Current Breast Cancer Reports (2021) 13:19–27
https://doi.org/10.1007/s12609-020-00402-y

LYMPHEDEMA INCIDENCE, PREVENTION AND TREATMENT (J ARMER, SECTION EDITOR)

Surveillance Protocols for Survivors at Risk for Lymphedema

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Accepted: 17 December 2020 / Published online: 7 January 2021

Abstract

Purpose of Review Breast cancer treatments introduce risk for developing lymphedema. There are identifiable tissue and sensory changes that are associated with the onset of breast cancer–related lymphedema (BCRL) that can enhance early identification and treatment of the condition. Therefore, there exists an unprecedented opportunity to employ surveillance protocols to monitor for the earliest signs and symptoms of the condition.

Recent Findings Standardized methods for prospective surveillance have been investigated and show effectiveness in promoting early identification and early management of BCRL. Furthermore, there is emerging evidence that this approach can support broad assessment of physical function for individuals with breast cancer, improving quality of life and potentially reducing cost associated with treatment-related morbidity.

Summary This article provides an overview of the prospective surveillance model (PSM), an optimal framework for early identification of BCRL in individuals at risk, shares implementation strategies across two different cultures, and suggests future direction for research and clinical practice to enhance implementation.

Keywords Prospective surveillance model · Physical impairment · Lymphedema · Early detection · Risk reduction

Introduction

Although the risk of breast cancer–related lymphedema (BCRL) has diminished in the era of sentinel lymph node procedures, there remains between a 6 and 24% incidence rate of lymphedema [1]. BCRL risk is related to the antineoplastic treatment modalities [2], as well as surgery and individual risk factors [3]. The onset of the condition may be slow and gradually progressive over time or may be related to an incident such as an infection or injury to the affected limb. Either of these situations warrants protocols and clinical pathways that enable surveillance for the onset of BCRL among other treatment-related morbidities [4]. Every woman who has lymph nodes removed or irradiated as a part of breast cancer treatment is at risk for lymphedema and should be monitored on a surveillance schedule that uses standardized measurement methodology and offers consideration to the individual's self-reported symptoms. Risk differs among individuals, however, and risk stratification can inform a clinical pathway and optimal timing and intensity of monitoring for the condition.

Surveillance protocols for lymphedema detection rely on the premise that repeated, interval assessment using standardized methodology and measurement will enable an early identification of sensory and swelling symptoms that can be conservatively managed and prevent the progression to a more severe condition [5]. Even if the surveillance program misses the earliest onset of tissue changes suggestive of lymphedema, there is still rationale and evidence to suggest that the condition is better controlled and managed than without early intervention [6]. A surveillance program also enables the patient to have a consistent point of follow-up and a known health care professional contact for outreach if they do develop issues

This article is part of the Topical Collection on *Lymphedema Incidence, Prevention and Treatment*

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such as infections or swelling episodes. Having such follow-up may actually reduce anxiety about lymphedema risk [7].

The prospective surveillance model (PSM) is identified as an optimal framework for early identification of symptoms consistent with the onset of lymphedema, as well as other breast cancer–related sequelae [8, 9]. The PSM improves early identification and facilitates early, conservative management of BCRL [10]. The model has been validated in numerous trials [11–14] and is considered a standard of care in lymphedema treatment guidelines [15–17].

Prospective Surveillance Model

The model of care for breast cancer focuses on the treatment of the disease, followed by ongoing surveillance to detect recurrence. Providing a comprehensive plan for morbidity surveillance and monitoring offers the potential to prevent or limit secondary complications and can result in improved survivor quality of life and a significant decrease in economic burden both for the survivor and our healthcare systems [18–20]. This approach is heralded as an optimal construct to promote precision follow-up care and supportive care for cancer survivors [21, 22].

Timeline and Components

The PSM is a comprehensive model for cancer survivorship care that focuses on improving physical and functional status throughout the cancer treatment continuum. The PSM has three goals: (1) To establish an interval surveillance program that enables repeat assessment points over time to promote early identification of changes indicative of emerging functional impairment; (2) to facilitate engagement with individuals diagnosed with cancer for education and guidance to maintain function through treatment; and (3) to direct rehabilitation for physical impairments related to cancer.

The PSM is initiated at the time a breast cancer diagnosis is made. All survivors are seen for baseline (pre-operative/pre-medical intervention) assessment and seen then again at regular intervals post-operatively throughout medical treatment. Table 1 outlines the phases of the PSM and considerations for assessment and interventions in each phase. The components of the PSM during the initial breast cancer diagnosis and treatment planning phase include pre-operative rehabilitation, which consists of skilled evaluation and patient-centered education. The assessment consists of baseline measures of upper extremity and trunk range-of-motion and strength; limb volume and/or tissue assessment; activity and participation level; performance restrictions; pain, fatigue, and other symptoms; overall functional performance; and weight [10, 26]. The health promotion educational components include advice for physical activity and function through cancer treatment, the provision of post-operative exercise prescription, education on post-operative care, an assessment of premorbid conditions that impact function, and assessment of weight and weight management strategies [8].

The next checkpoint occurs during the post-operative period. It includes a repeat of the baseline measures with consideration for the individual's cancer treatment plan and their behavioral characteristics and preferences. The individual's activity limitations are assessed, and a tailored exercise program is prescribed based on their needs. If the individual is experiencing significant morbidity, referral to an appropriate exercise or rehabilitative program is provided. If no impairments are detected, then the PSM continues on its preset timeline for the next follow-up visit.

The last phase includes ongoing surveillance with adjuvant treatment and survivorship care. Assessment measures are repeated and assessed for change. Frequency and duration of interval follow-up is survivor-specific with a multidisciplinary approach proving optimal. Also, the survivor is assessed for neuropathy, bone health, and arthralgias, along with cardiovascular/cardiopulmonary concerns.

The PSM should be considered a clinical pathway for individuals undergoing cancer treatment. Ongoing monitoring and assessment of multiple body systems, function, and participation in activities is conducted, so that the earliest signs of impairment can be identified and the appropriate interventions or referrals can be made.

Time to Onset of BCRL

The time to onset of BCRL is variable, with a 5-year cumulative incidence of 13.7% [27]. Patients receiving axillary lymph node dissection (ALND) with regional lymph node radiation (RLNR) experienced the highest 5-year rate of lymphedema (31.2%), followed by those receiving ALND without RLNR (24.6%), and sentinel lymph node biopsy with RLNR (12.2%). The risk of lymphedema peaked between 12 and 30 months post-operatively; however, the time course varied as a function of therapy received. The researchers concluded that the time course for lymphedema development depends on the breast cancer treatment received, with ALND being associated with early-onset lymphedema, and RLNR is associated with late-onset lymphedema. These results can influence clinical practice to guide lymphedema surveillance strategies and patient education at more specific timelines with surveillance for at least 3 to 4 years post-operatively.

PSM and Evidence for Early Identification of BCRL

One of the most successful demonstrations of the effectiveness of the PSM is in promoting the early identification and

Table 1 Phases of the PSM and considerations for provider decision-making

Pre-operative baseline	Interval surveillance through active treatment	Continued surveillance through survivorship
Assessment Upper quadrant: - Functional movement patterns - Strength - Activities of daily living - Sensation - Tissue and limb assessment (limb volume or extracellular fluid) Pre-existing pain, fatigue, gait, or mobility issue. Performance status. Self-reported physical activity level and interest in exercise. Weight	Assessment Upper quadrant: - Functional movement patterns - Strength - Activities of daily living - Sensation - Tissue and limb assessment (limb volume or extracellular fluid) New onset of pain, fatigue, gait, cognitive, or mobility issue. Performance status. Self-reported physical activity level, barriers to exercise. Weight	Assessment Upper quadrant: - Functional movement patterns - Strength - Activities of daily living - Sensation - Tissue and limb assessment (limb volume or extracellular fluid) New onset or persistent pain, fatigue, gait, cognitive, or mobility issue. Performance status. Self-reported physical activity level, barriers to exercise. Weight
Education Basic education regarding treatment plan and ongoing functional assessment. Awareness of common cancer treatment-related morbidity and interventions to manage them. Provide exercise recommendations for therapeutic exercise post-operatively and for ongoing health maintenance throughout treatment [23].	Education Follow-up plan of care and treatment plan for ongoing assessment of function. Awareness of signs and symptoms of adverse events and when to expedite follow-up care. Reinforce exercise recommendations and provide resources to support continued activity and health maintenance [23, 24].	Education Progression of activity, return to social, recreational, vocational, and other roles. Awareness of signs and symptoms of adverse events and when to expedite follow-up care. Exercise and activity progression, independent monitoring of exercise and activity, healthy lifestyle choices [24, 25].
Risk-based decision points If pre-existing impairments are present consider interventions and referrals to alleviate condition prior to initiating cancer treatment. For individuals with multiple co-morbidities consider more frequent follow-up during treatment and assess need for additional referrals. Individuals with multiple co-morbidities, higher stage disease, and more extensive treatment plans should be followed with greater frequency. Personal factors such as health literacy, socioeconomic status, employment status, and family support should inform frequency of follow-up and educational strategies.	Risk-based decision points Assess severity of new onset symptoms or impairments for severity and manage through intervention or appropriate referral. At intervals when treatment changes or transitions in care occur, assess tolerance to new interventions, and identify adverse effects on function. Individuals with high co-morbidity burden, more severe disease stage, or more severe side effects of disease treatment should be followed with greater frequency. Significant changes in personal factors including changes in family support, employment security or status, housing status, food insecurity, and financial stress should inform referrals for supportive services.	Risk-based decision points Assess persistent or lingering impairment if condition is worsening, limiting activities of daily living, or restricting participation in roles and provide intervention or appropriate referrals. Individuals who are on continuous antineoplastic therapies should be followed with greater frequency. Individuals who have a high burden of functional sequelae after treatment, experience greater disability, or have greater anxiety or distress about function should be followed with greater frequency. Stability of personal factors should inform referrals for supportive care services.

management of BCRL. The model was initially validated for detecting early lymphedema in a prospective cohort study [10] and the findings replicated in further trials [12–14, 27–30]. The model provides a standardized framework for lymphedema screening and assessment and various aspects of the model's phases and measurement techniques verified through additional research.

Sun et al. sought to quantify the necessity of a pre-operative baseline measurement through PSM. Pre-operatively, 28.3 and 2.9% of patients had arm asymmetry of ≥ 5 and 10%, respectively. In the absence of incorporating pre-operative baseline measures into BCRL diagnosis, 41.6% of patients were under-diagnosed and 40.1% over-diagnosed at RVC ≥ 5%, increasing to 50.0% under- and 54.8% over-diagnosed at RVC ≥ 10% [31]. Blaney et al. also noted the importance of pre-surgical quantification of inter-limb variance in achieving an accurate and early diagnosis of BCRL [29]. Absent baseline comparisons, a large percentage of survivors are at risk of being undiagnosed or misdiagnosed, both of which could have significant implications on quality of life and psychological well-being. Work by Hahamoff et al. reported on the importance of the model to enable more definitive risk

assessment and evaluation of individuals at high risk in order to prompt early detection and reduce the progression of the condition [32].

Evolving evidence suggests that surveillance and early detection through PSM may be associated with lower incidence and severity of BCRL when compared with a traditional referral model of care. Koelmeyer et al. reported that women in a surveillance group received lymphedema care significantly earlier than those in the traditional referral group and that those in the traditional referral group were diagnosed with clinical lymphedema (stage I–III, 39% vs. 14%; $P < .001$) and with greater severity (stage II–III, 24%) compared with those in the early surveillance group (4%) [6]. Further studies by Kilgore et al. [30] and Soran et al. [18] show that early conservative intervention for breast cancer patients at high risk for BCRL who were prospectively monitored presented with significantly lower rates of BCRL [30] and that periodic monitoring of women at high risk for lymphedema reduced the incidence of clinical lymphedema [18]. While these trials demonstrate the model's effectiveness in diagnosing lymphedema, questions remain regarding the sensitivity of diagnostic thresholds and the timing of intervention based on limb and tissue changes to assure optimal treatment of lymphedema.

PSM also impacts long-term survivorship. Longitudinal cohort studies of survivors with incident breast cancer reveal that survivors with BCRL used greater than 30% more services annually. While utilization lessened over time, the increase persisted for at least 10 years after diagnosis suggesting that BCRL may be a driver of survivors' healthcare utilization [33]. BCRL also has a profound impact on long-term vocational roles, relationships, and social functions [34]. Women who experience disablement related to chronic lymphedema report changed relationships with colleagues and superiors, required adaptations to their workplace, and even changed vocation due to their disability, suggesting substantial impact on work and professional life throughout survivorship.

Early Identification of Impairment: Impact Beyond Lymphedema

The PSM as a clinical pathway brings value to the healthcare delivery system beyond just early identification and treatment of a single impairment like BCRL. The model supports patient management through improved physical function and quality of life. As a clinic management tool, this pathway can improve clinical workflows by creating efficiencies, reduce overutilization of resources, and improving costs.

Physical Function

Patients at highest risk of lymphedema, specifically those who have undergone nodal surgery or regional nodal radiation, are also at highest risk of impaired function [1]. In fact, up to 51% of patients experience pain and/or impaired range-of-motion up to 6 years after their surgery [35]. It should be noted that the median time to onset of lymphedema is approximately 3 years, but it may develop at any point post-operatively [27]. Clinicians should be knowledgeable of the side effects of chemotherapy and radiation, which bear substantial negative impact on patients' activities of daily living and need to be addressed [35, 36].

As patients who are treated for breast cancer are at higher risk of shoulder morbidity, it is important for the clinician to consider high potential for functional impairments in later-stage lymphedema, when the weight of the extremity increases pulling on the chronically weakened joints of the shoulder, resulting in a cycle of increasing shoulder pain and impaired function. Furthermore, issues such as fatigue [37], peripheral neuropathy [38], upper quadrant function [39], and falls [40] are prevalent; when BCRL is detected and managed early, such as through the PSM, this can prevent functional decline and disability.

In addition to alleviated swelling, the PSM may be used to interrupt the cycle of disability caused by lymphedema. There is evidence that early intervention with compression therapy may prevent progression to BCRL, thereby interrupting the cycle of the disablement process and limiting functional impairments associated with later-stage BCRL [10, 11, 18, 28, 41, 42].

Quality of Life

BCRL is a highly feared sequela of cancer treatment, even for those at low risk. A prospective study of 120 women found that at 6 months post-operatively, 75% and 52% of patients undergoing axillary lymph node dissection (high risk) and sentinel lymph node biopsy (lower risk), respectively, reported worry about developing BCRL, which was sustained at 12 months (both $P > .45$) [43]. It is important to address this fear in order to maximize quality of life for patients at risk.

There is abundant evidence that patients with lymphedema have decreased quality of life [44, 45]. Specifically, patients who have been measured as having lymphedema [46], patients who are symptomatic (with or without lymphedema), or who perceive lymphedema (in absence of objective diagnosis) [47], have poorer quality of life [48]. This impaired quality of life may manifest as fear, anxiety, frustration, sadness, decreased self-confidence, impaired body image, and self-consciousness. It affects social and leisure activities (55%) and has sexual ramifications [49]. These effects lead to elevated rates of depression and anxiety in those with

BCRL [50, 51]. Patients with BCRL may experience significant impairments in quality of life, even with early-stage lymphedema, or those with later-stage lymphedema may report minimal effect on quality of life, as severity of lymphedema is not directly correlated to its impact on quality of life [52].

When patients receive treatment within a screening-based model of care, this improves access to timely treatment and patient education, validating patient fears and concerns which they often feel have gone unaddressed by the medical team [53, 54]. Timely diagnosis and treatment are imperative in order to successfully manage BCRL [10], and improvements in depression and anxiety have been shown following treatment [55].

Cost

The healthcare utilization and out-of-pocket patient costs of BCRL are high. Cheville et al. found that, in a cohort of 1800 patients treated for BC with or without BCRL, those with BCRL used > 30% more services annually and this increased utilization persisted for at least 10 years [33].

Most studies do not address direct out-of-pocket expenses for women with BCRL, including co-payments for BCRL treatment or hospital admissions, cost of compression garments, or antibiotics for cellulitis. Boyages et al. [20] found that 56% of women with BCRL reported financial impact of BCRL, and that these costs increased with BCRL severity. The costs of compression garments formed 40.1% of these costs, and the average out-of-pocket cost was AU$977 per annum, up to AU$1400 for severe BCRL. Patients commonly reported high cost of garments and lacking governmental or insurance coverage. A qualitative Canadian study also reported lack of financial support for compression costs [56]. Contrary to the USA, both Australia and Canada have socialized healthcare, but patients still experience a lack of coverage for compression, a mainstay of lymphedema management [57].

Early intervention, which is feasible within the PSM, is hypothesized to reduce the need for intensive treatment and therefore to be cost-saving [19, 33, 58]. Stout et al. found that the direct cost (intervention and supply) to manage early-stage BCRL per patient per year using a prospective surveillance model was $636.19, versus managing late-stage BCRL using an impairment-based model at a cost of $3124.92 [19].

Women face significant financial burden due to BCRL, a lifelong sequela of BC treatment. Timely diagnosis and treatment of BCRL are imperative in order to provide more cost-effective, conservative approaches to BCRL while maximizing patient outcomes [19, 33, 58].

Implementation Strategies

A decade of clinical research supports the efficacy and effectiveness of the PSM. However, to translate this model into a standard of practice requires targeted strategies in dissemination and implementation, including systematic monitoring, evaluation of programmatic outcomes, and adaptation of the model as required by the specific setting.

Implementing the model requires an understanding of the work flow for clinical implementation and the supporting evidence for its effectiveness in promoting referrals to appropriate services. An evaluation of the barriers and facilitators that exist in a particular setting will influence the implementation, as will the preparation needed to adopt the model [59]. Putting into place the necessary collaborations, policies, funding, and supportive procedures and processes are necessary to deliver the program on a large scale with fidelity.

The extant body of evidence supporting the PSM's clinical effectiveness provides some insight to the barriers and facilitators for the model's implementation; however, more formal research is needed in this regard. Table 2 outlines identified barriers and facilitators, extrapolated from the lymphedema and cancer survivorship literature, that should be considered regarding PSM implementation.

Table 2 Barriers and facilitators for consideration when implementing PSM [60–65]

Barriers	Facilitators
• Cost-centered silos in healthcare systems. • Prevailing urgent needs of medical management in cancer care reduce the focus on symptom management. • Lack of familiarity with tools that can enable screening and assessment. • Inadequately trained workforce. • Lack of proximity of rehabilitation providers to oncology care.	• Increasing focus on early symptom management in cancer care and promotion of models of care that facilitate prospective, precision survivorship care. • National policy priorities have identified the need for services. • Patients report they want and need this service. • Organizational benefits of increased patient satisfaction.

To facilitate improved preparation across the field of rehabilitation medicine, we highlight two successful implementation cases, one in Karachi, Pakistan, and one in Boston, MA, in the USA. Table 3 highlights the components of their programs. Aga Khan University Hospital (AKUH) is a tertiary-care hospital providing a full range of care for specialty diseases and conditions with multi-specialty outpatient clinics meeting a wide variety of patient needs. Massachusetts General Hospital (MGH) is a tertiary-care hospital and conducts the largest hospital-based research center in the world. Each of these centers has implemented PSM using similar strategies, but have adapted the model to suit their particular environment and needs.

Both institutions cite a multidisciplinary team-based approach as a key facilitator to implementing the PSM. Both centers leverage partners in the oncology professional disciplines, albeit from different specialty disciplines, to support the structure and function of the model. While the team-based approach is optimal, centers often struggle with a lack of an adequately trained workforce. A specialty-trained workforce is necessary to meet the needs of the oncology population [68]. In Pakistan, there is a substantial deficit in trained tertiary-level professionals dedicated to BCRL. In 2018, there were only four identified professionals in Pakistan [69]. To address this deficit, AKUH has developed a training program for nurses and physiotherapists to implement their screening program. In general, there is a need for post-graduate training programs to incorporate elements of knowledge and skill building in oncology and lymphedema [70, 71]. International certification programs in lymphedema management can enable a robust workforce to carry out this mandate.

The policies and procedures that are put in place to specifically assess patients through the continuum of care are the most critical points to address. The clinic workflow is a critical factor to develop and requires procedures that standardize the model, the content of educational materials, the measurement methods for each interval visit, and the thresholds for intervention. The MGH program has published their lessons learned from establishing the PSM, including the measurement methodology, standardization of their workforce training, and funding [9].

Lastly, measures of program success are necessary to validate the effectiveness of the model and can be used to re-evaluate needed programmatic changes. Measures that quantify the success or impact of a screening program may include the following: proportion of patients screened who received a pre-operative baseline measurement; duration of time between diagnosis of BCRL and initiation of treatment; response to

Table 3 Implementation use cases for PSM

Factors influencing implementation	Aga Khan University Hospital in Karachi Pakistan	Massachusetts General Hospital in Boston, MA, USA
Multidisciplinary	Breast Surgery Department	Physical and Occupational Therapy
Partners	Physiotherapy and Rehabilitation Department	Radiation Oncology
Workflow	All patients undergoing mastectomy and axillary node resection undergo a pre-surgical assessment by the surgical nursing team consisting of standardized girth measurements permitting extrapolation of limb volume.	Baseline pre-operative perometry measurement is a goal for all patients treated for breast cancer.
	Following surgery patients participate in two sessions of physiotherapy: the first visit occurs 2 weeks following surgery and the second, 3 months later.	Patients are screened with perometry and the Lymphedema Symptom Experience Index [66] every 3–8 months, with clinical examination as indicated, with a median follow-up of 3.4 years [9].
	Each visit includes clinical assessment of standardized girth measurements permitting extrapolation of limb volume; range-of-motion and grip strength; documentation of self-reported signs and symptoms, if any; photographs of the upper limbs; and completion of the Lymphoedema Life Impact Scale Version 2 [67].	Timepoints for screening visits coincide with oncology follow-up visits, so as to minimize the need for isolated BCRL screening visits.
	Patients are asked to submit photographs of their upper limbs every 3 months, and these are compared to the photographs obtained immediately following surgery, through 3 years of survivorship. If physiotherapists suspect BCRL, the patient is asked to attend an in-person or tele-consultation	Patients are encouraged to contact the team should they suspect the development of BCRL.
	Patients are extensively educated on individual risk factors for developing BCRL and provided with educational resources. They are taught the signs and symptoms of BCRL so as to enhance early diagnosis of BCRL. Patients are followed from pre-operative baseline through 3 years.	All patients are extensively educated on individual risk factors for developing BCRL and are provided with educational resources. They are educated on the signs and symptoms of BCRL.

treatment; the impact of self-management and quality of life, including patient perception of the effects of prospective screening; and cost of screening versus a traditional model of care. Programmatic goals should be established that would target all patients receive a baseline pre-operative measurement, that treatment is initiated in a timely fashion, and that the program is successful when BCRL is identified and treated in stage I. Additional goals for the program would be for screening to empower women to be vigilant about looking for signs and symptoms; to better understand BCRL; and when to seek medical advice.

Future Directions

While the evidence and consensus surrounding PSM as an optimal framework for morbidity detection and lymphedema management continues to mature, standardized implementation of the model into oncology practice is needed. Screening for early lymphedema is still not a universal standard of care, despite being recommended by the National Comprehensive Cancer Network's Survivorship Guideline [72] and the International Society of Lymphology [17] among other groups [15, 73, 74]. Guideline-concordant care is a tenant of providing high-quality health care and efforts are needed to improve adherence to these guideline recommendations.

Currently, there are no universal diagnostic criteria inclusive of clinical measures, clinical examination, and subjective-reported measures. Each of these measurement domains has ample evidence to suggest thresholds beyond which risk escalates, and lymphedema becomes evident. Effort should be undertaken, by international consensus, to establish comprehensive diagnostic criteria. This ideally includes the use of baseline measures and surveillance to detect clinically important and meaningful differences over time using measurement tools that are both sensitive and specific to identifying subclinical and early lymphedema [75].

Further research to understand the effectiveness of early intervention for BCRL is needed; understanding the impact on participation, later physical function, and quality of life over the duration of the individual's lifespan can help to better elucidate the value of the PSM model. Further exploration is also warranted to identify the potential cost-saving nature of PSM as a secondary prevention model.

Summary

The prospective surveillance model is a preferred framework for facilitating surveillance protocols for the early identification and management of BCRL. The model should become a standard practice for all oncology providers. Every patient experiencing a diagnosis of breast cancer should be assessed at pre-operative baseline with standardized tools and should be screened prospectively to identify clinically meaningful changes in baseline measures that may indicate increased risk for condition onset and progression. While standardized methodology is critical, the components of the model are flexible and should be tailored to encourage best practices that can meet the needs of the majority of patients in the clinical context.

Compliance with Ethical Standards

Conflict of Interest Nicole Stout, Nicole Scheiman, and Habiba Thawer declare that they have no conflict of interest.

Cheryl Brunelle is on the Scientific Advisory Board of Puretech Health.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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