of young  
349 children reported experiencing approximately 6.8 physically unhealthy days, 7.4  
350 mentally unhealthy days, and 5.5 activity-limited days over the course of the past 30  
351 days.

352 Table 4 displays the associations within mothers with young children's clinical  
353 characteristics and CBO-focused outcome measures with their general health and overall  
354 QoL (as indexed by the number of unhealthy days, where higher scores indicate poorer  
355 QoL). On average, mothers with young children who had better general health were  
356 mothers who were at lower risk for cancer ( $r = -0.12, p = 0.011$ ), employed ( $r = 0.2, p <$   
357  $0.001$ ), had positive PN experience ( $r = 0.09, p = 0.04$ ), and a stronger sense of psychosocial  
358 empowerment ( $r = 0.09, p = 0.04$ ). Mothers with young children who had a better quality of  
359 life (based on fewer unhealthy days in a month) were those at lower risk for cancer,  
360 employed, had a more positive PN experience and overall CBO satisfaction, and had a  
361 strong sense of psychosocial empowerment.

**Table 4. Within-group associations for maternal quality of life**

Variables	General Health	Quality of Life*
	<i>r, p</i>	<i>r, p</i>
<b>Clinical characteristics</b>		
Risk for cancer	-0.12, 0.011	0.123, 0.008
Level of education	0.08, n.s.	-0.059, n.s.
Employment status	0.2, < 0.001	-0.17, < 0.001
Age of child(ren)	0.02, n.s.	0.07, n.s.
<b>Outcomes</b>		
Patient navigation quality	0.09, 0.04	-0.13, 0.006
CBO care satisfaction	0.07, n.s.	-0.17, <0.001
Empowerment	0.09, 0.04	-0.156, 0.001

\*Higher scores indicate poorer QoL. "n.s." = non-significant

#### 4. Discussion

This study reveals important insights regarding the efficacy of CBO-led cancer control programming to empower, support, and engage mothers who are surviving breast-ovarian cancer. Specifically, when mothers are given the opportunity to gain access to tailored programming, high-quality resources, and family support services they not only use those services but feel satisfied and empowered by them. In our community-based sample, we identified that most women who utilize the CBO of interest identify as mothers. This study is the first to investigate how mothers of minors, who are particularly vulnerable due to both their cancer diagnosis and responsibility as mothers to young children, are impacted by CBO programming. Although we did not observe differences in the CBO experience of mothers based on whether they had older or younger children, however, we did observe that mothers with younger children appeared to benefit more from programs that assisted them in speaking to their kids about their diagnosis and services that assisted with the cosmetic side effects of cancer treatment. For other services, we observed a mutual minimal utilization between all groups of mothers regarding the use of genetic services and a relative decrease in utilization by young mothers for services related to guiding survivorship behaviors. There could be various sociocultural factors contributing to why mothers may not be utilizing genetic services despite belonging to a population at high genetic risk for breast/ovarian cancer, thus it is a notable point of further analysis or improvement for the CBO. Furthermore, mothers with adult children benefited more from a customized cancer survivorship booklet than from resources assisting with family communication. These differences in utilization suggest a prioritization of mothers with young kids to pursue services that support the well-being of their families, and they are less inclined to reach out for services specifically meant to support their personal well-being during the survivorship phase. These differences in the pattern of mothers' utilization critically inform how the CBO can continue to address the needs of mothers depending on the status of their children.

These findings underscore the downstream benefits of program utilization, including improved quality of life. Mothers surviving cancer face challenges, including in decision making and managing their risk while being parents, which can impact their physical and mental wellness. Thus, the significance of motherhood status on quality of life cannot be ignored in the context of providing holistic clinical care. In our analysis comparing the CBO experience and QoL of mothers with younger children (Group A) to those with adult children (Group B), our results do not provide evidence that the quality of life of mothers with young children is worse than that of mothers raising adult

401 children. In fact, we observed that mothers with adult children had decreased quality of  
402 life compared to mothers of young children, though this could be due to age-related  
403 decreases in quality of life among cancer patients [40,41]. However, in our within-group  
404 analysis of just mothers with young children (Group A) we observed that when these  
405 mothers had a highly positive experience with the CBO's PN and services then they also  
406 experienced, on average, fewer total unhealthy days. These findings are consistent with  
407 previous research that suggests that survivors who participate in CBO programs and PN  
408 experience psychosocial benefits and increased quality of life [42,43]. Moreover, by  
409 analyzing the utilization of specific CBO programs alongside participants' self-reported  
410 satisfaction measures, we can better understand how behavior-focused survivorship  
411 programs, especially those aimed at mothers, can enhance their quality of life.

412 For mothers surviving cancer in our community-based population, these findings  
413 underscore the significance of PN in a mother's feelings of empowerment and  
414 satisfaction with CBO services. Mothers raising young children who had a better PN  
415 experience were also more empowered and satisfied with CBO services. These results  
416 are a testament to how PN services allow for more effective and personalized cancer care  
417 delivery since they account for an individual's unique situation, behaviors, and  
418 preferences [44]. CBOs can play a critical role in the well-being of mothers who are  
419 surviving cancer because their PN services aim to connect mothers with resources and  
420 programs that care for their psychosocial well-being, not just their biological disease.  
421 Engel's biopsychosocial model emphasizes the need to understand what social,  
422 biological, and psychological elements contribute to maintaining good health, and for  
423 mothers who must raise children while simultaneously fighting an aggressive chronic  
424 disease, survival is much more than just physical well-being [45]. Services that aim to  
425 assist a mother in talking to her young children about her disease or survivorship kits  
426 are meaningful and, as we have demonstrated, utilized by at-risk populations [45,46].  
427 PN services helped mothers take advantage of the CBO's health information services  
428 and resources to support their healthy survivorship. Despite the limited nature of our  
429 population of interest, our results suggest that these services can be expanded to other  
430 community populations surviving or at-risk for cancer. Thus, offering PN to programs  
431 for vulnerable populations who suffer disproportionately from cancer continues to be a  
432 point of success for CBOs.

#### 433 *4.1. Limitations*

434 This study has several limitations. Firstly, the reliance on self-reported data introduces  
435 the possibility of subjectivity and recall bias, which might affect the accuracy of responses.  
436 Nevertheless, patient-reported outcomes are considered the gold standard for gaining  
437 insights into individuals' perspectives on their healthcare and their needs for information  
438 and support. Another limitation is the potential for selection bias: the data were collected  
439 from survivors who voluntarily participated in at least one of the CBO's cancer control  
440 programs and completed a survey. This means the experiences of those who opted out or  
441 did not respond to the evaluation are not represented, and we did not analyze potential  
442 differences among those who engaged with multiple programs. This could limit the  
443 generalizability of our findings to the wider population of breast cancer survivors. Finally,  
444 although the response rate for this nonrandom survey was comparable to previous studies  
445 and existing literature, it was still lower than ideal for ensuring broad generalizability

#### 446 **5. Conclusions**

447 This study underscores the critical role of community-based cancer control programs  
448 in meeting the informational and support needs of mothers surviving breast-ovarian  
449 cancer through patient navigation (PN) and tailored programming. Continued

investment in community-based organizations (CBOs) and their support services can enhance the quality of life for these mothers, addressing their dual roles as patients and caregivers. The significant participation of mothers in CBO services, particularly those with minor children, indicates a clear need for ongoing enhancement of resources that aid mothers in communicating about cancer with their young children. This study also highlights the essential contribution of PN in the success of CBOs in meeting the specific needs of vulnerable populations. This research informs ongoing efforts to address health disparities, especially to populations at unique biological risk, through targeted community interventions and PN. The findings can guide healthcare organizations and policymakers in improving PN services and informational support programs to support parents in balancing childrearing and cancer survivorship. CBOs are well-positioned to address systemic healthcare challenges, providing comprehensive and quality care to mothers and a broader spectrum of cancer survivors. In sum, this research highlights the need to strengthen CBO-led cancer-control services so they can continue to address the psychosocial needs of mothers at risk for and surviving breast-ovarian cancer, with the purpose of allowing them to flourish as mothers and patients alike.

**Author Contributions:** Conceptualization, K.P.T., M.M.S., and T.Z.; methodology, M.M.S.; software, D.O.; validation, K.P.T., M.S.S and T.Z.; formal analysis, T.Z., D.O.; investigation, M.S.S, T.Z., and K.P.T; resources, E.S. and A.F.; data curation, D.O. and T.Z.; writing—original draft preparation, T.Z.; writing—review and editing, M.S., T.Z., and K.P.T.; visualization, M.S., K.P.T., and T.Z.; supervision, K.P.T; project administration, K.P.T., A.F., and E.S.; funding acquisition, K.P.T., A.F., and E.S. All authors have read and agreed to the published version of the manuscript.

**Funding:** This work was conducted in collaboration by Sharsheret and Lombardi Comprehensive Cancer Center under Cooperative Agreement U58DP005408, funded by the Centers for Disease Control and Prevention. This work was also supported in part by the Lombardi Comprehensive Cancer Center Comprehensive Cancer Center Support Grant P30CA051008 by the National Cancer Institute at the National Institutes of Health. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Centers for Disease Control and Prevention, the National Cancer Institute, the National Institutes of Health, or the Department of Health and Human Services. Additional funding for summer research given by the Laidlaw Foundation and the Georgetown University Laidlaw Scholars Programme.

**Institutional Review Board Statement:** Ethical review and approval were waived for this study due to the provision of an external partner's continuous quality improvement initiative. The Institutional Review Board at Georgetown University determined this protocol to be exempt (00002112).

**Informed Consent Statement:** Patient consent was waived due to the minimal risk in survey questions.

**Data Availability Statement:** The datasets presented in this article are not readily available because they are sensitive survey data.

**Acknowledgments:** The authors would like to thank the participants in this study.

**Conflicts of Interest:** The authors declare no conflict of interest.

## References

1. Siegel RL, Giaquinto AN, Jemal A. Cancer statistics, 2024. *CA A Cancer J Clinicians*. 2024;74(1):12-49. doi:10.3322/caac.21820
2. Weaver KE, Rowland JH, Alfano CM, McNeel TS. Parental cancer and the family: A population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer*. 2010;116(18):4395-4401. doi:10.1002/cncr.25368
3. Arida JA, Bressler T, Moran S, D'Arpino S, Carr A, Hagan TL. Mothering With Advanced Ovarian Cancer: "You've Got to Find That Little Thing That's Going to Make You Strong." *Cancer Nurs*. 2019;42(4):E54-E60. doi:10.1097/NCC.0000000000000550

- 
- 498 4. Davey MP, Niño A, Kissil K, Ingram M. African American Parents' Experiences Navigating Breast Cancer While Caring for  
499 Their Children. *Qual Health Res.* 2012;22(9):1260-1270. doi:10.1177/1049732312449211
- 500 5. Fisher C, O'Connor M. "Motherhood" in the Context of Living With Breast Cancer. *Cancer Nursing.* 2012;35(2):157-163.  
501 doi:10.1097/NCC.0b013e31821cadde
- 502 6. Billhult A, Segesten K. Strength of motherhood: nonrecurrent breast cancer as experienced by mothers with dependent  
503 children. *Scandinavian Caring Sciences.* 2003;17(2):122-128. doi:10.1046/j.1471-6712.2003.00219.x
- 504 7. Kim S, Ko YH, Jun EY. The impact of breast cancer on mother-child relationships in Korea. *Psycho-Oncology.* 2012;21(6):640-  
505 646. doi:10.1002/pon.1941
- 506 8. Kuswanto CN, Stafford L, Schofield P, Sharp J. Self-compassion and parenting efficacy among mothers who are breast cancer  
507 survivors: Implications for psychological distress. *J Health Psychol.* 2024;29(5):425-437. doi:10.1177/13591053231222162
- 508 9. Tavares R, Brandão T, Matos PM. Mothers with breast cancer: A mixed-method systematic review on the impact on the parent-  
509 child relationship. *Psycho-Oncology.* 2018;27(2):367-375. doi:10.1002/pon.4451
- 510 10. Sleiman MM, Yockel MR, Fleischmann A, et al. The role of peer support and patient navigation for empowerment in breast  
511 cancer survivors: implications for community cancer control. *Journal of Psychosocial Oncology Research and Practice.* 2024;6(2).  
512 doi:10.1097/OR9.000000000000128
- 513 11. Arès I, Lebel S, Bielajew C. The impact of motherhood on perceived stress, illness intrusiveness and fear of cancer recurrence  
514 in young breast cancer survivors over time. *Psychology & Health.* 2014;29(6):651-670. doi:10.1080/08870446.2014.881998
- 515 12. Bodurka-Bevers D, Basen-Engquist K, Carmack CL, et al. Depression, Anxiety, and Quality of Life in Patients with Epithelial  
516 Ovarian Cancer. *Gynecologic Oncology.* 2000;78(3):302-308. doi:10.1006/gyno.2000.5908
- 517 13. Ferrell B, Cullinane CA, Ervin K, Melancon C, Uman GC, Juarez G. Perspectives on the Impact of Ovarian Cancer: Women's  
518 Views of Quality of Life. *Oncology Nursing Forum.* 2005;32(6):1143-1149. doi:10.1188/05.ONF.1143-1149
- 519 14. Roland KB, Rodriguez JL, Patterson JR, Trivers KF. A literature review of the social and psychological needs of ovarian cancer  
520 survivors. *Psycho-Oncology.* 2013;22(11):2408-2418. doi:10.1002/pon.3322
- 521 15. Von Gruenigen VE, Huang HQ, Gil KM, et al. A Comparison of Quality-of-Life Domains and Clinical Factors in Ovarian  
522 Cancer Patients: A Gynecologic Oncology Group Study. *Journal of Pain and Symptom Management.* 2010;39(5):839-846.  
523 doi:10.1016/j.jpainsymman.2009.09.022
- 524 16. Inhestern L, Bergelt C. When a mother has cancer: strains and resources of affected families from the mother's and father's  
525 perspective - a qualitative study. *BMC Women's Health.* 2018;18(1):72. doi:10.1186/s12905-018-0562-8
- 526 17. Hammersen F, Pursche T, Fischer D, Katalinic A, Waldmann A. Psychosocial and family-centered support among breast cancer  
527 patients with dependent children. *Psycho-Oncology.* 2021;30(3):361-368. doi:10.1002/pon.5585
- 528 18. Stiffler D, Haase J, Hosei B, Barada B. Parenting Experiences With Adolescent Daughters When Mothers Have Breast Cancer.  
529 *Oncology Nursing Forum.* 2008;35(1):113-120. doi:10.1188/08.ONF.113-120
- 530 19. Fisher CL, Kastrinos A, Curley A, et al. Helping Diagnosed Mothers and Their Adolescent-Young Adult Daughters Navigate  
531 Challenging Breast Cancer Conversations. *Cancer Care Res Online.* 2022;2(3):e025. doi:10.1097/cr9.000000000000025
- 532 20. Shelby RA, Taylor KL, Kerner JF, Coleman E, Blum D. The Role of Community-based and Philanthropic Organizations in  
533 Meeting Cancer Patient and Caregiver Needs. *CA: A Cancer Journal for Clinicians.* 2002;52(4):229-246.  
534 doi:10.3322/canjclin.52.4.229

- 
- 535 21. Wilson MG, Lavis JN, Guta A. Community-based organizations in the health sector: A scoping review. *Health Res Policy Sys.* 2012;10(1):36. doi:10.1186/1478-4505-10-36  
536
- 537 22. Chan RJ, Milch VE, Crawford-Williams F, et al. Patient navigation across the cancer care continuum: An overview of systematic reviews and emerging literature. *CA A Cancer J Clinicians.* 2023;73(6):565-589. doi:10.3322/caac.21788  
538
- 539 23. Lutgendorf SK, De Geest K, Bender D, et al. Social influences on clinical outcomes of patients with ovarian cancer. *J Clin Oncol.* 2012;30(23):2885-2890. doi:10.1200/JCO.2011.39.4411  
540
- 541 24. Lutgendorf SK, Sood AK. Biobehavioral factors and cancer progression: physiological pathways and mechanisms. *Psychosom Med.* 2011;73(9):724-730. doi:10.1097/PSY.0b013e318235be76  
542
- 543 25. Kenen RH, Shapiro PJ, Friedman S, Coyne JC. Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. *Psycho-Oncology.* 2007;16(8):763-771. doi:10.1002/pon.1152  
544
- 545 26. O'Neill SC, Evans C, Hamilton RJ, et al. Information and support needs of young women regarding breast cancer risk and genetic testing: adapting effective interventions for a novel population. *Familial Cancer.* 2018;17(3):351-360. doi:10.1007/s10689-017-0059-x  
546  
547
- 548 27. Pergolotti M, Bailliard A, McCarthy L, Farley E, Covington KR, Doll KM. Women's Experiences After Ovarian Cancer Surgery: Distress, Uncertainty, and the Need for Occupational Therapy. *The American Journal of Occupational Therapy.* 2020;74(3):7403205140p1-7403205140p9. doi:10.5014/ajot.2020.036897  
549  
550
- 551 28. McKleroy VS, Galbraith JS, Cummings B, et al. Adapting Evidence-Based Behavioral Interventions for New Settings and Target Populations. *AIDS Education and Prevention.* 2006;18(supp):59-73. doi:10.1521/aeap.2006.18.supp.59  
552
- 553 29. Rabin C, Simpson N, Morrow K, Pinto B. Intervention Format and Delivery Preferences Among Young Adult Cancer Survivors. *Int J Behav Med.* 2013;20(2):304-310. doi:10.1007/s12529-012-9227-4  
554
- 555 30. Samuels EA, Kelley L, Pham T, et al. "I wanted to participate in my own care": Evaluation of a Patient Navigation Program. *West J Emerg Med.* 2021;22(2):417-426. doi:10.5811/westjem.2020.9.48105  
556
- 557 31. Kinner EM, Armer JS, McGregor BA, et al. Internet-Based Group Intervention for Ovarian Cancer Survivors: Feasibility and Preliminary Results. *JMIR Cancer.* 2018;4(1):e1. doi:10.2196/cancer.8430  
558
- 559 32. Anglian Breast Cancer Study Group. Prevalence and penetrance of BRCA1 and BRCA2 mutations in a population-based series of breast cancer cases. Anglian Breast Cancer Study Group. *Br J Cancer.* 2000;83(10):1301-1308. doi:10.1054/bjoc.2000.1407  
560
- 561 33. Frey MK, Perez LR, Brewer JT, Fleischmann AK, Silber E. Breast Cancer in the Ashkenazi Jewish Population. *Curr Breast Cancer Rep.* 2024;16(1):98-105. doi:10.1007/s12609-024-00528-3  
562
- 563 34. Possick C, Kestler-Peleg M. BRCA and Motherhood: A Matter of Time and Timing. *Qual Health Res.* 2020;30(6):825-835. doi:10.1177/1049732319885113  
564
- 565 35. Tercyak K, Silber E, Johnson A, et al. Survey on Addressing the Information and Support Needs of Jewish Women at Increased Risk for or Diagnosed with Breast Cancer: The Sharsheret Experience. *Healthcare.* 2015;3(2):324-337. doi:10.3390/healthcare3020324  
566  
567
- 568 36. Rehberg K, Fleischmann A, Silber E, O'Neill SC, Lewis FM, Tercyak KP. Facilitators of peer coaching/support engagement and dissemination among women at risk for and surviving with breast cancer. *Translational Behavioral Medicine.* 2021;11(1):153-160. doi:10.1093/tbm/ibz186  
569  
570

- 
- 571 37. Van Den Berg SW, Van Amstel FKP, Ottevanger PB, Gielissen MFM, Prins JB. The Cancer Empowerment Questionnaire:  
572 Psychological Empowerment in Breast Cancer Survivors. *Journal of Psychosocial Oncology*. 2013;31(5):565-583.  
573 doi:10.1080/07347332.2013.825361
- 574 38. Moriarty DG, Zack MM, Kobau R. The Centers for Disease Control and Prevention's Healthy Days Measures – Population  
575 tracking of perceived physical and mental health over time. *Health Qual Life Outcomes*. 2003;1(1):37. doi:10.1186/1477-7525-1-37
- 576 39. Ziegler E, Hill J, Lieske B, Klein J, Dem OV, Kofahl C. Empowerment in cancer patients: Does peer support make a difference?  
577 A systematic review. *Psycho-Oncology*. 2022;31(5):683-704. doi:10.1002/pon.5869
- 578 40. Lavdaniti M, Owens DA, Liamopoulou P, et al. Factors Influencing Quality of Life in Breast Cancer Patients Six Months after  
579 the Completion of Chemotherapy. *Diseases*. 2019;7(1):26. doi:10.3390/diseases7010026
- 580 41. Kurian CJ, Leader AE, Thong MSY, Keith SW, Zeigler-Johnson CM. Examining relationships between age at diagnosis and  
581 health-related quality of life outcomes in prostate cancer survivors. *BMC Public Health*. 2018;18(1):1060. doi:10.1186/s12889-018-  
582 5976-6
- 583 42. Meluch A. Psychosocial benefits of the social support experienced at a community-based cancer wellness organization. *Qual*  
584 *Res Med Healthc*. 2022;5(3). doi:10.4081/qrmh.2021.10232
- 585 43. Ramirez AG, Muñoz E, Long Parma D, Perez A, Santillan A. Quality of life outcomes from a randomized controlled trial of  
586 patient navigation in Latina breast cancer survivors. *Cancer Medicine*. 2020;9(21):7837-7848. doi:10.1002/cam4.3272
- 587 44. Richardson-Parry A, Baas C, Donde S, et al. Interventions to reduce cancer screening inequities: the perspective and role of  
588 patients, advocacy groups, and empowerment organizations. *Int J Equity Health*. 2023;22(1):19. doi:10.1186/s12939-023-01841-6
- 589 45. Engel GL. The Need for a New Medical Model: A Challenge for Biomedicine. *Science*. 1977;196(4286):129-136.  
590 doi:10.1126/science.847460
- 591 46. Natale-Pereira A, Enard KR, Nevarez L, Jones LA. The role of patient navigators in eliminating health disparities. *Cancer*.  
592 2011;117(15 Suppl):3543-3552. doi:10.1002/cncr.26264

593

594 **Disclaimer/Publisher's Note:** The statements, opinions and data contained in all publications are solely those of the individual  
595 author(s) and contributor(s).