

Psychosocial consequences in offspring of women with breast cancer

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Abstract

Objective: Breast cancer (BC) accounts for 24% of female cancers, with approximately one quarter of women likely to have offspring aged less than 25 years. Recent publications demonstrate negative psychosocial well-being in these offspring. We prospectively assessed for psychological distress and unmet needs in offspring of BC patients.

Methods: Eligible offspring aged 14 to 24 years were consented and completed the Kessler-10 Questionnaire and Offspring Cancer Needs Instrument. Demographic and BC details were obtained.

Results: Over a 7-month period, 120 offspring from 74 BC patients were included. Fifty-nine mothers had nonmetastatic BC (nMBC), and 27 had metastatic BC (MBC) with median time from diagnosis of 27.6 and 36.1 months, respectively. The prevalence of high/very high distress was 31%, with significantly higher scores reported by female offspring ($P = .017$). Unmet needs were reported by more than 50% of offspring with the majority of needs relating to information about their mother's cancer. Greater unmet needs were seen in female offspring and offspring with none or one sibling for several domains (practical assistance, time-out, dealing with feelings, and support from friends; $P < .05$). Greater unmet needs were seen in regard to feelings for MBC patients' offspring compared with nMBC but were similar for other unmet needs.

Conclusions: Our study confirms high levels of psychological distress in offspring of BC patients, with female offspring reporting significantly higher emotional distress and unmet needs. More than 50% of respondents reported unmet needs in areas that can potentially be supported, including greater information provision, improving practical issues, and enabling sufficient recreational time.

KEY WORDS

breast cancer, offspring, oncology, psychological distress, unmet needs

1 | BACKGROUND

Breast cancer (BC) is the most common cancer diagnosed and the fifth most common cause of cancer death in women in the world.^{1,2} In Australia, approximately 23% of newly diagnosed BC occur in women aged 50 years.³ It is likely that many of these women will have adolescent and young adult children (offspring) at the time of their diagnosis, with the illness having a significant impact on both the patient and their family.⁴

The emotional status of offspring with parents who have cancer has been recently highlighted. One meta-analysis that only focussed on BC patients identified children who were at a significantly increased risk of internalizing emotional distress.⁵ A second publication involving over 6000 cancer patients (approximately 52% with BC) reported negative psychosocial impact on children. The study also recognized substantial differences between study methodologies, which limit the development of effective interventions.⁶

The current study was designed to assess the prevalence of psychological distress and identify areas of need as reported by the offspring of women with BC managed in a single centre. The study was initiated in response to the clinical observation that offspring were impacted by their mother's BC diagnosis and the understanding that the factors, which were associated with higher levels of emotional distress and unmet needs in the offspring, could inform future interventional studies to support the offspring.

2 | METHODS

Consecutive male and female biological offspring aged 14 to 24 years of female BC patients managed at Breast Cancer Research Centre-WA (a comprehensive BC centre based in Perth, Western Australia) were invited to participate, after identification of suitably aged offspring from mothers. Key eligibility criteria for offspring were written consent from the offspring (in addition, mother's consent was required for offspring aged <18 years), mother had stages I to IV BC (with an anticipated survival >6 months), were able to read English, and resided in Western Australia at the time of the study. Offspring were ineligible if they had no social contact with their mother, had a personal history of cancer, had another immediate family member undergoing cancer treatment, were deemed by their mother as being unsuitable for the study, or failed to complete the questionnaire within 28 days of consent. Demographic information, details of BC characteristics, and treatment received by the mothers were obtained from a prospectively collected database, created, and held by the principal investigator. Demographic information including gender, age, number of siblings, living arrangement, education, and employment status was obtained from the offspring.

Each offspring was given password-protected access to a study-specific website. Participants recorded demographic data and completed the Kessler-10 questionnaire (K10)⁷ and the Offspring Cancer Needs Instrument (OCNI).^{8,9} The K10 is a validated 10-item

questionnaire, which measures psychological distress experienced in the preceding 4 weeks (Data S1).¹⁰⁻¹² Respondents use a five-point Likert scale with scores of 22 to 29 and more than or equal to 30 indicating high or severe emotional distress, respectively. Offspring with a score more than or equal to 30 were contacted and offered psychological counselling.

The OCNI is a validated 47-item questionnaire that measures unmet psychosocial needs of those aged 12 to 24 who have a parent with cancer (Data S2).^{13,14} The seven domains include as follows:

- a. Information (INFO): parent's cancer, treatment, and recovery
- b. Family issues (FAM): family support, open/honest communications about parent's cancer, and behaviour around parent
- c. Practical assistance (PRAC): practical and daily-living support (chores, work, or education) and relevant support services
- d. Time-out/recreation (TOR): participation in social/sporting events
- e. Feelings (FEEL): feelings about parent's cancer and impact on their life, dealing with sadness, anxiety, and anger
- f. Support from friends (SF): friends understand what they are going through and communicate about cancer experience
- g. Support from other young people (SOYP): supported by or learn from young people who have experienced parental cancer

A four-point Likert scale of no, low, moderate, or strong needs is used, with moderate and strong grouped as "unmet" needs. Mean prevalence of "unmet" need was calculated by the proportion of 3 or 4 scored per domain, with high needs defined as a mean¹³ of more than or equal to 3.

All patients provided consent to use of their deidentified BC information for research. The study was approved by the Hollywood Hospital Human Ethics and Research Committee (ACTRN12617001272381) and was conducted in line with the 2008 Declaration of Helsinki.

2.1 | Statistical analysis

Descriptive statistics of predictor variables (offspring demographic information, maternal BC, and treatment) were reported by gender. Frequency, means, standard deviations, and ranges of the outcome variable K10 scores were calculated for offspring, where psychological distress (K10 score) was low (10-15), moderate (16-21), high (22-29), or very high (30-50),⁷ and analysed by gender. Associations between offspring and maternal (OM) variables and K10 score were performed using linear (or logistic) regression models and the coefficient, β (or odds ratio [OR]), and 95% confidence interval (CI) reported. Another outcome variable, OCNI unmet needs in offspring,¹³ and associations between OM variables and percentage of each domain's unmet needs were analysed using linear regression models. All models were adjusted for potential confounding variables. All statistical analyses were performed using Stata 14.2 (StataCorp, Texas). Significance was set at less than .05.

3 | RESULTS

From September 2017 to March 2018, 163 offspring of 110 women with BC were considered eligible. Forty three of the 163 eligible offspring did not participate, with 79% declining or failing to complete the questionnaire following consent; thus, 120 offspring from 74 mothers constituted the study population.

3.1 | Characteristics of the mothers

Fifty-nine (80%) women with nonmetastatic BC (nMBC) (early BC or local recurrence surgically resected with curative intent) had

TABLE 1 Offspring and mother's characteristics

	Female, %	Male, %
Total offspring	68 (57)	52 (43)
Offspring age, mean (y)	19	18
Living with		
Both parents	50 (74)	38 (73)
One parent only	11 (16)	10 (19)
No family member or alone	7 (10)	4 (8)
Number of siblings		
0	4 (6)	5 (10)
1	32 (47)	24 (46)
≥2	32 (47)	23 (44)
Education		
Secondary	25 (37)	26 (50)
Tertiary	28 (41)	14 (27)
Not studying	15 (22)	12 (23)
Employment		
Unemployed	22 (32)	20 (39)
Part-time	30 (44)	24 (47)
Full-time	16 (24)	8 (15)
BC status		
Nonmetastatic	54 (79)	39 (75)
Metastatic	14 (21)	13 (25)
Treatment nMBC		
Median time since diagnosis, mo	25	50
On intravenous treatment	8 (15)	1 (3)
On endocrine treatment	39 (72)	31 (80)
Completed treatment	7 (13)	7 (18)
Treatment MBC		
Median time since metastatic diagnosis, mo	139.8	59
On intravenous treatment	9 (64)	11 (85)
On endocrine treatment	5 (36)	2 (15)

Abbreviations: BC, breast cancer; MBC, metastatic BC; nMBC, nonmetastatic BC.

93 offspring (78%), and 27 offspring had mothers with metastatic BC (MBC). Mother's mean age at the time of study was 50.6 years (50.6 nMBC and 50.7 MBC). One woman was of Asian ethnicity, and all others were Caucasian.

At the time of the study, the majority of nMBC patients was receiving oral endocrine therapy, whilst most MBC patients were receiving intravenous chemotherapy (Table 1).

3.2 | Characteristics of the offspring

The majority of offspring was female, and most were living with one or both parents (Table 1).

3.3 | Psychological distress

The mean K10 score for offspring was 19.3 (females 20.6 and males 17.6), indicating a moderate level of psychological distress (Table 2). The rate of high and very high distress (ie, K10 > 22) was 31%. A significant association between gender and distress level was found ($P = .046$). Twelve offspring who reported very high levels of distress were offered review with a clinical psychologist, with only one accepting counselling.

There was a statistically significant higher level of distress reported by female offspring (OR, 2.77; 95% CI, 1.190-6.43; $P = .018$). On average, female offspring scored three points higher than males (mean difference: 2.99; 95% CI, 0.54-5.45; $P = .017$). The higher distress score among female offspring remained significant after adjusting for offspring age, number of siblings, and time since mother's diagnosis and cancer stage (adjusted β : 3.10; 95% CI, 0.72-5.48; $P = .011$). The likelihood of higher distress was significantly greater in offspring who were an only child or had only one sibling (OR, 2.67; 95% CI, 1.17-6.09, $P = .020$), compared with offspring with two or more siblings. Lower psychological distress was seen with increasing time since their mother's diagnosis after adjusting for factors as above, albeit clinically insignificant due to a difference of 0.03 in scores. There were no statistically significant differences in distress levels whether mothers had nMBC or MBC, after adjusting for offspring gender, age, or number of siblings (adjusted OR, 1.55; 95% CI, 0.60-4.05).

3.4 | Unmet needs

The highest rate of unmet needs is related to information about their mother's cancer, with a mean of 59.4% across that domain. The domains in descending order of unmet needs were family issues (56.7%), support from friends (41.3%), time-out and recreation (34%), feelings (27.8%), practical issues (23.1%), and support from other young people (18.5%). There were 12 items in which more than 50% of offspring reported having unmet needs with eight items relating to information provision (Table 3).



TABLE 2 Offspring psychological distress (K10 test)

K10 Score	Females (n = 68)	Males (n = 52)	Total (n = 120)
Range	10-50	10-33	10-50
Median	18	16	18
Mean	20.6	17.6	19.2
10-15 (low distress)	16 (23.5%)	20 (38.5%)	36 (30%)
16-21 (moderate distress)	25 (36.8%)	22 (42.3%)	47 (39.2%)
22-29 (high distress)	20 (29.4%)	5 (9.6%)	25 (20.8%)
>30 (very high distress)	7 (10.3%)	5 (9.6%)	12 (10%)

TABLE 3 Unmet needs reported by offspring

Domain	Statement Begins "I currently need"	Unmet Need Numbers, %
INFO	Information about what to do if I notice a particular side effect or symptom in my parent with cancer	83 (69)
INFO	To be informed about my parent's condition—good or bad	81 (68)
INFO	Information about the chances of my parent's recovery	81 (68)
FAM	To feel that my parents were being open with me about what was going on regarding my parent's cancer	80 (67)
INFO	Information about the side effects of my parent's treatments	79 (66)
INFO	Information about what happens after my parent comes home following treatment	77 (64)
INFO	Information about my parent's cancer and its impact on their life	76 (63)
FAM	To feel that I can talk about my parent's cancer	69 (58)
FAM	To feel that I have support from my family regarding my parent's cancer	67 (56)
TOR	To be able to have fun	66 (55)
INFO	To get information about my parent's cancer in a way that I can understand	66 (55)
INFO	To be informed about what is involved in my parent's treatment	61 (51)

Abbreviations: FAM, family issues; INFO, information; TOR, time-out/recreation.

When compared with offspring with at least two siblings, offspring who were an only child or had one sibling reported 11% more unmet needs related to practical assistance (95% CI, 1.7-21.1) and 15% more unmet needs related to recreational activities (95% CI,

3.0-27.2), after adjusting for offspring age, gender, and maternal cancer stage.

Female compared with male offspring reported a higher percentage of unmet needs in domains of practical assistance, time-out, feelings, and support from friends (Table 4). After adjusting for offspring age, number of siblings, and time since mother's diagnosis and maternal cancer stage, unmet needs related to practical assistance (adjusted β : 14.62; 95% CI, 4.93-24.31), recreational activity (adjusted β : 17.80; 95% CI, 6.07-29.52), feelings (adjusted β : 16.67; 95% CI, 6.01-27.33), and level of support from friends (adjusted β : 18.43; 95% CI, 3.35-33.50) were on average about 15% to 18% more among female offspring.

More offspring whose mother had MBC reported unmet needs in dealing with their feelings including stress, guilt, negative self-esteem, anger, and fear than offspring of nMBC patients (Table 4). After controlling for offspring age, gender, and number of siblings, offspring of MBC patients reported 16% more unmet needs for "dealing with feelings" (95% CI, 3.13-28.79) than those of nMBC patients. For all other domains, similar levels of unmet needs were seen, irrespective of mother's disease status (data not shown).

Compared with offspring of patients who received nonchemotherapy treatment, offspring of those receiving chemotherapy reported 16% more unmet needs for "dealing with feelings," whilst offspring of patients who had completed treatment reported 27% greater unmet needs for "support from friends" (Table 4).

The domains of unmet needs differed when analysing for an association between treatment received and unmet needs by maternal BC stage. Offspring of nMBC patients who received chemotherapy reported 23%, 30%, 31%, and 32% more unmet needs in "practical assistance" (β : 23.34; 95% CI, 4.74-41.94), "time-out and recreation" (β : 30.42; 95% CI, 6.19-54.65), "dealing with feelings" (β : 31.46; 95% CI, 11.19-51.73), and "support from friends" (β : 31.82; 95% CI, 1.98-61.66), respectively, when compared with those whose mother received nonchemotherapy treatment. Offspring of nMBC patients who had completed treatment reported 22% lesser unmet needs in "practical assistance" (β : -22.45; 95% CI, -44.55 to -0.34) than those on chemotherapy. Offspring of MBC patients who received chemotherapy reported 32% lesser unmet needs in "information" (β : -32.17; 95% CI, -59.05 to -5.30) and 26% lesser in "practical assistance" (β : -26.53; 95% CI, -51.94 to -1.12) when compared with those mothers receiving nonchemotherapy treatment.

4 | DISCUSSION

Although there has been an increased interest in quantifying the nature of distress in offspring with parents diagnosed with cancer, there are differences between previous publications and the current study. These include studies with small sample size, heterogeneity of parental cancers, inclusion of fathers with cancer, and varied methodologies used for recruitment and assessment of the children.¹⁵⁻¹⁸

The current study is one of the largest conducted solely in offspring of women with BC. The restricted recruitment to one

TABLE 4 Unmet needs: Association between offspring and maternal variable

	Domains of Unmet Needs (Coefficient, β) (95% CI)					
	1. INFO	2. FAM	3. PRAC	4. TOR	5. FEEL	6. SF
Offspring siblings						
None or one sibling	12.0 (-1.9 to 26.0)	6.4 (-7.4 to 20.3)	11.5 (1.6 to 21.4)	14.4 (2.2 to 26.7)	2.3 (-9.0 to 13.6)	8.2 (-7.3 to 23.7)
Three or four siblings ^a	RG					
Offspring gender						
Female	7.2 (-6.9 to 21.3)	11.8 (-2.1 to 25.6)	14.1 (4.2 to 23.9)	17.9 (5.7 to 30.1)	16.5 (5.5 to 27.4)	19.3 (4.1 to 34.6)
Male ^a						
BC stage						
Metastatic	8.8 (-8.0 to 25.5)	-2.6 (-19.2 to 14.0)	6.4 (-5.6 to 18.4)	2.0 (-13.0 to 17.0)	15.2 (2.03 to 28.4)	1.7 (-16.8 to 20.3)
Nonmetastatic ^a						
Treatment						
No treatment	15.4 (-6.7 to 37.4)	14.3 (-7.5 to 36.2)	-2.6 (-18.6 to 13.4)	8.0 (-11.6 to 27.6)	10.3 (-7.2 to 27.7)	27.2 (3.3 to 51.2b>)
Chemotherapy	0.02 (-18.6 to 18.7)	-7.1 (-20.2 to 16.7)	2.1 (-11.4 to 15.7)	14.2 (-2.4 to 30.7)	16.13 (1.4 to 30.9)	15.9 (-4.3 to 36.1)
Nonhemotherapy ^a						

Abbreviations: BC, breast cancer; FAM, family issues; FEEL, feelings; INFO, information; PRAC, practical assistance; RG, reference group; SF, support from friends; SOYP, support from other young people; TOR, time-out/recreation.

^aReference group.



treatment centre was an effort to evaluate a BC population where management of patients and support offered to the family was consistent. We elected to include offspring aged 14 to 24 years given that the OCNI tool has been validated in this age group. We demonstrated higher levels of moderate distress than that seen in studies of 16- to 24-year-old (Australian population 9%; Western Australia 9.6%).^{19,20} Further, 31% of offspring reported high distress in our study, which is significantly higher than the 9% reported in the 2007 National Survey of Mental Health and Wellbeing study of adolescents in both males (19% vs 6%) and females (40% vs 13%), respectively.¹⁴ In comparison with a study of comparable aged youth diagnosed with a mental disorder, there was a twofold higher incidence of high or very high distress in our study (31% vs 15.4%).¹⁹ In studies that focussed on parents diagnosed with cancer, our incidence of high or very high levels of distress is similar.²⁰⁻²²

Our study confirms the higher levels of distress experienced by female offspring, which has been noted by others.^{21,23-25} Although it was not specifically assessed in our study, one aspect of distress in female offspring may relate to their perception of a heightened risk of developing BC. Others have shown that females aged 11 to 19 years with a positive BC family history had a 5.7-fold higher likelihood of considering themselves at risk of BC. Further, 11% reported significantly higher levels of distress as measured by the Impact of Event Scale.¹⁵ The greater distress seen in female offspring has also been associated with personality resources of BC patients and their daughters. One study demonstrated higher levels of distress in the offspring when mothers scored high levels of attachment anxiety or offspring scored high levels of avoidant attachment. Identifying insecurities experienced by mothers and daughters may allow strategies to be developed.¹⁶

We noted that a longer time since diagnosis of BC irrespective of BC stage was associated with lower levels of distress. There are conflicting results with some studies showing a similar association²⁶ whilst others showing no such association.²² Our results may relate to one third of our patients having been diagnosed 5 years or more prior to the study, whilst other studies conducted their evaluation at an earlier time point (8 months up to 2 years).^{27,28} The impact of treatment type showed higher levels of distress in offspring whose mother was receiving chemotherapy, as compared with the lesser toxicity of anti-HER2 or endocrine therapy. For the first time, our study demonstrates a difference in the unmet needs reported by offspring, whether their mother is receiving chemotherapy in the adjuvant or palliative setting. Despite the curative intent of adjuvant chemotherapy as compared with the palliative focus for women with MBC, there were more unmet needs seen in the offspring of the former and lesser unmet needs in the latter. This knowledge may allow specific interventions to be offered to offspring to provide greater individualized benefits.

It was anticipated that offspring would experience greater distress if their mother had MBC. Studies that included parents in the terminal phase of their illness or including children in the bereavement period have reported greater distress and needs.⁵ Our finding that offspring of patients with MBC did not report significantly greater distress, even when adjusted for offspring age and time since diagnosis,

may potentially be explained by the sampling bias of our study. Symptomatic MBC patients were less likely to be approached to enter the study. Further, the long interval from diagnosis in the recruited MBC patients likely reflects responsive disease with potentially fewer symptoms. Thus, offspring of MBC patients may have been living in less stressful environments and consequently experience lower levels of distress. Future studies may utilize our findings to identify offspring at greatest risk of distress depending on the acuteness of the BC diagnosis, cancer stage, and the type of treatment their mothers are receiving, for psychological and social support.

Some studies have found that adolescents are at the highest risk of psychosocial disturbance compared with younger or older children.^{13,17,18} Others have reported that older adolescents and young adults are more likely to have psychological issues compared with younger.^{4,6,18,29} When comparing our study with these previous publications, we recognize that ours is the only study limited to women with BC. Whilst we did not identify any differences in distress or unmet needs based on age differences within our population, it should be noted that we restricted our study to offspring aged 14 to 24 years. We did so to enable our results to be applicable to future interventional studies utilizing the resources that exist in CanTeen, which now extends its services to 12- to 25-year-old.

A cancer diagnosis in the parent may alter family dynamics, resulting in the offspring undertaking additional family responsibilities with less time for social activities. Our study confirmed that one quarter of offspring reported unmet needs with respect to family duties and one third reported insufficient recreation time from their mother's condition. This in turn may impair personal development resulting in high levels of emotional and psychological distress.^{21,26,30} It was not surprising to see a strong association between distress levels and unmet needs, which has been reported by others.^{8,13}

5 | CONCLUSION

We found a high level of distress in the offspring of BC patients, with up to 69% of participants reporting unmet needs, in areas that can potentially be supported. The latter include efforts to improve information provision, assisting with family-related issues, and strategies to normalize recreational time. As BC remains the commonest solid cancer in women and indeed, the number of BC survivors steadily increases in our community as a result of effective treatment, our results indicate the need for more research in this area. Evidence-based approaches in clinical practice are needed to address the unmet needs of these offspring, particularly those who are female and have no or only one sibling.

5.1 | Study limitations

There are limitations in our study. We did not include a baseline evaluation of family cohesiveness, mental health status, or resilience in the parents or offspring, which can impact on the offspring mental

health and their ability to cope.^{4,22,28,31} Specifically, family conflict can significantly impact on the extent and nature of unmet needs.²⁶ It would be valuable to include an assessment of these factors in future studies, to broaden the scope of interventions that can be developed. In addition, we did not record if offspring were receiving mental health support at the time of study. Including these factors into larger prospective cohort studies across different institutions and regions would be of value. Despite these limitations, to our knowledge, this is the first BC-specific study to evaluate offspring-reported psychological and emotional needs, incorporating mother's disease stage and treatment.

5.2 | Clinical implications

Given the global BC incidence and the likelihood that many women will have offspring under the age of 25 years, our findings have important implications on ongoing clinical practice. Methods to identify offspring who are experiencing difficulties, coupled with effective interventions, are needed. In addition, our primary analyses were adjusted for confounding variables and provide useful insights into the development of specific resources that target the needs of the offspring in an effort to improve their emotional well-being. It has been identified by others that the development of these interventions requires close collaboration between the counsellors and the medical staff.³²

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CONFLICT OF INTEREST

None to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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