

Psychosocial Support Needs of Women with Breast Cancer in the Waikato Region of New Zealand

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Key words: breast cancer, psychosocial support, women, New Zealand, referral reasons

Short title: Psychosocial Support Breast Cancer New Zealand

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Breast cancer (BC) is the most frequently diagnosed cancer among women and the third most common cancer in New Zealand (NZ), with more than 3000 registrations and 600 deaths annually¹. While survival from BC in NZ is better than many other cancers, Māori women – the indigenous peoples of NZ – have a higher mortality rate than NZ European women². Therefore, for many NZ women, a BC diagnosis still threatens possible mortality, and frequently results in significant psychosocial distress that adversely impacts quality of life. Indeed, around 20-50% of women with BC will develop anxiety or depression within one year of diagnosis³.

NZs Ministry of Health (MoH) recognises the importance of psychological support as an integral part of cancer care. As such, from 2016 the MoH has funded a Cancer Psychological and Social Support Service (CPSSS) in six District Health Boards (DHBs). This includes Waikato DHB, which serves more than 400,000 patients across a large area encompassing the midland region of NZs North Island. CPSSS provides emotional, psychological and social support to cancer patients and their families from early diagnosis through to completion of treatment. NZs psychosocial support services are still relatively new, and have not been extensively evaluated. We aimed to determine the characteristics of women diagnosed with BC in the Waikato region who were referred to CPSSS and compare these to women who were not referred. We also sought to determine the most common concerns that led NZ women to seek a referral.

Methods:

January 2016 to October 2018 data was reviewed from the Waikato Breast Cancer Register (WBCR), which holds the clinical details of all women diagnosed regionally. Psychosocial support information was obtained from CPSSS for the same period and linked to the WBCR via a unique National Health Index (NHI) number. CPSSS referrals are made by hospital staff following completion of a screening tool (1=no distress/impact, 10=extreme distress/impact) modified from the National Comprehensive Cancer Network (NCCN) Distress Thermometer with additional impact thermometer⁴. With good internal consistency ($Alpha=0.81$) and validity⁵, the distress tool correlates well with other measures (e.g., Hospital Anxiety and Depression Scale (HADS))⁴. Generally patients must score at least 5 on the distress/impact scale to be accepted by CPSSS, although referrals are accepted with lower distress but high impact scores or at a clinician's discretion.

Data were analysed using IBM SPSS Statistics version 25. Domicile code was used to categorise urban/rural residence based on Statistics New Zealand's urban/rural profile. Ethnicity was categorised as Māori/non-Māori based on hospital recorded ethnicity. Independent *t*-test and Pearson chi-square tests compared patient characteristics. Logistic regression compared age, ethnicity, rural/urban status and clinical factors (mode of detection, treatment, type of surgery, stage). Referral reasons were analysed thematically. Ethical approval for the study was granted by the Northern A Health and Disability Ethics Committee, reference: 12/NTA/42/AM10.

Results:

A total of 998 women with stage 0-IV BC were identified from 2016-2018. Of these, 95 (10%) were referred to CPSSS. The characteristics of women referred and not referred are shown in Table 1. A further 21 women, diagnosed prior to 2016, were not registered on the WBCR, but were referred to CPSSS from 2016 to 2018, bringing the total number of women referred to 116. These 21 women were excluded from Table 1, but are included in the thematic analysis.

Women referred to CPSSS were significantly younger (mean age of 54 vs 63 years; $t=6.669$, $p<0.001$), with 25% of referred patients being <45 years of age. The distribution of Māori referred and not referred was similar (see Table 1). For those treated surgically, 46% of those referred received breast conserving surgery (BCS) compared to 67% not referred, and 43% received mastectomy compared to 23% not referred ($p<0.001$). For women treated with mastectomy, those referred were twice as likely to have reconstructive surgery (22% vs 11%; $p<0.001$). Women undergoing radiotherapy and chemotherapy were more likely to be referred. Just over 80% of referred women had stage I-II disease compared to 77% of women not referred ($p<0.001$).

Logistic regression showed that women aged 70+ were significantly less likely to be referred compared to women aged 45-69 years (odds ratio (OR): 0.18, 95% Confidence Interval (CI): 0.08-0.41)(see Table 2). Women <45 were significantly more likely to seek support (OR: 2.11, 95% CI: 1.14-3.90). Women undergoing mastectomy were significantly more likely to receive a referral (OR: 4.11, 95% CI: 2.29-7.39) compared to women treated with BCS. Women who had had no surgery at the time of analysis were also more likely to be referred (OR: 4.24, 95% CI: 1.38-12.99), as were women receiving radiotherapy (OR: 3.84, 95% CI: 2.05-7.23). Stage 0 cancers were significantly less likely to be referred to CPSSS (OR: 0.28, 95% CI: 0.07-1.19). Ethnicity, mode of screening, rurality, endocrine therapy, chemotherapy, and reconstructive surgery were all non-significant factors.

Thematic analysis identified seven referral themes, with the most common in relation to treatment, with 68% of women citing apprehension around treatment options- including declining treatment, side effects, and outcomes. These were followed by family-related distress (38%), mental/emotional support (33%), worry about the diagnosis itself (32%), uncertainty/fear of death/recurrence (21%), financial worries (15%) and body image and/or sexuality (10%).

Table 1. Characteristics of women registered on the WBCR who were not referred to CPSSS (n=903) (left) compared to women registered who were referred for the same period (n=95) (right).

Waikato Breast Cancer Register 2016-2018						
Factors		Not referred to CPSSS (n=903)		Referred to CPSSS (n=95)		P-value (Chi-square)
		n	%	n	%	
Age group	<45	61	6.8	24	25.3	<0.001
	45-69	592	65.6	64	67.4	
	70+	250	27.7	7	7.4	
Screen detected	Yes	403	44.6	33	34.7	0.064
	No	500	55.4	62	65.3	
Ethnicity	Māori	157	17.4	18	18.9	0.704
	Non- Māori	746	82.6	77	81.1	
Urban/rural	Urban	688	76.2	65	68.4	0.094
	Rural	215	23.8	30	31.6	
Type of surgery	Mastectomy	208	23.0	41	43.2	<0.001
	BCS	609	67.4	44	46.3	
	None/not yet	86	9.5	10	10.5	
Reconstruction	Yes	97	10.7	21	22.1	0.001
	No	806	89.3	74	77.9	
Treatment	Chemotherapy	123	13.6	37	38.9	<0.001
	Radiotherapy	367	40.6	60	63.2	<0.001
	Endocrine therapy	563	62.3	58	61.1	0.804
Stage	0	144	15.9	5	5.3	<0.001
	I	408	45.2	36	37.9	
	II	283	31.3	41	43.2	
	III	31	3.4	5	5.3	
	IV	30	3.3	8	8.4	
	Unknown	7	0.8	0	0.0	

Table 2. Logistic regression of women registered on the WBCR from 2016 to 2018 who were referred to CPSSS versus those not referred.

	Factors	Odds ratio	95% Confidence Interval		P-value
Age	<45 vs 45-69	2.11	1.14	3.90	<0.001
	70+ vs 45-69	0.18	0.08	0.41	0.017
Stage	Stage II vs I	1.19	0.69	2.06	0.540
	Stage III vs I	0.57	0.18	1.77	0.328
	Stage IV vs I	2.93	0.91	9.37	0.071
	Stage 0 vs I	0.36	0.14	0.93	0.036
	Unknown vs I	0.00	0.00		0.999
Type of surgery	Mastectomy vs BCS	4.11	2.29	7.39	<0.001
	No surgery vs BCS	4.24	1.38	12.79	0.011
Radiotherapy	Yes vs no	3.59	2.06	6.27	<0.001

Discussion:

Ten percent of women diagnosed with BC in the Waikato region were referred for psychosocial support from 2016 to 2018. There were key differences in the characteristics of those referred to CPSSS; they were significantly more likely to be younger, treated with mastectomy, had had no surgery, or were receiving radiotherapy. Ethnicity, mode of screening, rurality, endocrine therapy, chemotherapy, and reconstructive surgery were not significant factors in whether women were referred to psychosocial services.

Women younger than 45 were significantly more likely to be referred to CPSSS compared to older women, which is consistent with other data⁶. A recent systematic review highlighted some of the factors that lead to distress in younger women, such as managing financial/career stability, understanding the healthcare process and treatments, reproductive issues/ infertility due to treatment and fears of cancer recurrence and dying⁷. Our data agree that younger women in particular may benefit from psychosocial support targeted to the needs of this age group.

The most common reason for psychosocial referral was treatment apprehension, with radiotherapy the more distressing treatment. Radiotherapy represents ongoing hospital appointments, is difficult to access if living remotely and can be associated with anxiety if patients feel uninformed about treatment expectations⁸. Surgically, women referred to CPSSS were significantly more likely to have a mastectomy. Mastectomy is a disfiguring surgery which impacts on body image, femininity and sexuality, and is in itself associated with high levels of distress⁹. Women treated with mastectomy must also decide whether to undergo reconstruction, increasing decision-making stress. A higher proportion of women who underwent mastectomy were also under 45 years old, which confirms the need for support with this type of surgery, particularly for younger women. Women who had not received surgery at the time of analysis were also significantly more likely to be referred, possibly either due to the stress of waiting itself, or the stress of having advanced disease which may preclude women from surgery as a treatment option.

This is the first study to evaluate the characteristics and reasons why women with BC are referred to cancer psychosocial services in the Waikato region. We used data from two prospectively maintained regional datasets which contain comprehensive and near complete clinical and psychosocial details. One limitation is that, while using a widely used distress tool, most CPSSS referrals are completed by nursing staff, who are not specialised in detecting

psychosocial distress. Therefore patients not presenting with any psychosocial “red flags” may be missed for referral. Future research should seek to quantify any unmet need.

Ten percent of women were referred (and accepted) to CPSSS between 2016 and 2018, which is lower than referral numbers previously reported in Australia of 22%¹⁰. Reasons for referral are consistent with those reported internationally⁶. While CPSSS is still a relatively new service among a range of other services available to cancer patients (e.g. Cancer Society), the 10% referral rate may still suggest an unmet need for this service. For younger women diagnosed with BC, and women awaiting surgery or radiotherapy, access to psychosocial support services may be particularly beneficial.

Acknowledgement:

We acknowledge the Waikato Breast Cancer Register and the Cancer Psychological and Social Support Service for providing the data. We thank the University of Auckland Waikato Clinical Campus Summer Studentship scholarship for funding. The Waikato Breast Cancer Trust is supported by the NZ Breast Cancer Foundation and the Waikato Bay of Plenty Division of the Cancer Society.

Conflict of Interest:

The authors declare no conflict of interest.

Authorship:

E dM-R collected the data. E dM-R and TB analysed the data. TB drafted the final manuscript. RL conceived the initial idea for the project. All authors contributed to the writing and revision of the manuscript.

Data availability:

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.

The authors declare that this article contains original unpublished work and is not being submitted for publication elsewhere.

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