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**Advancing shared decision making for symptom monitoring in people living beyond cancer**

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## **ABSTRACT**

It is increasingly being recognized that well-being after successful cancer treatment consists of more than a mere lowering of risk for disease recurrence. Cancer survival can be characterized by uncertainty, fear, and the interpretation of bodily sensations as potentially symptomatic. This fear can lead to vigilance for bodily sensations and precautionary visits to the doctor, both of which may increase the chance of early detection but may also increase anxiety and decrease quality of life. In this Personal View article, we consider the medical, psychological, and ethical issues surrounding the practice of self-directed symptom monitoring after successful cancer treatment, focusing on the role of doctor-patient communication. We ask how clinicians can make room for the plurality of values that patients might bring to the table when it comes to deciding how to manage—and respond to—experiences of post-cancer symptoms. We advocate a shared decision-making approach that incorporates an assessment of the magnitude of the individual's cancer recurrence risks as well as psychosocial considerations of fear of cancer recurrence and mental health. We aim to raise awareness of the potential quality-of-life implications of symptom monitoring practices, emphasizing the need for a balance between physical and psychological health in cancer survivorship.

### **1. The problem of symptom appraisal after cancer**

Improvements in treatment and early detection mean that more people are surviving cancer than ever before. Now, there is increased attention on how to optimize follow-up care, with a focus on not only physical, but also psychological health. The practice of symptom monitoring is critical to both but has received relatively little attention. Many, if not most individuals living beyond cancer will engage in symptom monitoring practices of

some kind, purposefully attending towards and internally scanning their body for fluctuations in such sensations as pain, fatigue, and breathlessness. Symptom monitoring is most likely pursued with the goal of detecting signs of disease recurrence, second malignancies, or late-effects of treatment. These practices may be actively encouraged by clinicians or may be entirely self-directed.

Within the context of active cancer treatment, symptom monitoring and reporting has generally been shown to have more benefit than harm<sup>1,2</sup>. However, the phase beyond active treatment may be very different. It is typically characterized by a sudden loss of clinical contact, a termination of most or all symptom-inducing treatment, and extreme psychological uncertainty regarding the late effects of treatment and potential disease recurrence<sup>3</sup>. Thus, ambiguous bodily sensations such as those described above can cause fear and anxiety<sup>4-7</sup>. Knowing how to appraise and respond to bodily sensations after cancer is a central challenge of survivorship<sup>5</sup>.

How beneficial, then, is 'symptom monitoring' after cancer treatment? Here, we focus on those individuals who successfully complete active treatment and, although commonly under active follow-up and monitoring for recurrence, are considered disease free. The answer is not straightforward. First, bodily sensations such as fatigue, itch, pain, poor appetite, and breathlessness can indeed be markers of disease recurrence, but can also be unreliable. Fluctuating bodily sensations are an ordinary part of everyday life, especially after chemotherapy, radiotherapy, and surgery<sup>8-11</sup>. Indeed, although we use the term 'symptom-monitoring' in this article, we refer not exclusively to true symptoms of disease but more broadly to (often benign) bodily sensations that characterize our daily lives.

Second, in many countries, long-term follow-up care involves extensive routine surveillance to detect new or recurrent disease in its early stages, before it is symptomatic. In these cases, the added practice of symptom monitoring is unlikely to be of medical benefit but can still cause psychological harm.

Given that bodily sensations can be untrustworthy as markers of disease, whose constant surveillance may not add benefit beyond regular screening, a challenge is raised as to how individuals should best monitor, respond to, and report on bodily sensations following successful cancer treatment. This challenge is especially relevant given potential (adverse) quality of life implications that may be associated with constant and/or heightened self-surveillance<sup>12</sup>. It is our suggestion that clinicians working in an oncology context play a prominent role in deciding **with** patients how much to engage in ‘symptom monitoring’ practices, taking into consideration the overall quality-of-life implications for the patient based on their values and psychological needs. We highlight and discuss the ethical role of the oncology clinician in directing patient symptom monitoring practices, asking how clinicians can best communicate with patients about this challenge.

Central to this challenge is the following question: Is it better for clinicians to encourage a ‘better safe than sorry’ approach, counseling patients to present for assessment when bodily sensations change? Or is it better to encourage a ‘wait and see’ approach, focusing on reducing unproductive worry about the potential negative meanings associated with such changes? Of course, this is an oversimplification: it need not be either/or. And the ‘right’ answer will likely differ depending on different approaches to screening and imaging in long-term follow-up programs across countries and clinical settings. But it is worth

considering the benefits and risks of placing more or less emphasis on each approach. The clinical and ethical challenge, we believe, is in finding a patient-relative position of optimal ‘vigilance’: neither hyper- nor hypo-vigilant, cautious concern without excessive anxiety or avoidance.

## **2. The case for reducing symptom monitoring**

Clinicians may choose to encourage symptom monitoring to increase odds of survival. Especially in countries and clinical settings where cost-effective medicine decisions discourage frequent follow-up tests, the patient’s bodily sensations may be a primary guide for indications of disease recurrence or secondary cancer. Indeed, encouraging symptom monitoring may be included as one component of survivorship care plans. Relatedly, the ASCO guidelines for the management of (chronic) pain in people living beyond cancer is to *“evaluate and monitor for recurrent disease, second malignancy, or late-onset treatment effects in any patient who reports new-onset pain”*<sup>13</sup>. Clinicians may also offer specific recommendations for symptom monitoring. For example, a patient may be guided to be especially attentive to new, persistent pain in the previous tumor site or in sites of likely metastatic disease, rather than simply to monitor all bodily sensations. Thus, when the goal is to boost the chance of survival through early detection of disease recurrence and the assumption is that (certain) physical symptoms *are* relevant indicators of disease, symptom monitoring is entirely appropriate.

However, one must also consider the psychological context and consequences of symptom monitoring. Critical to this is integrating knowledge from decades of research outside of oncology revealing that that bodily sensations such as pain are highly modulated by

cognitive and contextual variables<sup>14-18</sup>. Pain is not, as was once commonly believed, a simple read-out of the state of the body tissues. Its salience, frequency, and quality can change in the face of *fear and anxiety*<sup>19-22</sup> which, in turn, can further increase the unreliability of pain as a marker of disease. Of vital importance here is recognition that fear and anxiety are very common after cancer. Indeed, fear of cancer recurrence (FCR) is among the most commonly reported problems in people living beyond cancer, one of the most prevalent areas of unmet need<sup>23</sup>, and is strongly associated with poor quality of life<sup>12</sup>. Maladaptive health behaviors (including over-surveillance/body checking and under-surveillance), aversive psychological reactions, and functional impairments have been identified as consequences of FCR<sup>12</sup>. Given that fear and anxiety are shown to worsen pain and other sensations, and that fear and anxiety are common after cancer, it is unsurprising that the presence of bodily sensations such as pain is repeatedly shown to be associated with higher FCR<sup>24</sup>.

To bring attention to this issue, we recently presented the Cancer Threat Interpretation (CTI) model of symptom appraisal in the context of cancer-related uncertainty, reviewing the relevant literature and highlighting the cognitive, affective, and behavioral consequences of interpreting ambiguous bodily sensations as indicating potential cancer recurrence<sup>5</sup>. Within the CTI framework, it is possible that even when given specific advice about which symptoms to attend to, anxiety and fear may primarily drive the felt experience of those symptoms and thus their overall perception as indicating danger. Recent research has also revealed that metacognitions, including negative beliefs about worry, are associated with increased FCR and may maintain FCR over time<sup>25</sup>. This is

particularly relevant within the context of symptom monitoring, in which individuals can hold beliefs that actively worrying about symptoms may increase their chance of survival.

Taken together, when the goal shifts beyond medical considerations to include psychological health, *reducing* symptom monitoring can sometimes be appropriate, especially in those for whom it induces severe anxiety. We argue here that any consideration of symptom monitoring practices, especially within the context of clinician communication about such practices, must include a consideration of the impact that bodily symptoms may have on FCR. As we will discuss later, communication regarding symptom monitoring practices would be best considered when individual patient level of FCR is adequately screened and detected, and thus can be considered within this broader psychological context.

### **3. Striking a balance: shared decision-making in cancer uncertainty**

Given such complexities and trade-offs, how should clinicians communicate about symptom monitoring? One answer lies in how we characterize the communication between clinicians and patients following successful treatment and moving into long-term follow-up. There is increasing consensus among bioethicists of the value of shared decision-making (SDM) in clinical encounters as a way of enhancing autonomy. Multiple studies report that integrating enhanced SDM improves outcomes, including within cancer contexts<sup>26,27</sup>, which supports the principle of beneficence. Indeed, the SDM framework is not new in cancer care and has been applied to topics such as cancer screening adherence and decisions regarding preventative surgery and treatment<sup>28</sup>, which also connects SDM to beneficence. It has also been applied to the provision of emotional support, such as relieving fear and anxiety and



addressing mental health issues during cancer diagnosis and treatment <sup>28</sup>. However, less research has focused on SDM in the post-treatment, survivorship stage.

SDM has been termed “the pinnacle of patient-centered care” <sup>29</sup>. From an ethical perspective, strengthening SDM within the context of directed symptom monitoring after cancer carries a number of advantages. One advantage is that SDM maximizes patient autonomy. People with cancer may feel particularly vulnerable and disempowered, especially given a history of cancer treatment in the West that has all-too-often been characterized by norms of silence <sup>30</sup>. At times, as in the case of breast cancer, physician-proponents of one class of interventions (e.g., lumpectomy + radiation vs. prophylactic mastectomy) often refused to seriously discuss the harms and benefits of the other option in consultation with their patients, with the idea that ‘doctor knows best’ <sup>30</sup>. Conversely, people in pain often do not share their pain experiences with their doctors (or others): they may not want to ‘burden’ others with regular reports of discomfort; or they may even experience denial that pain in the context of serious illness could signal something as distressing as treatment-refractory recurrence. Accordingly, any approach that allows patients to express and engage meaningfully with their experiences strengthens the voice of the patient and therefore enhances autonomy.

Another advantage of SDM is that it can promote what is known as ‘epistemic justice’ in healthcare encounters. Epistemic justice involves respecting an agent’s legitimacy as a knower—especially when it comes to her own subjective experiences, of which pain is a paradigm example. In this case, acknowledgment by the clinician that a patient may have her own valid concerns regarding clinical and psychological consequences of symptom

perception can serve as an important starting point. In the case of chronic non-cancer pain, listening to people in pain and taking their experiences seriously is not only essential to ensuring epistemic justice, but its absence practically guarantees that they will be stigmatized<sup>31,32</sup>. Within the context of cancer survival, it is possible that at least some reports of pain may be less likely to be outright ignored given their potential clinical relevance, but they may also sometimes be inappropriately discounted precisely because the clinician is aware that the patient has grounds to be extra-sensitive. There is increasing recognition that epistemic justice is an important ethical consideration in health care encounters<sup>31</sup>, and any tool that enhances it is therefore of ethical significance.

On the other side of the coin, individuals who express a desire *not* to prioritize constant vigilance about pain over all other considerations (such as their quality of life in the context of their own goals and values) may also have their perspective questioned and may be stigmatized, discouraged, or dismissed, in favor of a ‘better safe than sorry’ (or ‘doctor knows best’) approach. A nuanced deployment of SDM, by contrast, would begin by helping individuals identify and express their particular values, including those that may diverge from a preference for hypersensitivity to, and never-ending worry about, the experience of pain or other bodily sensations. Indeed, one of the hallmarks of a commitment to SDM in health care is an understanding of risk and benefit in pluralistic terms: people can and do weigh risks and benefits differently and come to divergent but often entirely reasonable decisions<sup>33</sup>. People will value essential dimensions of well-being differently, and these differences are paramount when considering the threat of cancer recurrence<sup>34</sup>.

To guide clinicians in structuring their discussions with individuals living beyond cancer, we present in Figure 1 a shared decision-making (SDM) framework for symptom monitoring in cancer survival. This framework includes both disease/treatment-related considerations (clinician communication about individual risk of recurrence and symptom reliability) as well as psychological considerations. It would be optimal if it involved:

- (1) measurement of the patient's fear and anxiety around cancer recurrence, including fear that physical symptoms may be a sign of recurrence
- (2) acknowledgement that the practice of directed symptom monitoring can have effects on fear, wellbeing, and quality-of-life
- (3) an explicit opportunity for the expression of multiple concerns regarding these effects, from all relevant agents
- (4) an acknowledgement of a plurality of views, including possibly dissonant goals
- (5) a balancing of different perspectives and, ideally, reaching of a shared agreement regarding the approach to symptom monitoring

#### **4. One size does not fit all**

We have argued previously<sup>5</sup> and here that bodily sensations may cause fear and anxiety in individuals living beyond cancer, and that this fear may drive vigilance and symptom monitoring. However, every individual's experience of survivorship is unique, and a consideration of symptom monitoring would be remiss without recognition of individual differences. For example, it is important to recognize that not all individuals living beyond cancer will engage in active symptom monitoring. For some, FCR may be minimal. For others, especially those for whom cancer was relatively asymptomatic, bodily sensations may not be a key source of concern. In addition, whilst FCR may drive symptom monitoring

in some individuals, for others fear may prompt *avoidance* of surveillance altogether. In this case, an ethical argument could be made to *increase* symptom monitoring if appropriate and relevant for physical health. Relatedly, within the context of the SDM framework, individuals with very high levels of FCR may describe being risk-averse as a highly rated value. Yet, for those individuals, being instructed to monitor symptoms could counterproductively drive further fear and lower quality of life. In these cases, the agreements arising through SDM might need to change over the course of survivorship. That is, if individuals opt for a risk averse position, but this in turn leads increased fear and anxiety over time, a referral for treatment of FCR may be most appropriate<sup>35,36</sup>, followed by a renegotiation of decisions after successful treatment. Ultimately, it is important to recognize that there are well-documented vulnerable groups who are at higher risk of FCR (e.g., young women with breast cancer)<sup>37</sup> and that extreme cases of symptom hypervigilance or negligence, as depicted in Figure 1, may be more highly represented in individuals with high FCR.

Beyond individual differences in psychological responses to cancer, individual differences in disease state and risk of recurrence are also important. First, risk of disease recurrence differs greatly among different cancers and depends largely on tumor biology, extent of disease, and treatment administered. Clinician communication about the patient's individual risk for disease recurrence is increasingly recognized as an important part of follow-up care and is likely also important within the context of communication about symptom monitoring. For example, Janz and colleagues<sup>38</sup> previously found that women living beyond breast cancer who reported receiving insufficient information about risk of recurrence subsequently reported a decrease in emotional wellbeing over time. Thus, these

authors, among others<sup>37</sup>, argue that communicating about individual risk of recurrence is warranted. Second, the extent to which physical symptoms are useful or reliable indicators of recurrence for that individual must be taken into consideration. There is evidence for some diseases, including breast cancer, that most symptoms arising after successful treatment are not due to cancer recurrence<sup>39</sup>. Moreover, in diseases such as localized prostate cancer, therapy completion is often accompanied by the development of long-term treatment-related side effects such as urinary and bowel dysfunction and associated physical symptomatology. For other diseases, (certain) symptoms may be more reliable indicators of disease recurrence.

Third, there is also variability in whether early detection improves outcomes. In a recent review of the literature, Le and Tzeng<sup>40</sup> noted that whilst early detection is not always associated with improved outcomes, there are clear instances (e.g., resection of liver and lung metastases in colorectal cancer) in which early detection and treatment are beneficial. Therefore, targeted monitoring for symptoms that may reflect treatable tumor recurrence may have value. Fourth, there is also mixed evidence for the beneficial impact of symptom monitoring on physical and psychological well-being across different diseases. Within the context of active cancer treatment, symptom monitoring and reporting has largely been shown to have more benefit than harm<sup>1,2</sup>. In opposition, studies of men who have been successfully treated for prostate cancer indicate little positive impact of symptom monitoring interventions<sup>41</sup>. Interestingly, beyond detection of recurrence, research on the utility of survivorship care plans has identified where symptom monitoring may be particularly useful for certain demographic groups. For example, Faul and colleagues<sup>42</sup> indicate that older people may misattribute modifiable symptoms (e.g., late effects of

treatment) to “normal aging” or believe that their symptoms are not treatable. They thus argue for promoting active and guided symptom monitoring as part of survivorship care plans in this population. Taken together, individual differences in disease state are important to consider in weighing the relative risks and benefits of symptom monitoring. Within an SDM framework, it is important that the clinician provides clear communication about the individual’s status across these disease-related factors, in balance with recognizing and measuring psychological risk, in order to guide the clinician-patient discussion.

## **5. Clinical examples and future steps**

Whilst recognizing the layers of individual difference and uncertainty described above, we propose specific points that are appropriate for clinicians to consider when broadly reflecting on how to best communicate with their patients about the challenge of symptom monitoring after cancer (see Panel 1). We also offer two clinical examples in which individual patient differences are taken into account and an SDM framework could be usefully employed. Of note, in the first example, clear communication about risk, recognition of psychological concerns, and reassurance regarding physical symptoms is sufficient, whereas in the second example a more specific symptom monitoring plan is developed.

*Example 1:* Nathan is a 20-year-old young man who completed chemotherapy and radiation therapy for Ewing sarcoma in his pelvis 2 years previously. He was originally diagnosed after presenting with persistent sciatic pain and is now very vigilant and fearful when

experiencing changes in physical sensations, including pain, in the lower half of his body. His remembers a friend with Ewing sarcoma, whom he met in hospital, whose disease metastasized to the lungs and subsequently proved fatal. Nathan is therefore also vigilant of changes to his breathing or a new cough. Nathan attends his scheduled follow-up sessions at the hospital but is reassured by learning that his scans are clear each time that he does not actively indicate difficulties with fear of recurrence or knowing how to appraise and cope with physical symptoms.

### **Relevant doctor-patient communication**

- 1)** Through routine screening of FCR, identify if Nathan has clinically high levels of FCR and consider referring him for psychological support
- 2)** Enquire as to whether Nathan is worrying about physical symptoms and if so, which ones
- 3)** Discuss with Nathan that whilst there is some risk of his disease recurring and there are certain symptoms that could be a cause for concern (e.g., persistent, worsening sciatic pain), other symptoms should not cause concern (e.g., a cough is not a symptom of early recurrence of Ewing sarcoma). Also mention that as he is receiving regular scans (every 3 months), disease recurrence is likely to be detected before it becomes symptomatic
- 4)** Acknowledge that many individuals experience difficulty with symptom perception after cancer and that knowing how to appraise and respond to physical sensations is a significant challenge for both physical and psychological health
- 5)** Ensure that Nathan knows that the care team is available to help evaluate the significance of symptoms of concern to him, and can also assist him with psychological support if persistent worry interferes with quality of life or functioning

Example 2: Joanna is a 34-year-old woman who completed surgery, chemotherapy, and radiotherapy for primary breast cancer. She is scheduled to receive follow-up scans every 6 months although has missed two appointments due to fear of finding out that her cancer has returned. Although her cancer was originally asymptomatic and was detected throughout routine surveillance, she is increasingly fearful of changes in physical sensations in her breasts and palpates her breasts every day to monitor for disease recurrence.

### **Relevant doctor-patient communication**

- 1) Through routine screening of FCR, identify if Joanna has clinically high levels of FCR and consider referring her for psychological support
- 2) Enquire as to whether Joanna is worrying about physical symptoms and if so, which ones
- 3) Reassure Joanna regarding her relatively low risk of disease recurrence, and review symptoms of concern and non-concern
- 4) Acknowledge that many individuals experience difficulty with symptom perception after cancer and that knowing how to appraise and respond to physical sensations is a significant challenge for both physical and psychological health
- 5) Discuss with Joanna that examining her breast tissue every day is likely to cause soreness that is unrelated to disease recurrence. Develop a behavioral contract in which Joanna agrees to attend her 6-monthly scans but in between each scan to reduce the number of times she checks her breasts from once per day to once per month

Our proposed framework and points for consideration are not recommended as definitive solutions. Instead, our aim is to raise awareness of the potential quality-of-life implications of symptom monitoring practices, to recognize the need for a balance between physical and psychological health in cancer survivorship, and to generate cross-discipline discussion on



the medical, psychological, and ethical challenges of symptom monitoring after cancer. There are a number of future steps and research questions to guide continued discussion. First, we suggest above that screening for FCR is likely essential for successful employment of an SDM framework. A number of brief instruments indicating good reliability and validity are available for this purpose. For example, the Fear of Cancer Recurrence Inventory severity subscale comprises only nine items and provides clinical cutoffs to identify individuals with clinically high levels of FCR. The published cut-off score indicates that  $> 13$  is a “clinical” range, however, recent work suggests that a score of 22 or above is more likely to indicate a need for referral to a psycho-oncology specialist<sup>43</sup>. There is also now some evidence to support a 4-item measure<sup>44</sup>. However, there are no measures of FCR developed for or validated in children and adolescents. There are also no measures of fear of physical symptoms within the context of cancer survivorship. The development of pediatric and symptom-specific measures of FCR is an important next step to guide both research and clinical practice. Second, a wide survey of clinician beliefs, attitudes, and behaviors (communication strategies) regarding symptom monitoring after cancer treatment cessation is needed. Particularly useful will be survey data encompassing multiple disciplines (e.g., oncologists and psychologists working in oncology settings), clinical environments (private and public medical institutions), and international settings. The latter is particularly relevant given that the degree of routine surveillance, and relative reliance on physical symptoms to guide follow-up scans and tests, differ greatly between countries. Third, qualitative studies of patient experiences in coping with uncertainty around bodily sensations after cancer, and in communicating with clinicians about symptom monitoring, will be revealing. Overall, we need to understand the range of clinician communication practices about symptom monitoring, the impact of this communication on patient

wellbeing, the clinician's subjective level of comfort in weighing physical and psychological risks, and their interest in receiving training to enhance shared decision-making within this context.

## **6. Acting in uncertainty**

Many clinical decisions involve acting in uncertainty. In the case of directed symptom monitoring after cancer, and how clinicians communicate about this practice, such uncertainty has several layers. One layer involves the individual's risk of disease recurrence, the extent to which physical symptoms are useful or reliable indicators of recurrence for that individual, and the timeframe within which these symptoms are associated with a curable or symptom-relieving disease state. As techniques for recurrence detection through routine surveillance improve, the clinical need for patient-driven symptom monitoring will likely decrease. Also relevant is the extent to which physical symptoms are reliable indicators of late effects of cancer treatment beyond disease recurrence, such as cardio-pulmonary health and fertility issues. We have not addressed these issues within this paper, but we note that their consideration is relevant for guiding best practices in clinician communication surrounding directed symptom monitoring. Another layer concerns the physician's own tolerance of uncertainty. We highlight the important role that the clinician has in providing counselling about symptom monitoring. Yet, we recognize that this role can be difficult to navigate. Just like patients have variable risk tolerance, comfort with uncertainty, and degree of worry, so do physicians. It is both the physician's clinical experience and their own psychological milieu that affects how they view data (such as reported symptoms), weigh perceived risks for the patient, and make recommendations. In the presence of a patient reporting symptom-related concerns, the clinician may feel

obligated to 'do everything', leading to potentially unnecessary testing and biopsies, each of which can increase fear at least temporarily. Failing to 'do everything' may be viewed as not taking the patients' symptom-related concerns seriously, further contributing to issues of epistemic (in)justice described earlier. On the other hand, providing anticipatory guidance about the meaning of specific symptoms may be important in decreasing both (hyper-)vigilance and negligence. Eliciting an understanding of the patient's worries may permit the clinician to identify misperception and relieve misplaced worry. As a clinician, being aware of your own biases as you approach shared decision making with patients may be as important as understanding the patient's perspective.

## **7. Conclusion**

Life beyond cancer for many is like living next to a volcano, in the shadow of an ever-present, uncontrollable threat. To ignore the smoke would be to miss what little information is available, even when one knows it can be unreliable. Attending only to the smoke, however, brings the risk of chronic preoccupation with threat, heightened fear, and decreased well-being. In this Personal View article, we have considered the role of the clinician in providing guidance for individuals living beyond cancer as they navigate this uncertain environment. We propose a shared decision-making approach that encourages a discussion of the magnitude of the individual's cancer recurrence risks the relative reliability of symptoms for that individual, as well as psychosocial considerations of fear of cancer recurrence and mental health. Instead of a choice between a 'better safe than sorry' or 'wait and see' strategy, we propose an alternative, ethically pragmatic strategy in which one promotes the opportunity to acknowledge the plurality of values as well as ethical and personal preferences described above, and engages in shared decision-making that respects

the individual's chosen approach to symptom monitoring. We intend not to offer a definitive solution but instead to generate cross-disciplinary discussion on the medical, psychological, and ethical challenges of symptom monitoring after cancer in order to guide clinical practice.

### **SEARCH STRATEGY AND SELECTION CRITERIA**

We identified references for this Personal View article by searching PubMed and Google Scholar with the search terms "symptom monitoring", "surveillance", "shared decision making", "cancer", and "cancer survivors" at several stages during both the writing of the initial manuscript and in responding to reviewer comments. We also searched reference lists of papers that were identified as particularly relevant from the PubMed search. As this is not a systematic review, we included only the most relevant articles and review papers as well as individual smaller studies that provided nuanced perspectives.

### **AUTHOR CONTRIBUTIONS**

All authors contributed to the writing and editing of this paper. LCH was the primary writer. DSG and BDE led the section on shared decision-making. LCH and CE led the remaining sections. LS contributed to the discussion of fear of cancer recurrence. SLS provided guidance for considerations of clinical practice. LCH and LES developed Figure 1.

### **DECLARATION OF INTERESTS**

There are no financial or personal conflicts of interest to declare. All authors report nothing to disclose.

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There are no funding sources for this article.

## FIGURE LEGENDS

**Figure 1.** A shared decision-making (SDM) framework for symptom monitoring in cancer survival.

## REFERENCES

- 1 Basch E, Deal AM, Dueck AC, *et al.* Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. *JAMA* 2017; **318**: 197.
- 2 Basch E, Deal AM, Kris MG, *et al.* Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *J Clin Oncol* 2016; **34**: 557–65.
- 3 Garofalo JP, Choppala S, Hamann HA, Gjerde J. Uncertainty during the transition from cancer patient to survivor. *Cancer Nurs* 2009; **32**.  
DOI:10.1097/NCC.0b013e31819f1aab.
- 4 Miller LE. Sources of uncertainty in cancer survivorship. *J Cancer Surviv* 2012; **6**: 431–40.
- 5 Heathcote LC, Eccleston C. Pain and cancer survival : a cognitive-affective model of symptom appraisal and the uncertain threat of disease recurrence. *Pain* 2017; **158**: 1187–91.
- 6 Wang JW, Shen Q, Ding N, *et al.* A qualitative exploration of the unmet psychosocial rehabilitation needs of cancer survivors in China. *Psychooncology* 2016; **25**: 905–12.

- 7 Hanprasertpong J, Geater A, Jiamset I, Padungkul L, Hirunkajonpan P, Songhong N. Fear of cancer recurrence and its predictors among cervical cancer survivors. *J Gynecol Oncol* 2017; **28**: e72.
- 8 Gärtner R, Jensen M-B, Nielsen J, Ewertz M, Kroman N, Kehlet H. Prevalence of and factors associated with persistent pain following breast cancer surgery. *JAMA* 2009; **302**: 1985–92.
- 9 Polomano RC, Farrar JT. Pain and Neuropathy in Cancer Survivors: Surgery, radiation, and chemotherapy can cause pain; research could improve its detection and treatment. *AJN Am J Nurs* 2006; **106**.
- 10 Miltenburg NC, Boogerd W. Chemotherapy-induced neuropathy: A comprehensive survey. *Cancer Treat. Rev.* 2014; **40**: 872–82.
- 11 Harrington CB, Hansen J a, Moskowitz M, Todd BL, Feuerstein M. It's not over when it's over: long-term symptoms in cancer survivors--a systematic review. *Int J Psychiatry Med* 2010; **40**: 163–81.
- 12 Simard S, Thewes B, Humphris G, *et al.* Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *J Cancer Surviv* 2013; **7**: 300–22.
- 13 Paice JA, Portenoy R, Lacchetti C, *et al.* Management of chronic pain in survivors of adult cancers: American Society of Clinical Oncology clinical practice guideline. *J Clin Oncol* 2016; **34**: 3325–45.
- 14 Longo MR, Iannetti GD, Mancini F, Driver J, Haggard P. Linking Pain and the Body: Neural Correlates of Visually Induced Analgesia. *J Neurosci* 2012; **32**: 2601–7.
- 15 Moseley GL, Arntz A. The context of a noxious stimulus affects the pain it evokes. *Pain* 2007; **133**: 64–71.

- 16 Mancini F, Longo MR, Kammers MPM, Haggard P. Visual distortion of body size modulates pain perception. *Psychol Sci* 2011; **22**: 325–30.
- 17 Moseley GL, Parsons TJ, Spence C. Visual distortion of a limb modulates the pain and swelling evoked by movement. *Curr Biol* 2008; **18**: 1047–8.
- 18 Stanton TR, Moseley GL, Wong AYL, Kawchuk GN. Feeling stiffness in the back: A protective perceptual inference in chronic back pain. *Sci Rep* 2017; **7**.  
DOI:10.1038/s41598-017-09429-1.
- 19 Crombez G, Eccleston C, Van Damme S, Vlaeyen JWS, Karoly P. Fear-avoidance model of chronic pain: the next generation. *Clin J Pain* 2012; **28**: 475–83.
- 20 Leeuw M, Goossens MEJB, Linton SJ, Crombez G, Boersma K, Vlaeyen JWS. The fear-avoidance model of musculoskeletal pain: Current state of scientific evidence. *J Behav Med* 2007; **30**: 77–94.
- 21 Vlaeyen JWS, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: A state of the art. *Pain* 2000; **85**: 317–32.
- 22 Rhudy JL, Meagher MW. Fear and anxiety: divergent effects on human pain thresholds. *Pain* 2000; **84**: 65–75.
- 23 Armes J, Crowe M, Colbourne L, *et al.* Patients' supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. *J Clin Oncol* 2009; **27**: 6172–9.
- 24 Lebel S, Ozakinci G, Humphris G, *et al.* From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Support Care Cancer* 2016; **24**: 3265–8.
- 25 Butow P, Kelly S, Thewes B, Hruby G, Sharpe L, Beith J. Attentional bias and metacognitions in cancer survivors with high fear of cancer recurrence.

- Psychooncology* 2015; **24**: 416–23.
- 26 Kehl KL, Landrum MB, Arora NK, *et al.* Association of Actual and Preferred Decision Roles With Patient-Reported Quality of Care. *JAMA Oncol* 2015; **1**: 50.
- 27 Stacey D, Légaré F, Lewis K, *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst. Rev.* 2017.
- 28 Shay AL, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Mak* 2015; **35**: 114–31.
- 29 Barry MJ, Edgman-Levitan S. Shared Decision Making — The Pinnacle of Patient-Centered Care. *N Engl J Med* 2012; **366**: 780–1.
- 30 Katz J. The silent world of doctor and patient. Johns Hopkins University Press, 2002.
- 31 Buchman DZ, Ho A, Goldberg DS. Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain. *J Bioeth Inq* 2017; **14**: 31–42.
- 32 Williams AC de C. Defeating the stigma of chronic pain. *Pain* 2016; **157**: 1581–2.
- 33 Earp BD, Darby R. Circumcision, sexual experience, and harm. *Univ Pennsylvania J Int Law* 2017; **37**: 1–57.
- 34 Powers M, Faden R. Social Justice: The Moral Foundations of Public Health and Health Policy. In: *Social Justice: The Moral Foundations of Public Health and Health Policy*. 2008: 15–49.
- 35 Humphris G, Rogers S. AFTER and beyond: cancer recurrence fears and a test of an intervention in oral and oropharyngeal patients. *Soc Sci Dent* 2012; **2**: 29–38.
- 36 van de Wal M, Thewes B, Gielissen M, Speckens A, Prins J. Efficacy of Blended Cognitive Behavior Therapy for High Fear of Recurrence in Breast, Prostate, and Colorectal Cancer Survivors: The SWORD Study, a Randomized Controlled Trial. *J Clin Oncol* 2017; **35**: 2173–83.



- 37 Butow P, Sharpe L, Thewes B, Turner J, Gilchrist J, Beith J. Fear of Cancer Recurrence: A Practical Guide for Clinicians. *Oncol J* 2018; **32**: 32–8.
- 38 Janz NK, Friese CR, Li Y, Graff JJ, Hamilton AS, Hawley ST. Emotional well-being years post-treatment for breast cancer: Prospective, multi-ethnic, and population-based analysis. *J Cancer Surviv* 2014; **8**: 131–42.
- 39 Ghezzi P, Magnanini S, Rinaldini M, Al E. Impact of follow-up testing on survival and health-related quality of life in breast cancer patients: A multicenter randomized controlled trial. *JAMA* 1994; **271**: 1587–92.
- 40 Le A, Tzeng CD. Does finding early recurrence improve outcomes, and at what cost? *J Surg Oncol* 2016; **114**: 329–35.
- 41 M Davis K, Dawson D, Kelly S, *et al.* Monitoring of health-related quality of life and symptoms in prostate cancer survivors: a randomized trial. 2013.
- 42 Faul LA, Luta G, Sheppard V, *et al.* Associations among survivorship care plans, experiences of survivorship care, and functioning in older breast cancer survivors: CALGB/Alliance 369901. *J Cancer Surviv* 2014; **8**: 627–37.
- 43 Fardell JE, Jones G, Smith A Ben, *et al.* Exploring the screening capacity of the Fear of Cancer Recurrence Inventory-Short Form for clinical levels of fear of cancer recurrence. *Psychooncology* 2018; **27**: 492–9.
- 44 Humphris GM, Watson E, Sharpe M, Ozakinci G. Unidimensional scales for fears of cancer recurrence and their psychometric properties: The FCR4 and FCR7. *Health Qual Life Outcomes* 2018; **16**. DOI:10.1186/s12955-018-0850-x.