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CLINICAL CORRESPONDENCE

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Psychosocial support needs of women with breast cancer in the Waikato region of New Zealand

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1 | INTRODUCTION

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 annually.[1] 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 women.[2] Therefore, for many NZ women, a BC diagnosis still threatens possible mortality, and frequently results in significant psychosocial distress. Indeed, around 20% to 50% of women with BC will develop anxiety or depression within 1 year of diagnosis.[3]

NZs Ministry of Health (MoH) recognizes the importance of the psychological aspects of cancer care. 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 the midland region of NZs North Island. CPSSS provides emotional, psychological and social support to cancer patients and their families from early diagnosis to completion of treatment, with a particular focus on ensuring equal access and cultural responsiveness for Māori. CPSSS is still a relatively new service, and has not been extensively evaluated. We aimed to determine the characteristics of Waikato women diagnosed with BC 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 women to seek a referral.

2 | METHODS

January 2016 to October 2018 data was reviewed from the Waikato Breast Cancer Register (WBCR). Psychosocial support information for women who were referred, and accepted that referral was obtained from CPSSS for the same period and linked to the WBCR via a unique National Health Index (NHI) number. The number of declined referrals was unable to be ascertained. CPSSS referrals are generated by hospital staff using a screening tool (1 = no distress/impact, 10 = extreme distress/impact) modified from the National Comprehensive Cancer Network (NCCN) Distress Thermometer with additional impact thermometer.[4] Generally, patients must score at least 5 on distress and impact to be accepted, although referrals are accepted with low distress but high impact scores or at a clinician's discretion.

Data were analyzed using IBM SPSS Statistics version 25. Domicile code was used to categorize urban/rural residence based on Statistics New Zealand's urban/rural profile. Ethnicity was categorized 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 analyzed thematically by two researchers using a validated method.[5] Ethical approval for the study was granted by the Northern A Health and Disability Ethics Committee, reference: 12/NTA/42/AM10.

3 | RESULTS

A total of 998 women were identified. 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 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; $t = 6.669$, $P < .001$), with 25% being <45 years of age. The distribution of Māori referred and not referred was similar (see Table 1). For those treated surgically, 46% of referred women received breast conserving surgery (BCS) compared to 67% not referred, and 43% received mastectomy compared to 23% not referred ($P < .001$). For women treated with mastectomy, those referred were twice as likely to have reconstructive surgery (22% vs 11%; $P < .001$). Women undergoing radiotherapy and chemotherapy were more likely to be referred, as were women with stage I to II disease.

Key Points

- Breast cancer is the most frequently diagnosed cancer among women in New Zealand, with more than 3000 registrations and 600 deaths annually.
- Approximately 10% of women in the Waikato region of New Zealand were referred to the Cancer and Psychosocial Support Service from 2016 to 2018.
- Breast cancer patients referred for support were more likely to be younger, treated with mastectomy, had had no surgery, or were receiving radiotherapy.
- No ethnic disparity was shown with respect to psychosocial referrals, with similar numbers of Māori and non-Māori women being referred.
- The most common reason for referral in breast cancer patients was distress regarding treatment (68%).

TABLE 1 Characteristics of women who were not referred to CPSSS 2016 to 2018 (n = 903; left) compared to women who were referred for the same period (n = 95; right)

Factors		Waikato Breast Cancer Register 2016 to 2018				*P*-value (Chi-square)
		Not referred to CPSSS (n = 903)		Referred to CPSSS (n = 95)		
		n	%	n	%	
Age group	<45	61	6.8	24	25.3	<.001
	45 to 69	592	65.6	64	67.4	
	70+	250	27.7	7	7.4	
Screen detected	Yes	403	44.6	33	34.7	.064
	No	500	55.4	62	65.3	
Ethnicity	Māori	157	17.4	18	18.9	.704
	Non-Māori	746	82.6	77	81.1	
Urban/rural	Urban	688	76.2	65	68.4	.094
	Rural	215	23.8	30	31.6	
Type of surgery	Mastectomy	208	23.0	41	43.2	<.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	.001
	No	806	89.3	74	77.9	
Treatment	Chemotherapy	123	13.6	37	38.9	<.001
	Radiotherapy	367	40.6	60	63.2	<.001
	Endocrine therapy	563	62.3	58	61.1	.804
Stage	0	144	15.9	5	5.3	<.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 for factors associated with referral

	Factors	Odds ratio	95% Confidence interval		*P*-value
Age	<45 vs 45 to 69	2.11	1.14	3.90	<.001
	70+ vs 45 to 69	0.18	0.08	0.41	.017
Stage	Stage II vs I	1.19	0.69	2.06	.540
	Stage III vs I	0.57	0.18	1.77	.328
	Stage IV vs I	2.93	0.91	9.37	.071
	Stage 0 vs I	0.36	0.14	0.93	.036
	Unknown vs I	0.00	0.00		.999
Type of surgery	Mastectomy vs BCS	4.11	2.29	7.39	<.001
	No surgery vs BCS	4.24	1.38	12.79	.011
Radiotherapy	Yes vs no	3.59	2.06	6.27	<.001

Logistic regression showed that women aged 70+ were significantly less likely to be referred compared to women aged 45 to 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 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 (OR: 0.28, 95% CI: 0.970.79). Ethnicity, mode of screening, rurality, endocrine therapy, chemotherapy, and reconstructive surgery were all non-significant factors.

Seven referral themes were identified. The most common concerned treatment, with 68% of women citing apprehension around treatment options. This was 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/sexuality (10%).

4 | DISCUSSION

Ten percent of Waikato women diagnosed with BC were referred for psychosocial support 2016 to 2018. There were key differences in the characteristics of those referred; 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 associated with referral to psychosocial services.

Women younger than 45 were significantly more likely to be referred to CPSSS, which is consistent with other data.[6] A recent systematic review highlighted some of the factors that lead to distress in younger women, including managing careers, understanding the healthcare process and treatment, reproductive issues/infertility due to treatment and fears of cancer recurrence and dying.[7] 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, especially around radiotherapy, which represents ongoing appointments, is difficult to access for rural women and is associated with anxiety if women feel uninformed about treatment expectations.[8] Surgically, women referred to CPSSS were significantly more likely to have a mastectomy. Mastectomy is a disfiguring surgery with obvious impacts on body image, femininity and sexuality, and is in itself associated with distress.[9] Women treated with mastectomy must also decide whether to undergo reconstruction, increasing decision-making anxiety. A higher proportion of women who underwent mastectomy were also <45 years old, highlighting the support needed for younger women. Women who had not received surgery at the time of analysis were also significantly more likely to be referred, possibly due to the stress of waiting for treatment itself, or the stress of having advanced disease which may have precluded them from surgery as a viable option.

A similar proportion of Māori were referred to CPSSS, which is encouraging given the NZ context and the importance of providing equitable access for Māori to health services. Initial feedback from Māori patients has noted culturally appropriate care with an inclusion of spiritual needs (*wairua*), an important feature of the holistic approach to Māori mental health and wellbeing.[10] With Māori identified as an at risk group for psychosocial distress,[11] it is vital that psychosocial services continue to provide culturally appropriate care.

This is the first study to evaluate BC referrals to cancer psychosocial services in the Waikato. We used data from two prospective datasets containing comprehensive data. Most CPSSS referrals are also completed by nurses, who are not specialized in perceiving distress. Therefore patients not presenting with psychosocial "red flags" may be missed. Future research should quantify this unmet need, in addition to quantifying the patient experience of screening. Importantly, it should also measure perceptions of Māori in the region to ensure their needs continue to be met.

Ten percent of women were referred (and accepted) to CPSSS between 2016 and 2018, which is lower than referral numbers previously reported in Australia (22%).[12] Reasons for referral are consistent with data reported internationally.[6] While CPSSS is still a relatively new service, the 10% referral rate may still suggest unmet need. For younger women diagnosed with BC, and women awaiting surgery or radiotherapy, access to psychosocial support services may be particularly beneficial.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Elaine del Mundo-Ramos collected the data. Elaine del Mundo-Ramos and Tania Blackmore analyzed the data. Tania Blackmore drafted the final manuscript. Ross Lawrenson conceived the initial idea for the project. All authors contributed to the writing and revision of the manuscript.

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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