

Identifying physical and psycho-social issues facing breast cancer survivors after definitive treatment for early breast cancer

A Nurse-Led Clinic Model

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Ethics Approval: QA2013124, QA2013.71



Conflict of Interest

- Victorian State Government funding



A Victorian
Government
initiative



Survivorship Project Team

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Aims

1. Identify symptoms reported by breast cancer survivors upon completion of definitive treatment
2. Evaluate the appropriateness and effectiveness of a nurse-led clinic pilot program to identify these issues and make timely referrals to available services

Method - Participants

Inclusion Criteria

- Diagnosis of early breast cancer or DCIS
- Post-definitive treatment (6-12 months post-diagnosis)

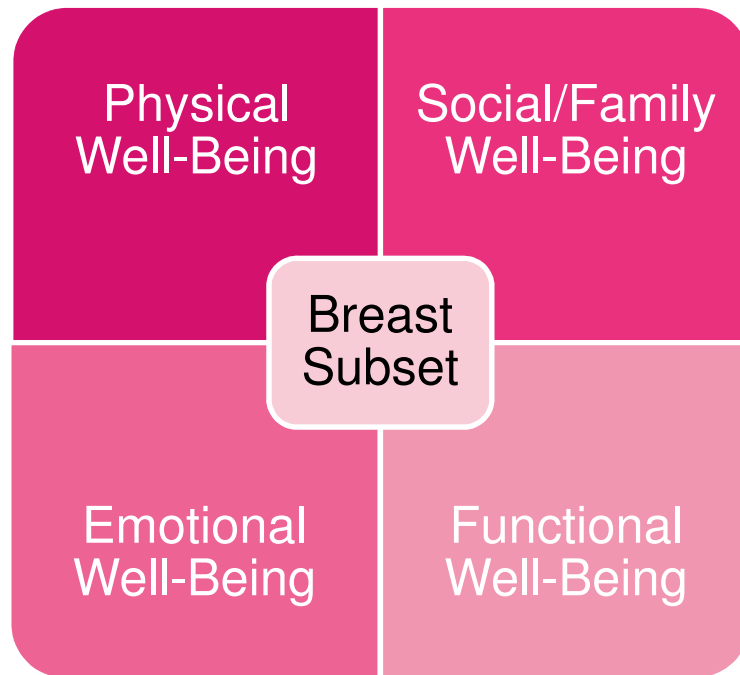
Exclusion Criteria

- Limited life expectancy/frailty
- Psychiatric co-morbidity

Method – Pilot Program



Methods - Instruments



Functional Assessment of Cancer Therapy – Breast (Version 4)

ADDITIONAL CONCERNS

		Not at all	A little bit	Some-what	Quite a bit	Very much
B1	I have been short of breath	0	1	2	3	4
B2	I am self-conscious about the way I dress	0	1	2	3	4
B3	One or both of my arms are swollen or tender	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
B6	I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
B7	I worry about the effect of stress on my illness	0	1	2	3	4
B8	I am bothered by a change in weight	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
F2	I have certain parts of my body where I experience pain....	0	1	2	3	4

Methods - Instruments

Menopause Rating Scale (MRS)

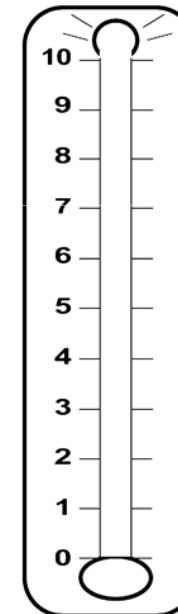
Which of the following symptoms apply to you at this time?
 (X ONE Box For EACH Symptom) For Symptoms That Do Not Apply, Please Mark "None".

Symptoms:

	none	mild	moderate	severe	extremely severe
Score =	0	1	2	3	4
1. Hot flashes, sweating (episodes of sweating).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Heart discomfort (unusual awareness of heart beat, heart skipping, heart racing, tightness).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Sleep problems (difficulty in falling asleep, difficulty in sleeping through the night, waking up early).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Depressive mood (feeling down, sad, on the verge of tears, lack of drive, mood swings).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Irritability (feeling nervous, inner tension, feeling aggressive)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Anxiety (inner restlessness, feeling panicky)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Physical and mental exhaustion (general decrease in performance, impaired memory, decrease in concentration, forgetfulness).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Sexual problems (change in sexual desire, in sexual activity and satisfaction).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Bladder problems (difficulty in urinating, increased need to urinate, bladder incontinence).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Dryness of vagina (sensation of dryness or burning in the vagina, difficulty with sexual intercourse).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Joint and muscular discomfort (pain in the joints, rheumatoid complaints)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

Nurse-Led Clinics

July 2012 – June 2013

	Total
NLC offered	274
NLC completed	183
Telephone consultations	40
Opted out	78
Cancelled	5
Failed to attend	8 (4%)

*Nurse-led clinics are ongoing since completion of project as identified above



Results - Physical

- **Poor quality of sleep**
 - 28% reported severe/very severe problems
- **Lack of energy**
 - 9% reported being “very concerned”
- **Difficulty participating in work**
 - 20% unable to participate at all/“only little bit”

Results - Physical

- Patients reported symptoms as “severe”:
 - Joint pain 21%
 - Hot flushes/episodes of sweating 18%
 - Vaginal dryness 8%
 - Bladder problems 5%
- Problems with sex life
 - 31% ‘not at all’ satisfied with sex life

Results - Physical

- Axillary Lymph Node Dissection
 - 9/35 reported significant arm swelling
- Chemotherapy
 - 16/68 reported significant hair loss

Results - Psychological

- Patients reported symptoms as “severe”:
 - Depressed mood (25/176)
 - Physical and mental exhaustion (24/175)
 - Irritability (19/172)
 - Anxiety (12/175)

Results – Distress

- 96/175 (55%) reported distress as ≥ 4 corresponding to significant distress
- 31/175 (18%) reported distress as ≥ 7 corresponding to extreme distress

New Referrals

New referrals	Total
Peer Support Services	66
Menopause	31
Psychology/Mindfulness	23
Plastics	12
PT/OT	6
Chronic Pain	4
Genetics	4
Dietician	4
Social Work	3
Other	13
TOTAL	166

- 166 referrals
- 156 accepted
- 94% acceptance rate

Other: continence clinic, lymphedema clinic, Bowen therapy, prosthetics, sexual counselling

Care Plan

Diagnosis & Treatment Summary

History – PMHx, FHx, menopausal status

Diagnosis – histology, type, grade, nodal status, receptor status

Treatment – surgery, chemotherapy, radiotherapy, biological, hormonal

the women's
Melbourne Hospital

Follow-Up Care Plan

Patient Name	
GP Details	

DIAGNOSIS & HISTORY SUMMARY

Diagnosis date	
Age at diagnosis	
Menopausal status at diagnosis	
Family history of breast cancer (Y/N)	
Other pertinent medical conditions	
Side	
Histological diagnosis	
Type	
Size (mm)	
Grade	
Nodal status	
Oestrogen receptor	
Progesterone receptor	
HER2 receptor	
Other receptors	

TREATMENT SUMMARY

SURGERY

Surgery date	
Breast Surgery	
Axillary Surgery	
Surgeon name	
Reconstruction (Y/N/Awaiting)	

ADJUVANT THERAPY

Radiotherapy Provider	
Radiotherapy Field	
Radiotherapy End Date	
Chemotherapy	
Biological Therapy	
Hormonal Therapy Type	Planned End Date:
Genetic Testing (Y/N)	

Investigations

Date of last mammogram	
Bone density, date and result	
Other	

Care Plan



Patient label

Health and Wellbeing Management Plan

Domain	Issues / Symptoms
Psychosocial / Mental Health	
Lifestyle (exercise / nutrition / weight / bone health)	
Menopause	
Sexuality	
Fertility	
Other (e.g. Tamoxifen)	

Referral Made	Resources Provided

Individualised Recommended Follow-Up Schedule

Date	Purpose of Visit	Provider Responsible (e.g. GP / hospital)
	Discussion of follow-up care plan	General Practitioner

Health & Wellbeing Management Plan

- Issues identified in QOL surveys/NLC
- Referrals & resources provided
- Individualized follow-up plan
- Signed by BCN & BCS
- Sent to GP



Evaluation

- Follow-up surveys - 65% response rate
- Majority either strongly agreed or agreed that BCNs were supportive, helpful in making referrals, and compassionate towards them
- 39% reported having made lifestyle changes as a result of the appointment with BCN - changes primarily related to diet and exercise

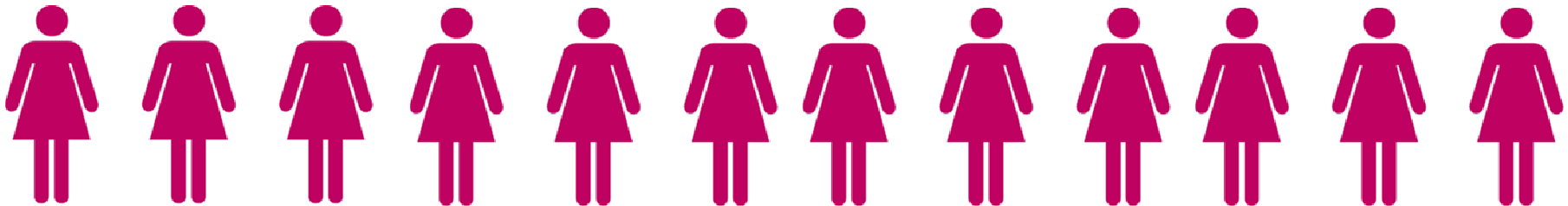
Engagement with Primary Care

- (71%) responded that after their GP appointment they felt they had a better understanding of what they could do to help themselves stay well



Conclusions

- Breast cancer survivors experience a unique set of physical and psycho-social challenges after definitive treatment
- Many survivors experience significant distress
- NLC model is appropriate and feasible
- Opportunity for health education and promotion of a healthy lifestyle



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Appendices

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Variable		Participants
Gender	Female	181
	Male	2
Age (years)	Mean	56.78
	Range	29-87
Menopause Status	Pre-menopausal	59
	Post-menopausal	105
	Peri-menopausal	17
Diagnosis	Invasive Ductal Carcinoma	130
	Invasive Lobular Carcinoma	16
	Ductal Carcinoma In Situ	31
	Other (Invasive)	6
Node Status	Positive	44
	Negative	139
Receptor Positive	Oestrogen	160
	Progesterone	147
	Her-2	20
	Triple Negative	13

Variable		Participants
Breast Surgery	Wide Local Excision	128
	Mastectomy	32
	Mastectomy & Reconstruction	23
Axilla Surgery	Sentinel Node Biopsy	133
	Axillary Lymph Node Dissection	36
	Nil	14
Chemotherapy	Yes	65
	No	114
	Ceased prematurely	4
Radiotherapy	Yes	133
	No	37
Endocrine Therapy	Tamoxifen	81
	Aromatase Inhibitor	45
	Changed/ceased therapy	11
	No	46
Biological Therapy	Yes	13
	No	168
	Ceased prematurely	2

Appendices

Table 5: Functional Assessment of Cancer Therapy – Breast (Version 4) Results

Score	GP1	GP2	GP3	GP4	GP5	GP6	GP7	GS1	GS2	GS3	GS4	GS5	GS6	GS7	GE1	GE2	GE3	GE4	GE5	GE6
0	27	129	100	65	80	120	122	5	10	11	9	11	23	28	48	9	130	60	79	50
1	51	29	27	39	33	26	26	24	13	18	4	12	7	7	63	16	20	50	45	59
2	41	13	24	28	25	20	17	29	26	26	22	16	14	19	31	29	12	36	29	32
3	40	4	15	29	23	7	8	46	33	54	28	31	23	14	23	60	4	22	10	14
4	16	2	7	12	12	2	3	70	95	66	110	103	97	21	8	59	6	5	12	19
DNA	7	5	9	9	9	7	6	8	5	7	9	9	18	93	9	9	10	9	7	8

Score	GF1	GF2	GF3	GF4	GF5	GF6	GF7	B1	B2	B3	B4	B5	B6	B7	B8	B9	P2
0	17	19	9	7	31	12	11	96	95	111	56	115	43	39	57	14	38
1	18	21	13	11	29	23	18	38	31	27	39	21	36	41	33	18	43
2	36	35	48	30	49	33	45	19	13	12	47	12	29	29	31	35	37
3	43	45	56	42	39	48	50	14	21	13	14	9	21	42	25	52	33
4	58	49	49	86	26	59	51	9	17	11	10	16	48	23	28	56	24
DNA	10	13	7	6	8	7	7	1	0	3	11	4	0	3	3	3	2

Key: FACT-B: Functional Assessment of Cancer Therapy – Breast; DNA: did not answer; GP1: I have a lack of energy; GP2: I have nausea; GP3: Because of my physical condition, I have trouble meeting the needs of my family; GP4: I have pain; GP5: I am bothered by side effects of treatment; GP6: I feel ill; GP7: I am forced to spend time in bed; GS1: I feel close to my friends; GS2: I get emotional support from my family; GS3: I get support from my friends; GS4: My family has accepted my illness; GS5: I am satisfied with family communication about my illness; GS6: I feel close to my partner (or the person who is my main support); GS7: I am satisfied with my sex life; GE1: I feel sad; GE2: I am satisfied with how I am coping with my illness; GE3: I am losing hope in the fight against my illness; GE4: I feel nervous; GE5: I feel worried about dying; GE6: I worry that my condition will get worse; GF1: I am able to work (include work at home); GF2: My work (include work at home) is fulfilling; GF3: I am able to enjoy life; GF4: I have accepted my illness; GF5: I am sleeping well; GF6: I am enjoying the things I usually do for fun; GF7: I am content with the quality of my life right now; B1: I have been short of breath; B2: I am self-conscious about the way I dress; B3: One or both of my arms are swollen or tender; B4: I feel sexually attractive; B5: I am bothered by hair loss; B6: I worry that other members of my family might someday get the same illness I have; B7: I worry about the effect of stress on my illness; B8: I am bothered by a change in weight; B9: I am able to feel like a woman; P2: I have certain parts of my body where I experience pain.

Appendices

Table 6: Menopause Rating Scale Results

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
Mean	1.28	0.59	1.61	1.23	1.09	0.92	1.34	0.91	0.64	0.66	1.59
Score ≥ 3	32	5	50	25	19	12	24	16	8	13	36
Score of 4	9	3	6	5	6	3	8	9	3	3	14
Total answered	176	174	176	176	172	175	175	169	173	171	174
Did not answer	7	9	7	7	11	8	8	14	10	12	9

NB: Score of 3 equates to "severe" symptoms; a score of 4 equates to "very severe" symptoms