Original Research

Differences in Perceived Risk at Which Clinician and Patient Stakeholders Initiate Activities to Prevent Late Effects Among Breast Cancer Survivors

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Abstract *Objective:* To characterize the level of probability or perceived risk that will trigger patients, physicians, nurses, or therapists to initiate clinical activities to prevent late effects, including chronic physical impairments and adverse symptoms that often occur among breast cancer (BC) survivors.

Design: Cross-sectional survey querying participants regarding the level of probability or perceived risk of a patient developing a late effect, 0%-100% visual analog scale, that would cause them to initiate activities to prevent or preemptively address late effects such as lymphedema, upper quadrant pain, chemotherapy-induced peripheral neuropathy, shoulder contracture, and fatigue.

Setting: A quaternary medical center and community medical and radiation oncology clinics.

Participants: A purposive sample of 50 BC survivors, 10 breast clinic physicians, 10 breast surgeons, 10 radiation oncologists, 10 medical oncologists, 10 breast clinic nurses, and 10 cancer rehabilitation therapists (N=110).

Interventions: Not applicable.

Main Outcome Measures: Stakeholder ratings of the probability level at which they would initiate clinical activities to prevent BC-related late effects: education, screening, prevention, and therapist referral, scored on a visual analog scale 0%-100% with verbal anchors, to address lymphedema, chronic upper quadrant pain, function-limiting chemotherapy induced peripheral neuropathy, shoulder contracture, and chronic fatigue.

Results: For the 5 late effects, mean probability level ranges across the stakeholder groups were ordered as follows: education (2.8-27.1), prevention (8.1-44.1), screening (11.1-50.2), and therapist referral (16.4-59.2). BC survivors had the lowest thresholds for initiating education: lymphedema 2.0, pain 3.6, neuropathy 1.4, shoulder contracture 3.3, and fatigue 3.3. Therapists, in contrast, had the lowest thresholds for initiating all prevention activities except

education. When averaged across late effects, mean probability levels for initiating activities were higher among physicians with breast surgeons having the highest mean levels for all activities except therapist referral. Nonetheless, mean probability levels differed significantly between survivors and clinicians (allied health and physicians combined) for only 2 of the 4 prevention activities and in these cases by ≤12%.

Conclusions: The probability level or perceived risk of a BC-related late effect at which stakeholders recommended initiating preventive activities differed across groups, with therapists generally having the lowest levels and breast surgeons the highest. However, the mean levels endorsed by survivors were congruent with or differed limitedly from clinicians and should be considered as a guide to initiating activities.

Physical impairments and adverse symptoms, commonly referred to as late effects, are prevalent and enduring following breast cancer (BC) treatment. The majority of BC survivors develop multiple late effects.[1,2] These include, but are not limited to, lymphedema, chronic upper quadrant pain, fatigue, shoulder dysfunction, and chemotherapy induced peripheral neuropathy.[3,4] In isolation and more potently in concert, physical impairments and symptoms degrade survivors' quality of life, capacity for gainful employment, and resumption of defining life roles.[5-8] Further, a growing evidence base suggests that survivors with late effects consume up to 30% more health care resources in the decades following diagnosis.[9]

Recognition of late effects' adverse consequences has spurred investigation into their prediction and prevention.[10,11] Greatest attention has centered on lymphedema and yielded predictive models with high discrimination as well as effective screening and preventive approaches.[12-15] The application of prediction models for specific BC-related late effects to retrospective cohorts has shown clustering of subgroups in the upper and lower probability ranges, indicating that screening and preventive activities are likely to benefit some survivors substantially more than others.[15] Since these activities may require survivors to invest time and resources in copayments, travel, and time off work, it becomes important to council them on the benefits in terms of risk reduction that they are likely to gain.

Ideally, the clinical activities recommended to prevent and preemptively address specific late effects should match a survivor's likelihood of developing them. However, such matching does not consistently occur, leading survivors to adopt practices that offer them meager or no benefit, for example, use of a compression sleeve when lymphedema risk is ≤5%.[16] Further, survivors often remain unaware of clinical activities that may offer them substantial benefit, for example, balance and gait exercises to prevent falls when the probability of developing chemotherapy induced peripheral neuropathy is high.[17] Unfortunately, an absence of empirical guidance regarding appropriate probability levels or perceived risk for initiating clinical activities to prevent late effects impedes our ability to engage patients in individualized shared decision making.

Knowledge of specialists' prevailing practices and BC survivors' preferences may offer guidance until estimates become available that rigorously characterize the effectiveness and benefits of late affect prevention activities when initiated at different levels of risk. To characterize the perceived risk or probability level that prompts initiation of clinical activities to prevent or preemptively address late effects, we conducted a multistakeholder quantitative assessment among a purposively sampled group of allied health professionals and physician BC specialists spanning key disciplines: surgery, radiation oncology, rehabilitation, and medical oncology, as well as BC survivors.

Methods

Data for this cross-sectional study were collected between October 1, 2017, and March 31, 2018. The study was approved by the Mayo Clinic's Institutional Review Board.

Study sample

We used several purposive sampling strategies to recruit participants. This was done in order to create a sample with equal representation of each BC specialist group of physicians and allied health providers. Our initial target sample size of 20 clinicians per group was arbitrary and was not based on a priori estimates. Because clinician recruitment proved challenging and slow, we reduced our target sample to 10 clinicians per group. No effort was made to balance sex, age, or years of experience across the subgroups.

Convenience sampling was used to enroll physicians who specialize in the treatment of BC and BC late effects: medical, radiation, and surgical oncologists, as well as internists staffing a breast medicine clinic. An email with the survey attached was sent to specialists practicing at the Mayo Clinic, Rochester as well as former residents and fellows who had graduated from the Mayo Clinic training programs in the target disciplines. Up to 2 follow-up surveys were sent to nonrespondents at 2-week intervals after the initial email. Recruitment continued until a total of 10 completed surveys were returned per discipline. The e-survey included a preface describing the empirical benefits of detecting and addressing BC treatment-related late effects in their early stages.

Similar convenience sampling was used to engage cancer rehabilitation physician specialists. In addition to physiatrists practicing at the Mayo Clinic, Rochester, members of a national special interest group affiliated with the American

Academy of Physical Medicine and Rehabilitation that held monthly teleconferences were sampled by email until a total of 10 completed surveys were returned.

Consecutive sampling of allied health professionals, physical or occupational therapists and nurses from a breast clinic, took place at staff meetings, 1 meeting per discipline. Additional surveys were emailed to individuals who did not attend the meetings. Up to 2 surveys were sent to nonrespondents until 10 representatives were recruited for each clinical group.

Fifty survivors were recruited from a population-based cohort of BC survivors in Olmsted County, MN.[9] Invitation letters were sent and the first 50 volunteers were invited to 1 of 3 rating sessions. Data were collected from BC survivors during center-based sessions which were held on at different days of the week and times of day to offer participants a range of options and minimize selection bias. The rating exercise was described to survivors who were encouraged to ask questions. Rating was performed on printed surveys.

Person-reported data

The same questionnaire was administered to physicians, allied health providers, and BC survivors. The face page, which queried participants about their clinical practices and survivorship characteristics, was divided into a section for clinicians and a separate section for BC survivors. Clinicians were asked about their clinical discipline, practice setting, years of clinical experience with BC, and number of patients with BC seen per week. The BC survivor section asked respondents about the duration of their survivorship.

Ratings of perceived risk or probability of a patient's developing a late effect

The survey was developed using validated methods.[18] A panel of 8 BC clinicians and 4 BC survivors were provided with lists of BC-related late effects mentioned in systematic reviews over the past decade. Through a modified Delphi process the panel selected 5 late effects from 12 that were identified as the most clinically relevant. A similar process was used to identify the 4 most clinically relevant late effect-related monitoring, prevention, and treatment activities. Cognitive pretesting of the questionnaire was conducted with 2 allied health, 2 physician, and 2 BC survivor participants. More specifically, these participants were queried about how they constructed their responses, what they interpreted the questions to mean, any difficulties they experienced in understanding or answering the questions, and thoughts that prompted them to select their answers. The survey was then pilot tested among 15 current medical and radiation oncology trainees at the Mayo Clinic, Rochester, MN. Pilot study participants were asked to identify sources of ambiguity and to suggest alternate word choices.

Stakeholder rated the probability level for initiating late effect-directed activities: "Education," "More frequent and sensitive screening," "Instruction in preventive activities," and "Referral to a physical therapist or occupational therapist." Examples of evidence-based late effect-directed activities were offered, for example, upper extremity resistive exercise to prevent lymphedema. Respondents were asked to indicate the perceived risk, explained as the value corresponding to the probability level or likelihood of developing a late effect at which they would recommend that a patient initiate a specific prevention activity on a numerical rating scale ranging from 0%-100% with tics at intervals of 10. They were asked to place an X at their perceived risk level for initiating each late effect-directed activity in order to address "lymphedema," "chronic ipsilateral upper quadrant (breast, arm, chest wall or shoulder girdle) pain," "functionally limiting chemotherapy-induced peripheral neuropathy," "chronic shoulder contracture," and "chronic fatigue." Verbal anchors were used at 0, "no risk," and at 100%, "has the condition." The survey questions are included in supplemental appendix S1 (available online only at http://www.archives-pmr.org/).

Statistical analyses

Descriptive statistics were calculated for stakeholder group demographic and clinical characteristics, and for probability levels for initiating impairment-directed activities. Proportions and means were used to describe categorical and continuous data, respectively. In order to adjust for possible participant-level correlation, mixed models were

Table 1 Study sample clinical practice, demographic, and survivorship characteristics

| Stakeholder Group	n	Years of Practice/Survivorship Mean ± SD	BC Patients Per Week Mean ± SD	Women n (%)	Based at Mayo Clinic
Therapists	10	21.4±14.3	16±14.3	10 (100)	8 (80)
Breast clinic nurses	10	11.4±9.8	25.4±10.5	10 (100)	10 (100)
Breast clinic physicians	10	10.1±8.1	16.3±8.5	10 (100)	10 (100)
Breast surgeons	10	11.4±6.1	13.6±9.2	6 (60)	6 (60)
Breast oncologists	10	12.3±11.7	20.7±9.0	7 (70)	7 970)
Radiation oncologists	10	13.8±14.9	6.8±5.6	5 (50)	4 (40)
Cancer rehabilitation physicians	10	13.5±12.5	10.3±6.1	4 (40)	2 (20)
BC survivors	50	11.4±7.5	NA	49 (98)	NA

Abbreviation: NA, not applicable.
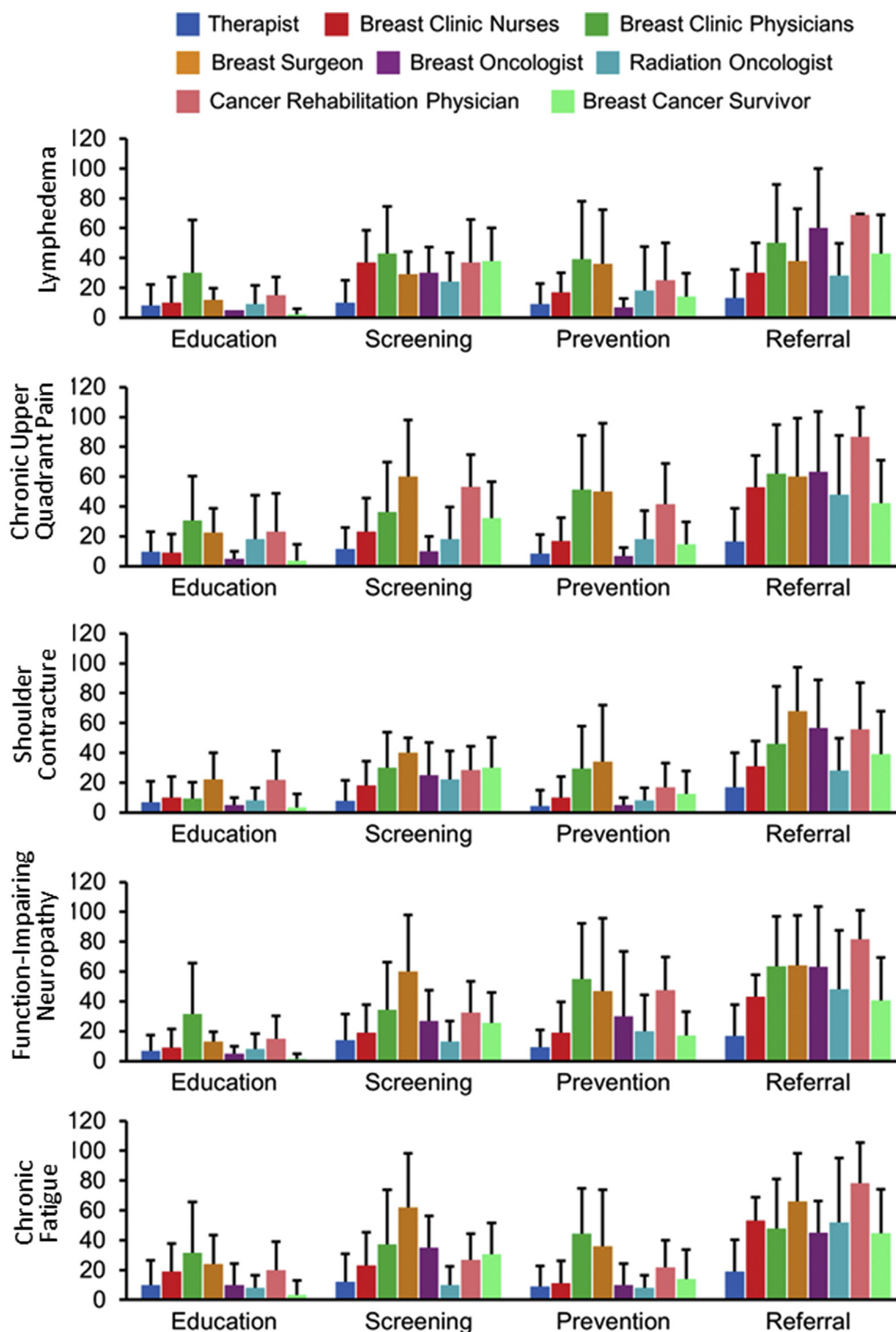
Fig 1 Mean perceived risks or probability levels for initiating activities to prevent BC-related late effects for all subgroups, late effects, and activities.

constructed to estimate associations between collapsed stakeholder groups of BC survivor, physician, and allied health professional (independent variable), and aggregated risk thresholds for general classes or activities to prevent late effects (eg, education and screening).[19] A similar approach was used to estimate differences between BC survivors and clinicians. All analyses were performed using Stata version 14.0.[a]
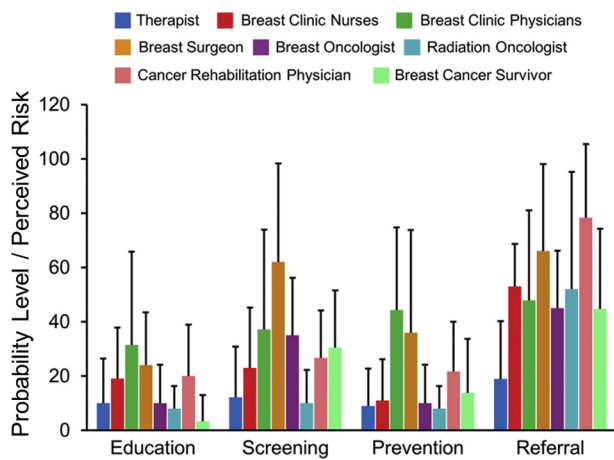
Fig 2 Mean perceived risks or probability levels for initiating each activity to prevent BC-related late effects averaged across late effects for each stakeholder group.

Results

Study sample description

The study sample included a total of 70 BC clinical specialists (10 each from 7 discipline-defined groups: medical, radiation, and surgical oncologists; cancer rehabilitation physicians; physical (n=5) and occupational (n=5) therapists specialized in cancer rehabilitation; and nurses staffing a breast clinic) with mean years of practice ± SD ranging from 10.1-21.4±6.1-14.9 years and mean BC patients per week ± SD ranging from 6.8-25.4±5.6-14.3 patients. As well as 50 BC survivors with mean years as a survivor ± SD: 11.4±7.5 years. The specific breakdown of the types of BC clinical specialists and survivors are listed in table 1.

Figure 1 illustrates each subgroup's mean probability levels for initiating preventive activities across the late effects. Mean probability levels for initiating the different activities were consistently ordered as follows across all subgroups and late effects: education (2.8-27.1), prevention (8.1-44.1), screening (11.1-50.2), and therapist referral (16.4-59.2). BC survivors had the lowest mean probability levels for initiating education for all late effects: lymphedema 2.0±4.0, pain 3.6±10.9, neuropathy 1.4±3.6, contracture 3.3±9.1, and fatigue 3.3±9.7. Therapists, in contrast, had the lowest probability levels for initiating screening: lymphedema 10.0±14.7, pain 11.5±14.0, neuropathy 13.9±16.7, contracture 7.8±12.8, and fatigue 12.2±17.7, and therapist referrals for all late effects: lymphedema 13.0±19.2, pain 16.5±21.1, neuropathy 16.7±19.7, contracture 16.7±22.1, and fatigue 18.9±20.0. Physicians were less consistent. Across the subgroups, physician risk thresholds varied between late effects, activities to prevent late effects, and disciplines. When probability levels for initiating each prevention activity were averaged across the different late effects, as shown in figure 2, physicians generally had higher probability levels for initiating prevention activities. Radiation oncologists were a notable exception, as they endorsed the lowest probability levels among the clinical stakeholder groups for initiating all prevention activities except therapist referral. Breast surgeons stood out as having among the highest probability levels for initiating all prevention activities: education 18.6±14.3, prevention 40.6±38.6, screening 50.2±30.7, and referral 59.2±33.0. Associations between the probability levels or perceived risk at which the subgroups, collapsed to general disciplines (physicians, allied health, survivors), recommended initiating each activity are listed in table 2. Allied health providers had significantly lower probability levels for initiating all activities, except education, than any other group. Physicians had significantly higher probability levels for initiating all activities with the exception of screening.

Table 2 Associations between stakeholder groups and probability levels for initiating activities to prevent BC-related late effects

Reference Group	Stakeholder Group	Coefficient	Std. Err.	P Value
Education				
Physician	Allied health	-9.29	4.65	.05
Survivor	Allied health	6.38	4.81	.18
	Physician	15.67	4.15	<.001
Screening				
Physician	Allied health	-19.09	6.39	<.001
Survivor	Allied health	-17.11	6.61	.01
	Physician	1.97	5.71	.73
Prevention				
Physician	Allied health	-21.23	6.28	<.001
Survivor	Allied health	-4.10	6.49	.53
	Physician	17.13	5.60	<.001
Referral				
Physician	Allied health	-33.72	8.19	<.001
Survivor	Allied health	-17.34	8.46	.04
	Physician	16.37	7.31	.03

Table 3   Differences between BC survivors and clinicians in probability levels to initiative activities to prevent BC-related late effects

Preemptive Activity	Patients	Clinicians	Clinician Coefficient	P Value
	Mean ± SD	Mean ± SD		
Education	2.76±7.96	14.80±19.16	12.04	<.001
Prevention	14.39±16.26	23.53±28.04	9.13	.01
Screening	31.26±21.64	27.28±25.64	-3.99	.17
Specialist referral	41.82±27.91	46.03±33.92	4.20	.27

Aggregating probability levels across all clinical groups and comparing these with BC survivors, as presented in table 3, demonstrated that, with the exception of screening, survivors' levels were consistently lower than clinicians'. However, survivors' levels differed significantly from clinicians' for only 2 of the 4 activities and in these cases the differences were only 12% for education and 9% for prevention.

Discussion

To the best of our knowledge, this is the first study to examine the level of probability or perceived risk that would cause stakeholders to initiate preemptive measures to prevent various types of BC-related late effects. Our findings highlight inconsistencies between survivors' and clinicians' probability levels, as well as between different subgroups of clinicians. Despite inter and intrasubgroup variations, some consistent patterns emerged. First, from lowest to highest, risk thresholds increased monotonically from education, to prevention, to screening, and finally, to therapist referral. Second, BC survivors endorsed lower probability levels than clinicians for initiating most late effects, but the differences were not marked, ≤12%. Third, therapists consistently had the lowest thresholds for initiating late effect prevention activities among the clinical subgroups. Fourth, BC surgeons endorsed either the highest or second highest probability levels for initiating late effect prevention activities among all the clinician subgroups.

The beliefs and assumptions that drive differences in probability levels or perceived risk across stakeholder groups for initiating late effect prevention activities have been limitedly characterized. The issue warrants further study since it suggests that late effect-related care may vary systematically across disciplines in a manner that does not align with patients' preferences and priorities. This is problematic since a strong empirical basis supports initiating exercise, self-monitoring and many other low-risk activities to mitigate BC-related late effects.[12-15]

Study limitations

This study's strengths include its innovation as an initial effort to characterize clinicians' and survivors' probability or perceived risk levels for initiating clinical activities to prevent BC-related late effects, as well as its diverse, multistakeholder sample. The study also has weaknesses that should be considered in gauging its internal validity, including its use of a nonvalidated questionnaire (items were cognitively pretested but lack rigorous psychometric vetting), and exploratory analyses that did not adjust for multiple comparisons. The study's generalizability is constrained by predominant recruitment from a quaternary, National Cancer Institute-designated comprehensive cancer center. Additionally, the findings are restricted to BC. Despite these issues, the findings suggest several themes that warrant further examination and consideration in efforts to systematically address cancer-related late effects. Such themes include the relatively low perceived risk at which BC survivors believe that preventive activities should be initiated, and its contrast with the higher perceived risk at which many clinicians endorse initiating activities, especially referring patients to therapists. Additionally, despite variation, the general congruence of averaged probability levels—survivors' and clinicians' mean levels differed significantly for only 2 of the 4 activities—suggests that survivors' preferences are reasonable and should be considered in clinical decision making.

Conclusions

The probability levels or perceived risk at which BC survivors believe that preventive clinical activities should be initiated to reduce their risk of developing specific BC-related late effects differed significantly from those of both allied health providers and physicians. However, for the most part, these differences were relatively small, and BC survivors' probability levels should be considered as a basis for initiating clinical activities to prevent late effects.

Supplier

a Stata version 14.0; StataCorp.

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