

Breast Cancer Survivor Advocacy at a University Hospital: Development of a Peer Support Program with Evaluation by Patients, Advocates, and Clinicians

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Abstract Peer-to-peer support programs provide unique psychosocial and educational support for breast cancer patients. A Patient Survivor Advocacy (PSA) program was developed by the University of Wisconsin Breast Center (UWBC) to provide support for newly diagnosed patients from peers who had completed primary treatment. In this study, we evaluated patient, advocate, and clinician experience with the PSA program. A program matching volunteer peer advocates at least 1 year removed from primary treatment with newly diagnosed patients was developed. Peer advocates were recruited from the practices of UWBC clinicians and received in-person training on six dimensions of peer advocacy. Trained advocates were then paired based on demographic and medical history with new patients referred to the program. Survey assessment tools were distributed to assess peer advocate and patient satisfaction, as well as clinician experience. Forty patients have been matched with seven advocates, with contact largely by email (53 %) or phone (36 %). Patients and peer advocates reported satisfaction with the program. The majority of patients (92.9 %) reported that the program was "helpful" and that they would recommend the PSA program to another woman with breast cancer. All peer advocates (100 %) responded with a sense of achievement in their advocate roles. Clinicians noted challenges in referral to the program. Peer advocates can provide key emotional and psychosocial support to newly diagnosed breast cancer patients. The

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peer advocate, patient, and clinician feedback collected in this study will inform the future development of this program at our and peer institutions.

Keywords Peer-to-peer · Cancer survivorship · Advocacy

Introduction

Following a cancer diagnosis, the cancer team's traditional focus has been on clinician-to-patient education regarding diagnosis and treatment, often with little attention to social, emotional, or practical difficulties. A significant need exists for both cancer education and psychosocial support in the wake of a cancer diagnosis [1]. To address these needs, cancer support programs have been described in the medical literature since 1981, beginning with the publication of the TOUCH oncology self-help group experience [2]. In the past 30 years, over 90 additional papers have been published reporting institutional experiences with cancer support programs. These programs have been implemented in face-toface settings as one-on-one and group peer support, as well as one-on-one, group phone call interactions, and internet support groups. Variability in program structures, methodologies, and reporting have made comparing cancer support programs and their outcomes challenging. Three systematic reviews [3–5] and 20 randomized controlled trials [2, 6–25] of peerto-peer support programs as a psychosocial intervention have been reported.

The limitations of reported cancer support programs include (1) a paucity of clear measures assessing outcomes relevant to the aims of the intervention, (2) overall failure to demonstrate intervention efficacy at the level of the patients or the medical care team, (3) omission of intervention details pertaining to training, supervision, and documentation of the



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peer support interaction, and (4) lack of long-term follow-up measurements [4, 5]. These evaluations are critical to the rigorous assessment of cancer psychosocial support resources.

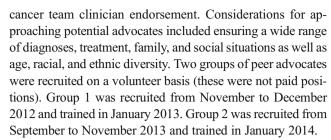
In 2013, the University of Wisconsin Breast Center (UWBC) developed a Patient Survivor Advocate (PSA) program to facilitate peer-to-peer support between those who have completed primary breast cancer treatment and newly diagnosed patients. The primary purpose of this program was to provide peer psychosocial support and education to decrease anxiety in newly diagnosed patients, as well as improve patient-physician interactions and understanding of the steps involved in cancer care. We independently surveyed patients, peer advocates, and UWBC clinicians to assess their experience with the PSA program and report the results here. This study was designed to address three of the four limitations identified among previous reports of peer support literature to date, specifically assessment of aim-relevant outcomes, the mechanism of peer support, and utility of the program to patients, advocates, and clinicians. To address the third limitation, omission of intervention details, we are providing a peer support advocacy toolkit via the University of Wisconsin's HIPxChange, a website for distribution of materials for evidence-based health system change.

Methods

Human Subjects The UW Health Sciences Institutional Review Board (IRB) waived consent for access to existing PSA program demographic and survey data for research purposes. All surveys were conducted anonymously, and as such consent was waived by the IRB.

Program Development Development of the PSA program was informed by the results of UWBC Survivorship Program Focus Groups conducted from January through March 2011. The primary issues identified from the patient focus group sessions included an unmet need to talk with other, vetted survivors who had "been where they are." Distinct from support groups, these peer advocates would have training to meet and address the concerns of a woman with newly diagnosed breast cancer. In response to the results of the focus group sessions, the UWBC received a grant from the Komen South Central Wisconsin affiliate for the development of a navigation and peer support advocacy program. The PSA program is led by a UWBC patient navigator and officially launched in November 2012. It is currently implemented at two UWBC sites, the UW campus hospital (UWHC) and an off-campus UW Health Clinic.

Advocate Selection and Training Women with a diagnosis of breast cancer, who had completed primary treatment at the UWBC greater than 1 year prior, were recruited based on



The UWBC PSA training program was adapted from training materials provided by After Breast Cancer Diagnosis (ABCD). ABCD is a non-profit organization that offers telephone-based support and resources to breast cancer patients. ABCD training materials were created to support phone-based interventions. Thus, the materials required revision to address the range of potential contact types anticipated for our peer advocates (i.e., phone, email, text, or face-toface). Training for each group occurred over 2 days and included orientation, standard hospital volunteer training required by the UW, and themed sessions addressing peer advocacy. Themed sessions explored each of six ABCD topics (diagnosis, treatment, listening/communication skills, emotions, ethics/confidentiality, survivorship) and were presented by UWBC clinicians. ABCD training materials were tailored to provide advocates with guidance for one-on-one telephone and face-to-face support. Training presentations culminated in a group discussion of personal experiences with breast cancer and a group role-play session. Upon completion of the training, advocates received a copy of the ABCD "Mentor Manual, " a collection of additional guidance and resources for support in their role as advocates.

Patient Triage and Referral Process Beginning in May 2013, patients newly diagnosed with breast cancer were referred to the PSA program by UWBC clinicians (physicians, advanced practice practitioners [APPs], and nursing staff) at the time of diagnosis. The UWBC patient navigator matched patients to advocates based on age, type of breast cancer, and life factors (e.g., marital status) identified as important by each patient.

PSA Program Evaluation The UWBC patient navigator prospectively collected demographic and tumor characteristic data for each patient and advocate-patient matching records. To evaluate intervention outcomes, surveys were planned from program conception to assess the PSA program's impact upon three groups: peer advocates, patients, and clinicians. Advocate-patient contact logs were distributed to peer advocates upon completion of training and collected at the time of survey distribution.

The goal of the patient survey was to determine the success of the peer support intervention in addressing previously unmet psychosocial needs, improving patient-physician interactions, and providing a resource for cancer education. Patient



survey questions reviewed individual experience with the matched advocate, impacts on interpersonal communication about cancer, and additional quality-of-life topics. The goal of the advocate survey was to determine the peer advocates' experience and invite feedback to guide the direction of the program. Advocate survey questions included individual experience with matched patients, as well as assessing the PSA training and perceived utility for themselves as well as the new patients. The clinician survey's goal was to assess their experience with the program at the level of new patient referral and impact on patient care, program utilization, and perceived patient benefit. All surveys are available via the HIPXChange (http://www.HIPxChange.org/CancerAdvocacyProgram).

At the time of survey (June 2014), any patients matched with an advocate for more than 1 month and any advocates who had completed training were eligible for survey. All UWBC clinicians were eligible for survey. The patient survey was delivered as paper via postal mail. The advocate and clinician surveys were delivered online through our institutional survey service (UW Qualtrics; http://survey.wisc.edu). Surveys were distributed to all three groups in June 2014 and collated for analysis on a rolling basis.

Analysis Items evaluated by Likert-type scale (1, strongly agree, to 5, strongly disagree) were coded and summarized by frequency and percentage, while open-ended feedback questions were tabulated and summarized. Student's *t* test was used for comparison of the advocate and patient group demographic and cancer/treatment characteristics. Content analysis [26] of these open-ended feedback questions and contact log topics submitted by advocates was conducted to reveal underlying themes among responses.

Results

Demographics Advocate and patient demographics, cancer, and treatment characteristics are summarized in Table 1. Age, diagnosis, and other variables reported here did not differ significantly between the advocate and patient groups when analyzed by t test (p>0.01). This suggests that the two groups share similar distributions of personal and medical history descriptors and that patients and advocates were matched as intended on the basis of these factors.

A total of 14 advocates were trained over two recruitment periods, from November 2012 to December 2012 and September 2013 to October 2013. Between November 2012 and April 2014, 40 newly diagnosed breast cancer patients were referred to the program. Half of patient referrals (20) were from UW physicians, while 18 were from UW nursing staff, in addition to nine self-referrals (this includes overlapping referrals for some patients by multiple clinicians). Six patients (15 %) declined to participate or were removed from the

program after referral but before being matched, and one (2.5 %) was transferred to hospice before being matched. Common cited reasons for referred patients declining the match were that they had too many additional concurrent health issues or "had too much going on." A further eight patients (20 %) were referred to the ABCD program due to lack of suitable UW advocate matches based on the patient's requested need for advice or peer support. The remaining 25 patients (62.5 %) were successfully matched to a peer advocate based on age, type of breast cancer, and other life factors identified as important by each patient. The success in matching patients to advocates was strongest in the category of diagnosis (100 % dyad matching on the basis of receptor status as well as histology), menopausal status (86 %), BRCA1 or 2 mutation carrier status (86 %), and receipt of endocrine therapy (84 %) within each patient-advocate dyad. Patients were distributed unevenly among the active advocates due to variability in advocate availability. Thus, at the time of survey in June 2014, 7 of the 14 trained advocates had been matched with at least one patient and were considered "active" advocates.

Contact and Activity Peer advocates received standardized contact logs and were asked to document their interactions with patients. Of seven active advocates solicited for contact documentation, four returned contact logs to the UWBC, representing 20 advocate-patient dyads. Advocates logged a mean of 7.5 contacts per patient (range 1–47 contacts/patient). Recorded contacts occurred via email (53 %), telephone (36 %), texts (8 %), face-to-face visits (2 %), and cards (1 %). The most common topics were management of emotions such as anxiety and uncertainty, concerns about pre- and post-procedure care, finding balance between treatment and work, family life, and/or interpersonal relationships, complementary/alternative medicine, and information "overload" (Table 2).

Patient Experience Forty patients were referred to the program but seven declined; thus, 33 patients were potentially eligible for survey. However, at distribution of the patient surveys (June 2014), less than 1 month had elapsed since the peer advocate match date of three patients; these three patients were not eligible for evaluation. Thus, 30 patients were mailed surveys, and 14 responded (47 % response rate). Patients were generally positive about their experience with the PSA program, as summarized in Table 3. The majority of patients (92.9 %) report finding the program helpful and that they would recommend the PSA/ABCD program to a woman with breast cancer (92.9 %). Most (57 %) reported planning (agree or strongly agree) to stay in contact with their advocate. Reasons cited for not staying in contact included different communication styles and difficulty finding time. Examples of different communication styles included preferences for text or email compared to phone-based communication, as well as



 Table 1
 Demographic and tumor characteristics

			Peer advocates	Patients	
Age, at diagnosis (mean±SD, range) (years)			50.10±12.22, 27–69	49.06±12.63, 26–75	
Menopausal status		Pre-menopausal	9/14 (64.3 %)	20/33 (60.6 %)	
		Post-menopausal	5/14 (35.7 %)	13/33 (39.4 %)	
Race/ethnicity		African American	2/14 (14.3 %)	2/33 (6.1 %)	
		Hispanic	1/14 (7.1 %)	1/33 (3.0 %)	
		Asian	=	2/33 (6.1 %)	
		Caucasian	11/14 (78.6 %)	28/33 (84.9 %)	
Diagnosis		Invasive cancer	13/14 (92.9 %)	31/33 (93.9 %)	
		In situ	1/14 (7.1 %)	2/33 (6.1 %)	
Hormone receptor status		ER+PR+HER2-	7/14 (50.0 %)	23/33 (69.7 %)	
		ER-PR-HER2+	3/14 (21.4 %)	2/33 (6.1 %)	
		ER+PR+HER2+	2/14 (14.3 %)	6/33 (18.2 %)	
		ER-PR-HER2-	2/14 (14.3 %)	2/33 (6.1 %)	
BRCA status		Negative	13/14 (92.9 %)	30/33 (90.9 %)	
		Positive	1/14 (7.1 %)	3/33 (9.1 %)	
Surgery	Breast	Lumpectomy	5/14 (35.7 %)	13/29 ^a (44.8 %)	
		Mastectomy	9/14 (64.3 %)	16/29 ^a (55.2 %)	
	Reconstruction	No	7/14 (50.0 %)	18/29 ^a (62.1 %)	
		Yes	7/14 (50.0 %)	11/29 ^a (37.9 %)	
Radiation therapy		No	4/14 (28.6 %)	9/30 ^a (30.0 %)	
		Yes	10/14 (71.4 %)	21/30 (70.0 %)	
Chemotherapy		None	2/14 (14.3 %)	14/32 ^a (43.8 %)	
		Chemo only	7/14 (21.4 %)	13/32 ^a (40.6 %)	
		Chemo+Herceptin	5/14 (57.1 %)	6/32 ^a (18.8 %)	
Hormone therapy		No	5/14 (35.7 %)	13/32 ^a (40.6 %)	
		Yes	9/14 (64.3 %)	19/32 ^a (59.4 %)	

ER estrogen receptor, PR progesterone receptor, HER2 human epidermal growth factor receptor 2, SD standard deviation

cases where the patient and advocate life experiences did not match although the diagnoses did. Patients reported that contact with advocates improved communication with family (57 %) and friends (57 %) and the healthcare team (50 %). Contact with advocates helped patients make treatment decisions (57 %), increased their confidence in making treatment decisions (57 %), and provided information about resources available for breast cancer (50 %). Eleven respondents provided free response feedback (see Supplemental Material). The majority (80 %) of responses were positive.

Two negative responses suggested that "commonality of life experience" and geographic distance from the patient to the advocate (to facilitate face-to-face meeting) be considered in future matching criteria.

Peer Advocate Experience Response rate to the online advocate survey was 71 % (10/14). Advocates were generally positive about the PSA program. Respondents reported a sense of achievement from being part of the PSA program (100 %),

receiving adequate support from the UW staff (90 %), and that the training prepared them to be a peer advocate (80 %). Most advocates (89 %) felt that they had made a difference to their patient match(es). Advocates identified medical updates (90 %) as the top choice for future PSA training topics, followed by integrative medicine (50 %). Most advocate respondents (90 %) provided additional free response feedback, with themes centered around training and cancer education (78 %) and/or the outreach experience, and how they impacted both patients and advocates (33 %).

Clinician Experience The clinician response rate to our clinician utilization survey was 15/36 (41.7 %). Survey respondents included five MDs, one nurse practitioner, six nurses, one medical assistant, and one UWBC scheduler. Of 15 survey respondents, six had referred patients to the program. Half of the referring clinicians were "heavy referrers," having referred five or more patients. To assess areas for improvement, the survey asked clinicians about the perceived barriers to



^a At the time of survey, some patients were undergoing neoadjuvant therapy and and had not yet decided on elements of treatment, such as surgery, radiation or chemotherapy

Table 2 Survivor advocacy themes: in training and in practice

Advocate training themes

Patient/peer advocate contact themes

Treatment

Breast cancer diagnosis and treatment

- Presenters: UWBC Director (LGW)^b and UWBC medical oncologist (AJT)^b
- Topics: breast cancer screening and genetics; medical, surgical, and radiation therapies for breast cancer; breast reconstruction; shared patient-clinician decision making

Emotional and social support

Breast cancer and emotions

- Presenter: health psychologist^a
- Topics: breast cancer and depression; resources including psychosocial support groups, counseling, family, friends

Survivorship and self-care

- Presenters: UWBC Director (LGW)^b, UWBC medical oncologist (AJT)^b, and ABCD Executive Director^c
- Topics: stages of survivorship (acute, extended, and permanent);
 resources for survivorship, including a sample survivorship care plan

Interpersonal

Listening and communication skills

- Presenters: UW Oncology and Palliative Care Chaplain^{a, b} and UWBC clinic coordinator^{a, c}
- Topics: empathy and active listening; how to communicate well in person and over the phone; communication styles

Confidentiality and ethics

- Presenter: ABCD Executive Director^a
- Topics: legal and ethical issues in meeting and managing expectations as a peer advocate; liability and confidentiality

Pre- and post-procedure care

- Topic of 18 % of patient/survivor advocate contacts
- Example advocate quote: "Preparing/managing aftercare for diagnostic procedures, lumpectomy, radiation, and chemo-induced neuropathy."

Complementary medicine

- Topic of 8 % of patient/survivor advocate contacts
- Example advocate quote: patient and survivor advocate discussed "acupuncture, yoga, medication, natural vitamins, smooth and juice drink recipes."

Emotions, anxiety, and uncertainty

- Topic of 34 % of patient/survivor advocate contacts
- Example advocate quote: "[The patient] starts chemo today and is frightened
 at the prospect. In addition to letting her know that asking for help is not a
 sign of weakness, I also suggested that she use meditation and deep
 breathing techniques to reduce her anxiety."

Information overload

- Topic of 11 % of patient/survivor advocate contacts
- Example advocate quote: "[We discussed] managing information overload with diagnosis and treatment options, [and] understanding information offered at visits."

Balancing treatment with work, life, and relationships

- Topic of 11 % of patient/survivor advocate contacts
- Example advocate quote: "[a] topic that has been discussed on each of my
 calls is how I responded to chemo and if I worked during or could maintain a
 somewhat 'normal' work schedule."
- Example advocate quote: "Reprioritizing work/family responsibilities to care for self."

referral to the PSA program. The most common barrier reported by clinicians was forgetting to discuss the PSA program during face-to-face clinic visits. Common issues also included not having enough time (20 %) or referral materials on hand (20 %). Other issues identified by clinicians were uncertainty about which patients to refer to the program, which clinicians were most suited to refer to the program, and that patients were too overwhelmed in clinic by information about their diagnosis to discuss the program.

Discussion

The first year of the UWBC PSA program saw the successful development and implementation of a peer-to-peer psychosocial support program for newly diagnosed breast cancer patients. Patient and advocate survey responses suggest the PSA program fulfilled an unmet need on the part of our breast

cancer patients. Self-reported experiences from these two groups are favorable. Peer advocates are highly satisfied with the in-person training they received and expressed interest in continuing education, highlighting medical updates and other areas related to cancer education. Advocates requested this additional education so that they could better understand concerns or questions arising during their discussions with patients. For instance, if a new drug such as pertuzumab could be administered, the advocates felt that they should understand what it is and why it might be offered so that they could correctly contextualize. The advocates were specifically trained to not misrepresent their education level on topics and also to direct patients back to the appropriate clinicians for questions "out of their depth." We aim to incorporate these interests into future iterations of PSA training and assessment.

Our program uniquely encourages peer advocate and patient involvement in the design and evaluation of this intervention. The UWBC PSA program evolved from the



^a Speakers who are not authors on this report whom we have therefore left unnamed

^b Presenter at January 2013 advocate training session only

^c Presenter at January 2014 advocate training session only

Table 3 Patient and peer advocate survey results

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Patient responses	I plan to stay in contact with my advocate.	3/14 (21.4 %)	5/14 (35.7 %)	4/14 (28.6 %)	2/14 (14.3 %)	_
	It was helpful to have the advocate make the first contact with me.	8/14 (57.1 %)	6/14 (42.9 %)			_
	I received a call from my advocate in a timely manner.	9/14 (64.3 %)	5/14 (35.7 %)	-	-	_
	I found the program ^a helpful.	7/14 (50.0 %)	6/14 (42.9 %)	1/14 (7.1 %)	_	_
	I am satisfied with my experience with the program ^a .	8/14 (57.1 %)	5/14 (35.7 %)	1/14 (7.1 %)	-	_
	I would recommend the program ^a to a woman with breast cancer.	8/14 (57.1 %)	5/14 (35.7 %)	1/14 (7.1 %)	=	_
Peer advocate responses N=10	It was helpful to have patient information prior to making a phone call.	8/10 (80.0 %)	=	2/10 (20.0 %)	=	-
	I feel a sense of achievement from being part of the PSA program.	9/10 (90.0 %)	1/10 (10.0 %)	-	-	_
	The training prepared me for my role as a peer advocate.	8/10 (80.0 %)	2/10 (20.0 %)	-	-	_
	I feel that I made a difference to those patients I contacted	6/9 ^b (66.7 %)	2/9 ^b (22.2 %)	1/9 ^b (11.1 %)	-	_
	The UW staff supported me in my role as a peer advocate.	9/10 (90.0 %)	1/10 (10.0 %)	_	_	-
	It was helpful for the UW staff to contact the patient for me, rather than having the patient call me on her own.	5/10 (50.0 %)	1/10 (10.0 %)	4/10 (40.0 %)	-	_

^a The patient survey instructed them to consider both the ABCD and PSA program in replying to this question, if they had contact with both

recommendations of breast cancer patients invited to focus groups hosted by our institution and was developed to address specific unmet needs identified by focus group participants. The survey tools, results, and conclusions reported here were informed by the direct involvement of two active peer advocates (DD and MS) and are focused first and foremost on assessment of patient satisfaction with the PSA program and future directions for improvement of this intervention. Moreover, we address gaps in the published peer-to-peer support program literature [4, 5] by transparently reporting the aims, training and survey methodologies, contact documentation, and overall impressions of our PSA program. We have reported our recruitment and referral strategies, the timelines associated with these activities, the training materials used by our institution in the preparation of women for their role as advocates, and the survey tools we utilized for interim quality assessment of the PSA intervention. These resources are available as a toolkit at HIPxChange (http://www. HIPxChange.org/CancerAdvocacyProgram). We hope this toolkit will inform the development of cancer psychosocial support infrastructure at other institutions. We found only three published precedents for one-to-one patient-advocate contact [23–25], with the majority of cancer peer support program publications to date describing group-based support [2, 6-10, 12-22]. Unlike the prior studies, we provide a detailed description of the peer advocate training, report the common underlying themes of documented patient-peer advocate interactions, and make available the survey tools used in our assessment of patient, peer advocate, and clinician experience. A key element of this program is the in-person training provided to advocates.

One limitation of this study is that we are not able to assess the impact of variables in program design on peer advocate and patient outcomes. These variables include advocate training requirements, mode of patient referral to the program, patient-advocate matching criteria, mode of initial patient-advocate contact, number of patient-advocate contacts, and level of supervision of patient-advocate contacts by the UWBC navigator. These elements of the program may contribute significantly to the experience of the advocates and patients, and their optimization in a prospective trial would allow for determination of the best way to deliver this intervention. A second limitation of the study is the small sample size due to relatively low survey response rates for patients and clinicians.

During the course of development and implementation of this program, we learned several key lessons. We offer these here for the benefit of those who might undertake a similar project. One challenge to our PSA program is a lower-thanexpected referral rate. There are many possible reasons for a



^b A question skipped by one of the ten peer advocates who responded to this survey

patient to express disinterest in, or be inappropriate for, a peer support program. These may include discomfort with discussing one's health with another individual who is not a medical professional; a desire to avoid appearing "needy"; and not having enough time for the program. We identified issues with clinician referral, such as variable familiarity with the PSA program across our UWBC sites. Other barriers to clinician referral were cited as short clinic visits, lack of referral materials, and simply not knowing enough about the program. Advocate and patient survey responses additionally provided useful feedback critical to refinement of the program. Patients suggested that the emotional and geographic compatibility of the patients and peer advocates be considered in the matching paradigm. This input is being used to inform future patientadvocate matches: an additional 21 patients have been matched with six advocates since April 2014. Finally, we were not able to assess the program's impact on nursing burden. One envisioned impact is to allow redirection of the UWBC nursing staff efforts away from counseling patients and toward other elements of patient care. The intent here is not to replace clinician-patient interactions but to potentially redirect the nature of this care. For instance, nursing may currently be utilizing patient interaction time to discuss navigating the hospital, whether to bother with a wig or prosthesis, as well as managing patient anxiety or general "hand-holding." Some of these discussions do not require specific medical expertise and would even arguably be more meaningful from an advocate who has "been there." However, no mechanism exists to easily evaluate the impact on nursing effort allocation. Nursing burden is difficult to measure, and the current methodologies commonly employ qualitative scales for self-reporting of perceived clinician burden [27]. Addressing this limitation would require the development of a novel methodology to assess nursing burden through examination of nursing time dedicated to psychosocial support versus medical care.

In conclusion, future directions of this program include increased recruitment of advocates and referral of patients and raising awareness of the PSA program among clinicians at our institution.

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