

PO4-10-11 Needs of oncology nurse navigators serving young or metastatic breast cancer patients

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BACKGROUND

Oncology nurse navigators (ONNs) facilitate breast cancer patients' care via information, resources, and referral services.

Among breast cancer patients, they serve two important and distinct groups:

- young women with breast cancer (yBC), diagnosed age 45 or younger, and
- people living with metastatic breast cancer (mBC)

Both groups report psychosocial distress and quality-of-life issues, and also they have unique challenges:

- yBC patients face disruptions to family planning, potential emotional and psychological distancing from family and peers, and body image concerns.
- People living with metastatic breast cancer (mBC) face mortality and end-of-life issues, often intense treatment side effects and potentially substantial financial burdens.

Objective: To determine the needs and barriers of ONNs serving yBC and mBC patients.

METHODS

52 active ONNs completed an online needs assessment survey.

A survey created by a working group of patients, patient advocates, ONN and cancer and health communication experts lead by FORCE. ONN were recruited from May 4, 2020 to September 30, 2020. Respondents were excluded if they were not practicing ONNs ($n=13$), were outside the U.S. ($n=2$) or completed <25% of the survey ($n=34$).

46 of 52 participants provided length of work experience; responses were similar to the full cohort for all questions assessed. This study was certified as exempt (Protocol 000339) by the University of South Florida IRB.

PARTICIPANT DEMOGRAPHICS

Role as Oncology Nurse Navigator	
Work setting (N=52)	
Community cancer center	40%
Non-profit organization	21%
Academic institutions	15%
Federally funded health centers	6%
Industry	2%
Volunteer	2%
Rural setting	11%
Did not report	35%
Years practicing (N=46)	
5 years or less	48%
over 5 years	52%

In the prior 6 months,

- Most ONNs saw more yBC than mBC patients:
 - 10-19 yBC (35% of ONNs)
 - 1-4 mBC patients (34% of ONNs)
- Volume of yBC or mBC patients did not correlate with work experience.
- Overlap between yBC and mBC patients was not determined.

Participants could select more than one option; total may not add to 100%.

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RESULTS

ONNs' familiarity with topics varied.

- ONN were least familiar with tumor biomarker testing, clinical trial participation, fertility preservation, long-term health issues, menopause and pain management and sexual health or intimacy issues.

ONNs' familiarity with topics differed by career stage.

- Familiarity with genetic counseling/testing and clinical trial participation significantly increased with years of practice.

ONN Topic Familiarity

Topic	all ONN (n=52)		Earlier-career (n=22)		Later-career (n=24)	
	% familiar	Fisher's exact test ^a	% familiar	% familiar	Fisher's exact test ^b	
Breast reconstruction	87	comparator	82	92	ns	
Healthy lifestyles	85	ns	77	88	ns	
Genetic counseling and testing	83	ns	73	96	.0431	
Cancer preventive services	81	ns	73	88	ns	
Fatigue	77	ns	82	75	ns	
Palliative care	75	ns	77	79	ns	
Mental health	73	ns	73	79	ns	
Targeted therapy	71	ns	64	71	ns	
Financial issues	69	ns	59	83	ns	
Tumor biomarker testing	65	.0206	73	71	ns	
Clinical trial participation	62	.0066	45	79	.0315	
Fertility preservation	62	.0066	64	63	ns	
Long-term health issues	62	.0066	68	54	ns	
Menopause management	62	.0066	55	67	ns	
Pain management	62	.0066	59	67	ns	
Sexual health or intimacy	54	.0005	41	67	ns	

^a Familiarity with a topic (yellow) versus the most familiar topic (comparator, grey). Fisher's exact test ($p<0.05$)

^b Familiarity of earlier-career ONN compared to later-career ONN (blue). Fisher's exact test ($p<0.05$)

ns, not significant,

ONN referral

Service	ONN	all ONN		% earlier-career ONNs		% later-career ONNs	
		yBC	mBC	yBC	yBC	mBC	mBC
Financial	Patients	100	97	100	100	100	95
Genetic counseling and testing		93	82	82	100	64	94
Mental health		98	100	95	100	100	100
Breast reconstruction ^a		93 ^a	50 ^a	89	95	62	44
Healthy lifestyles		91	83	85	95	64	94
Clinical trials ^c		63	68	35 ^c	89 ^c	36 ^c	89 ^c
Long-term health		85	76	88	79	79	78
Menopause management		79	72	78	79	64	82
Fertility preservation ^a		72 ^a	25 ^a	71	76	31	22
Cancer prevention ^a		68 ^a	36 ^a	63	75	33	41
Fatigue		84	82	89	75	87	72
Sexual health or intimacy		76	65	78	68	57	67
Pain management		76	84	78	67	79	89
Palliative care ^b		52 ^b	83 ^b	53	53	88	79

^a Services for which ONN referred yBC significantly more frequently than mBC patients (blue).

^b Services for which ONN referred yBC significantly less frequently than mBC patients (orange, italicized).

^c Earlier-career ONNs referred both yBC and mBC patients to clinical trials significantly less often than later-career ONNs (bold, gray).

a-c, Fischer exact test, $p<0.05$.

ONNs reported substantial barriers to many services

- The majority of ONN reported barriers for 12 of 14 queried services.
- Barriers were reported most frequently for:
 - fertility preservation services
 - financial barrier
 - lack of programs/providers
 - clinical trial services
 - patient understanding of value
 - medical jargon/health literacy barriers
- The majority of ONN reported no barrier for fatigue, menopause management, and pain management services.

Barriers to referral KEY	
80% to 100%	Red
60% to 79%	Orange
40% to 59%	Yellow
20% to 39%	Light Green
0% to 19%	Dark Green

Referral barriers

Service	Financial	patient understanding of value	lack of programs / providers	Language barriers	Jargon/health literacy	No barrier	Most common barrier reported (or lack of barrier)	% ONNs reporting any barrier	% ONNs never referring
Fertility preservation	55	18	39	8	11	18	financial	82	19
Clinical trials	3	60	26	9	46	20	patient understanding value	80	22
Mental health	48	26	52	9	11	22	lack of programs/providers	78	2
Breast reconstruction	59	17	27	15	20	22	financial	78	11
Genetic counseling/testing	27	54	20	15	22	24	patient understanding value	76	13
Cancer prevention	26	57	20	17	20	26	patient understanding value	74	19
Long-term health issues	11	50	21	13	24	26	patient understanding value	74	12
Sexual health or intimacy	20	27	47	10	17	27	lack of programs/providers	73	23
Healthy lifestyles	22	54	24	12	12	27	patient understanding value	73	7
Financial issues	29	7	39	17	12	34	lack of programs/providers	66	5
Palliative care	8	51	30	3	16	35	patient understanding value	65	10
Fatigue	3	23	26	14	14	46	no barrier	54	17
Menopause management	11	19	22	11	6	53	no barrier	47	18
Pain management	17	19	25	6	17	56	no barrier	44	8

EDUCATIONAL NEEDS

Continuing education and patient material needs

Topic	% ONN		
	Continuing education needed	Patient materials needed	Familiarity with topic
Sexual health or intimacy	52*	54*	54
Complementary or alternative medicine	44*	50*	nd
Health disparities	44*	25	62
Financial issues	42*	46*	69
Long-term health issues	42*	48*	62
Mental health	42*	56*	73
Fertility preservation	38*	35	62
Menopause management	38*	35	62
Risk for other diseases	38*	38*	nd
Environmental exposures and breast cancer risk	37*	35	nd
Gender minority issues	37*	17	nd
Impact on family, relatives or caregivers**	37*	48*	nd
Risk for recurrence	35*	38*	nd
Genetic counseling and testing	33*	46*	83
Health literacy	31*	35	nd
Communicating using plain language techniques	29*	nd	nd
Lymphedema	29*	31	nd
Breast reconstruction	27	31	87
Cancer preventive services	25	31	81
Tumor biomarker testing	25	17	65
Direct-to-consumer genetic testing	21	19	nd
Healthy lifestyles	21	40*	85
Fatigue**	19	21	77
Breast cancer treatments	17	25	nd
Palliative care	17	33	75
Targeted therapies	17	19	71
Alcohol and tobacco	15	25	nd
Clinical trials	12	31	62
Treatment side effects	12	38*	nd
Pain management	6	25	62

* Topics of significantly greater interest (orange) compared to those of least interest (grey).

** Topics for which early and later-career ONN reported significantly different need for patient materials (blue). nd = not determined

- Most ONNs were interested in continuing education for sexual health and intimacy but not clinical trials, treatment side effects, or pain management.
- The most requested topics for patient education materials were mental health, sexual health/intimacy, and complementary/alternative medicine.

CONCLUSIONS

- Familiarity, referral patterns, educational needs, and barriers faced by earlier-career ONNs differ from later-career ONNs.
- Over 5 years of work experience seemed to be a meaningful threshold for distinguishing novice and expert ONNs.
- ONNs expressed significant barriers to referral for clinical trials, most commonly patient understanding of value.

PRACTICAL IMPLICATIONS

- Site-specific attention to differing needs of ONNs by job tenure may benefit patient outcomes.
- Barriers to clinical trial referral, most commonly reported as lack of patient understanding of value, suggesting that patient education and materials may help reduce this barrier.