Provider perspectives on presenting risk information and managing worry about recurrence among breast cancer survivors

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Abstract

Background: Although worry about recurrence is a persistent concern among breast cancer survivors, little is known about physicians’ confidence about presenting recurrence risk information, identifying women with considerable worry, and helping women manage worry.

Methods: Between January and June 2012, we surveyed 750 surgeons and 750 medical oncologists randomly sampled from the American Medical Association Physician Masterfile. We tested differences between surgeons and medical oncologists on confidence of presenting risk, identifying and managing worry using chi-square statistic and Student’s t-tests and developed multiple variable logistic regression models to explain odds regarding confidence and use of different strategies for managing worry.

Results: The analytic sample included 403 surgeons and 363 medical oncologists (n = 766; response rate = 60%). Compared with surgeons, medical oncologists were significantly more likely to report confidence in: presenting risk information (87.5% vs 73.2%), identifying women who are worried (74.1% vs 63.9%), and managing worry (66.9% vs 52.4%). Confidence in managing worry was associated with more regular inquiry about worry (p = 0.009). Models of the likelihood of using different management strategies varied by provider type (e.g., surgeons more likely than medical oncologists to recommend support group or online resources, oncologists more likely to refer to psychologist or use medications, all p < 0.05).

Conclusion: Cancer providers, particularly surgeons, may benefit from educational training to raise confidence in identifying women with high levels of worry and managing women with considerable worry. Communication between specialties and primary care physicians on efforts to manage worry is necessary for coordinated, quality care for women with breast cancer.

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Introduction

Considerable research has documented that worry about recurrence is a major concern among women with breast cancer in the survivorship period [1–7]. A recent review of studies of long-term cancer survivors concluded that modestly intense fear of recurrence is experienced by most long-term survivors [8]. Most studies to date have focused on the patients’ perceptions about recurrence risk and the potential negative consequences of excessive worry on decision-making, surveillance behaviors and quality of life [9–12], with significant negative associations between considerable worry, and psychological distress and quality of life [7]. Far less attention has been focused on how confident providers of cancer care are at presenting risk information, identifying women with considerable worry, and assisting women to manage worry about recurrence over time.

The Institute of Medicine has stated that psychosocial care is integral to quality survivorship care [13]. Indeed, studies that have focused on provider perceptions generally find that physicians caring for women with breast cancer consider addressing psychosocial concerns to be part of their responsibility [14–17]. Some attention has been devoted to developing online tools and other resources to assist physicians in presenting risk information to their breast cancer patients [18–22], although most communications of recurrence risk have focused on improving treatment decision-making more than clarifying risk of recurrence itself.

In order to address the psychosocial needs of cancer survivors, physicians need to routinely assess mental health concerns of their patients and refer to appropriate mental health professionals as needed. Cancer survivors whose mental health concerns are addressed report greater satisfaction with the quality of their care [23]. Previous
studies have suggested that physicians tend to underestimate the level of depressive symptoms in patients and may be unaware of the importance of assessing the more reliable symptoms of mental health distress [24–26]. Despite the demonstrated need for mental health support, a recent population-based survey found that less than half of the cancer survivors reported that they discussed the psychological effects of cancer with their physician and/or were referred to mental health specialists or support groups [23].

In addition to identifying women with elevated levels of worry about recurrence, better strategies to help these women manage their worry are also needed. A variety of approaches or strategies are available to help women manage worry ranging from information sources in print or online formats, support groups or peer counseling, referrals to other professionals, including mental health care providers, and/or the use of medicines or alternative therapies. A systematic review of the literature found that cancer patients with fulfilled information need experience less anxiety and depression [27]. Very few studies have assessed the frequency of use of these strategies to assist women coping with their worry [28], and even fewer have examined if provider characteristics or the practice setting influences the kinds of resources employed.

How confident cancer care providers are in presenting risk information, inquiring about worry about recurrence and suggesting strategies to manage worry, or the extent to which there is variation across provider type has not received sufficient research attention. Both surgeons and medical oncologists routinely present risk information during the treatment decision-making phase and provide ongoing follow-up care to women with breast cancer. A positive relationship between physician confidence and competence has been demonstrated in previous studies [29,30]. For example, in a nationally representative survey of primary care physicians and medical oncologists, physicians with greater confidence in their knowledge about possible adverse psychosocial outcomes were more likely to engage in psychosocial care of their patients [30]. A greater understanding of physicians’ attitudes and behaviors regarding worry about recurrence in breast cancer could help women make informed treatment decisions rather than decisions based on unfounded fears. In addition, knowing how physicians’ approach to managing worry about recurrence during the survivorship period could lead to greater understanding of common approaches employed, areas where additional training or skill building may be helpful, and system and resource barriers that may inhibit providing coordinated quality cancer care to women in the survivorship period.

To address these gaps in the literature, we evaluated physicians’ self-reported confidence in presenting risk information as well as in identifying women with high levels of worry and managing worry about recurrence in a randomly selected sample of medical oncologists and surgeons caring for women with breast cancer. We paid particular attention to whether these factors differed by specialty. We further sought to identify the frequency with which these providers utilize various potential strategies for managing worry about recurrence, as well as provider characteristics that correspond with use of different management approaches.

**Methods**

**Sampling and data collection**

Our sample was drawn from the American Medical Association Physician Masterfile (MF), a reasonably comprehensive list of US physicians, amassed on the basis of medical school and residency enrollment and licensing records. We obtained a randomly selected sample of physicians whose specialty was medical oncology or hematology/oncology, or surgery or surgical oncology, along with their contact information. Prior to survey mailing, we telephoned to confirm addresses and to eliminate subjects whose practices clearly excluded breast cancer. We originally randomly sampled 750 surgeons and medical oncologists from the MF. We then called practice to confirm treatment of breast cancer patients. Those not treating breast cancer patients were excluded. Afterward, another random sample was selected from the MF list equal to the number excluded. The process iterated such that three different random samples were chosen until we reached 750 mailed per group that we reasonably believed at the time of mailing treated breast cancer patients.

Between January and June 2012, we mailed 750 surgeons and 750 medical oncologists a questionnaire and a $50 cash incentive. We utilized a modified Dillman approach, including follow-up with nonresponders, to maximize response rate [31]. The survey asked potential participants whether they had seen at least one new breast cancer patient in the preceding year. If not, they were asked to return the uncompleted survey. Data were anonymously entered into a RedCap database and exported to the SAS System, version 9.2 (Cary, NC, USA) for analysis. This study was approved by the University of Michigan Institutional Review Board.

**Measures**

The questionnaire was developed after a literature review and search for existing measures where available. Next, we employed an iterative design process and standard techniques of content validation, including systematic review of questions by content matter experts and experts in survey design. Instrument refinement also included cognitive pre-testing with surgeons and medical oncologists outside our target sample.
Dependent measures

Confidence in presenting risk information, identifying women with high levels of worry, and managing worries about recurrence: Clinician confidence in their ability to (a) present risk information to a breast cancer survivor in a way they will understand, (b) identify breast cancer survivors with high levels of worry, and (c) help breast cancer survivors manage their worries surrounding recurrence was assessed on 5-point Likert-type scales with endpoints labeled ‘not at all confident’ and ‘extremely confident.’ For purposes of analysis, we collapsed the responses into two categories: <4 was considered ‘not confident’, and ≥4 was considered ‘confident’.

Initiate discussions on worry: Respondents were asked whether they routinely initiated discussions regarding worry about recurrence with the breast cancer patients who did not bring up the issue themselves (yes/no).

Strategies used to manage worry: We inquired about the likelihood that physicians would use nine different strategies if their patient appeared very worried about the likelihood of her cancer returning. The strategies included ‘address her concerns in detail yourself’, ‘encourage her to join a cancer support group’, ‘schedule follow-up visits more frequently’, and ‘prescribe medications’, among others (Table 2). Responses were on a 4-point Likert-type scale ranging from ‘definitely no’ to ‘definitely yes’. For purposes of analysis, we collapsed the response options into two categories: ‘definitely no’ and ‘probably no’ were collapsed into ‘no’, and ‘probably yes’ and ‘definitely yes’ were collapsed into ‘yes’.

Independent measures

Provider and practice characteristics: Provider characteristics assessed included gender (male/female), race/ethnicity (White/Caucasian, Black/African American, Hispanic/Latino, Arab or Arab American, American Indian or Alaska Native, Asian or Pacific Islander, and other; collapsed during analysis to White, Asian or Pacific Islander, other), age, and years since completing residency. Practice characteristics included whether the practice includes residents or fellows (yes/no), whether the practice arranged same-day appointment with other clinicians/specialists (yes/no), number of newly diagnosed breast cancer patients in the past year, with another 50% who saw between 11 and 50 patients, and slightly less than a quarter who saw more than 50 newly diagnosed patients in the past year. Significant differences by provider type were noted with 16% of surgeons versus 30% of medical oncologists reported seeing more than 50 new breast cancer patients in the past 12 months. The remaining 766 respondents constituted our analytical sample: 403 surgeons and 363 medical oncologists. Table 1 displays the physician demographic and practice setting characteristics. The majority of the sample was male (79.2%) and White (73.6%). The mean age was 52 years. A greater proportion of surgeons compared with medical oncologists were male (85.0% vs 72.7%; p-value < 0.001), White (81.0% vs 65.3%; p-value > 0.001), and older (53 years compared with 51 years, p = 0.014).

About a quarter of those surveyed saw less than 10 newly diagnosed patients in the past year, with another 50% who saw between 11 and 50 patients, and slightly less than a quarter who saw more than 50 newly diagnosed patients in the past year. Significant differences by provider type were noted with 16% of surgeons versus 30% of medical oncologists reported seeing more than 50 new breast cancer patients in the past 12 months (p < 0.001). Most of the survey respondents (74.8%) reported following the majority of their patients for 3 years or more compared with 51.2% who reported seeing patients for less than 3 years. Approximately, 56% of surgeons reported following the majority of
their patients greater than 3 years compared with over 90% of medical oncologists \( (p < 0.001) \).

Figure 1 displays the percent of respondents who indicated that they were confident in presenting risk information, identifying women who were worried about recurrence, and managing patients’ worry. Overall, both surgeons and medical oncologists more often reported having confidence in presenting risk, followed by identifying women who have worry, and then helping women manage worry about recurrence. Medical oncologists were significantly more likely to report confidence in presenting risk information compared with surgeons \( (87.5\% \text{ and } 73.2\%, \ p < 0.001) \). About 74% of medical oncologists reported being confident in identifying women who are worried compared with approximately 64% of surgeons \( (74.1\% \text{ vs } 63.9\%, \ p = 0.002) \). A similar pattern was seen with physician confidence in managing worry. Approximately, 67% of medical oncologists were confident in their ability to manage worry compared with just over 50% of surgeons \( (66.9\% \text{ vs } 52.4\%, \ p < 0.001) \).

About 60% of respondents reported routinely initiating discussions regarding worry about recurrence with their patients who themselves do not bring up the issue, with no statistically significant differences found between provider type. A significant association was found between those who regularly initiated discussions and their confidence in their ability to manage worry \( (p = 0.009) \). About 62% of those reporting they routinely initiate discussion regarding worry about recurrence reported confidence in their ability to help breast cancer survivors manage worry, whereas only about 53% who do not routinely inquire about worry reported being confident about managing worry.

When we modeled the three domains of confidence (i.e., presenting risk information, identifying survivors with high levels of worry, and managing worry about recurrence) by provider and practice characteristics, there were a number of significant relationships that emerged. Medical oncologists were more likely than surgeons to report confidence in presenting risk information (odds ratio \( (OR) = 1.92, 95\% \text{ CI } 1.25–2.99 \)) and in managing survivors worry about recurrence \( (OR = 1.66, 95\% \text{ CI } 1.18–2.34) \). Across clinician characteristics, female compared with male physicians were more likely to report confidence in identifying survivors with high levels of worry \( (OR = 2.71, 95\% \text{ CI } 1.27–5.66) \) and in managing worry about recurrence \( (OR = 1.42, 95\% \text{ CI } 1.12–1.82) \). Among practice characteristics, providers with larger patient volumes (i.e., having seen greater than 20 breast cancer patients in the last 12 months vs 20 or less such patients) were more likely to report confidence in presenting risk information \( (OR = 1.92, 95\% \text{ CI } 1.28–2.89) \) and in identifying survivors with high levels of worry \( (OR = 1.92, 95\% \text{ CI } 1.36–2.72) \). Finally, providers in practices that offer same-day appointments with different specialists versus those practices who do not were more likely to report confidence in managing women’s worry about recurrence \( (OR = 1.76, 95\% \text{ CI } 1.28–2.41) \). No significant relationships were found between reported confidence across the three domains and provider time in practice, availability of residents and fellows in practice, or length of clinical follow-up.

### Table 1. Provider and practice characteristics

<table>
<thead>
<tr>
<th>Provider characteristics</th>
<th>Total</th>
<th>Surgeons</th>
<th>Medical oncologists</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>598 (79.2)</td>
<td>340 (85.0)</td>
<td>258 (72.7)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Female</td>
<td>157 (20.8)</td>
<td>60 (15.0)</td>
<td>97 (27.3)</td>
<td></td>
</tr>
<tr>
<td>Race: N (%)</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>White</td>
<td>550 (73.6)</td>
<td>320 (81.0)</td>
<td>230 (65.3)</td>
<td></td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>132 (17.7)</td>
<td>39 (9.8)</td>
<td>93 (26.4)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>65 (8.7)</td>
<td>36 (9.1)</td>
<td>29 (8.2)</td>
<td></td>
</tr>
<tr>
<td>Age: mean (SD) [min.–max.]</td>
<td>52 (10) [32–76]</td>
<td>53 (9) [32–75]</td>
<td>51 (10) [33–76]</td>
<td>0.014</td>
</tr>
<tr>
<td>Years since completing residency: mean (SD) [min.–max.]</td>
<td>19 (10) [1.5–45]</td>
<td>20 (9) [1.5–41]</td>
<td>18 (10) [1.5–45]</td>
<td>0.005</td>
</tr>
<tr>
<td>Practice characteristics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residents or fellows</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>193 (25.3)</td>
<td>108 (26.9)</td>
<td>85 (23.5)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>570 (74.7)</td>
<td>294 (73.1)</td>
<td>276 (76.5)</td>
<td></td>
</tr>
<tr>
<td>Same-day appointments available to meet with clinician specialists</td>
<td></td>
<td></td>
<td></td>
<td>0.672</td>
</tr>
<tr>
<td>Yes</td>
<td>340 (44.4)</td>
<td>176 (43.7)</td>
<td>164 (45.2)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>424 (55.6)</td>
<td>226 (56.3)</td>
<td>198 (54.8)</td>
<td></td>
</tr>
<tr>
<td>Number of newly diagnosed patients seen in the last 12 months</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>≤10</td>
<td>200 (26.2)</td>
<td>143 (35.6)</td>
<td>57 (15.7)</td>
<td></td>
</tr>
<tr>
<td>11–20</td>
<td>167 (21.9)</td>
<td>99 (24.6)</td>
<td>68 (18.8)</td>
<td></td>
</tr>
<tr>
<td>21–50</td>
<td>227 (29.7)</td>
<td>97 (24.1)</td>
<td>130 (35.9)</td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>170 (22.2)</td>
<td>63 (15.7)</td>
<td>107 (29.6)</td>
<td></td>
</tr>
<tr>
<td>Majority of cases followed for &gt;3 years</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>No: N (%)</td>
<td>188 (25.2)</td>
<td>165 (42.1)</td>
<td>23 (6.5)</td>
<td></td>
</tr>
<tr>
<td>Yes: N (%)</td>
<td>557 (74.8)</td>
<td>227 (57.9)</td>
<td>330 (93.5)</td>
<td></td>
</tr>
</tbody>
</table>

*Missing/not reported data were less than 5% for all characteristics and were omitted from this table. Percentage should total to 100 with the exception due to rounding.*
Figure 2 displays the frequency with which surgeons and medical oncologists reported that they would use each of several potential strategies for managing worry about recurrence, from the most to least frequently used across both provider types. Overall, the strategies endorsed most frequently included addressing the concerns themselves and encouraging the women to join a cancer support group. Surgeons were more likely than medical oncologists to recommend joining a support group or offer reading material, whereas medical oncologists were more likely to suggest alternative therapies, make referrals to a psychologist or social worker, and prescribe medication.

Table 2 presents the associations when modeling the use of potential strategies to manage worry by a number of provider and practice characteristics. Significant differences remained by provider type (surgeon versus medical oncologist) as seen in Figure 2, even when controlling for all other provider and practice factors. Other noted differences included that female (compared with male) physicians were more likely to report referring women to a psychologist/social worker and recommending alternative therapies. Providers who had been in practice longer were less likely to encourage their patients to get involved in peer counseling and to prescribe medication. Practice characteristics such as patient volume and the availability of residents and fellows influenced the likelihood of using referrals and alternative therapies. Physicians who reported following most of their patients longer were more likely to address patient concerns themselves compared with those who followed patients for less time.

Discussion

Although addressing worry about recurrence is an important need of breast cancer survivors [1–7], little research has focused on physicians’ behaviors and perspectives...
Table 2. Associations between use of worry management strategies with provider and practice characteristicsa

<table>
<thead>
<tr>
<th>Question</th>
<th>Provider characteristics</th>
<th>Practice characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medical oncologist versus surgeon</td>
<td>Female versus male</td>
</tr>
<tr>
<td>Address her concerns in detail yourself?</td>
<td>9.78 (1.83–181.95)</td>
<td>0.92 (0.27–4.29)</td>
</tr>
<tr>
<td>Refer her to a psychologist or social worker?</td>
<td>2.32 (1.61–3.36)</td>
<td>2.28 (1.52–3.43)</td>
</tr>
<tr>
<td>Encourage her to discuss her concerns with a support group?</td>
<td>0.38 (0.21–0.66)</td>
<td>1.79 (0.93–3.70)</td>
</tr>
<tr>
<td>Encourage her to join a cancer support group?</td>
<td>0.62 (0.44–0.88)</td>
<td>1.30 (0.88–1.93)</td>
</tr>
<tr>
<td>Recommend reading materials?</td>
<td>0.47 (0.32–0.69)</td>
<td>1.29 (0.83–2.04)</td>
</tr>
<tr>
<td>Direct her to online resources?</td>
<td>0.57 (0.40–0.82)</td>
<td>1.19 (0.79–1.82)</td>
</tr>
<tr>
<td>Schedule follow-up visits more frequently?</td>
<td>1.53 (1.09–2.14)</td>
<td>1.17 (0.80–1.73)</td>
</tr>
<tr>
<td>Recommend alternative therapies?</td>
<td>3.09 (2.16–4.47)</td>
<td>3.94 (2.53–6.28)</td>
</tr>
<tr>
<td>Prescribe medication?</td>
<td>7.75 (5.08–12.08)</td>
<td>0.90 (0.58–1.39)</td>
</tr>
</tbody>
</table>

aReported as odds ratios and 95% confidence intervals from multivariable logistic regression models with significant characteristics in bold.

bYears since completing residency (5-year increase).

cNumber of breast cancer patients seen during the past 12 months (>20 compared with ≤20).

dHaving a practice with residents and/or fellows compared to without.

eLength of clinical follow-up (majority of patients seen >3 years compared with ≤3 years).

fYes, the practice arranged same-day appointments for new patients with breast cancer to meet with different clinician specialists prior to definitive surgery compared if the practice did not arranging such appointments. Significant associations in bold.

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Assessing worry about recurrence: is there a role for clinicians to help manage psychosocial distress? A recent review of the literature suggests that the majority of patients who are worried about recurrence and have ongoing concerns about their health may benefit from interventions that focus on reducing worry and its impact on daily functioning [30]. In one study, patients with higher levels of worry were more likely to report lower quality of life and more symptoms of depression [31]. Focused worry management strategies for cancer survivors and their caregivers may include cognitive-behavioral therapy, mindfulness-based stress reduction, and group therapy [32].

In addition, the role of communication between providers and patients is crucial. Clear and open discussions about recurrence risk and management strategies can help alleviate worry and improve overall well-being [33]. Providers should also be trained to recognize and address patients' worries effectively [34].

Despite these findings, worry management strategies are often under-recognized by both providers and patients. A systematic review of worry management interventions in cancer survivors [35] highlighted the need for more research into effective strategies to help reduce worry and improve psychological well-being. In conclusion, addressing worry about recurrence is a multifaceted process that requires a collaborative approach between patients and providers. Further research is needed to identify effective strategies to manage worry and improve quality of life for cancer survivors.
problems [32]. Validated measures assessing worry need to provide guidelines for interpretation of clinically meaningful scores that indicate the need for intervention, such as referral to a mental health professional [8]. The current tools for evaluating fears about cancer recurrence are under-utilized. A systematic review identified a total of 20 relevant multi-dimensional instruments measuring fear of cancer recurrence, 10 of which were brief measures (containing between 2 and 10 items) that would be suitable for use in a clinical setting [48]. Additionally, several of these brief measures were developed specifically for use with breast cancer patients [49–51]. Further studies should evaluate the efficacy of using brief measures in the clinical setting as a means of identifying women with enhanced worry in need of supportive care.

Managing worry about recurrence may require a coordinated approach that enlists the services of multiple care providers and employs a variety of strategies tailored to the setting and the need of the individual patient. Although we found that the use of strategies differed primarily by provider type, some characteristics of the practice setting such as volume, availability of residents/fellows, and/or same-day appointments for patients can influence the supportive services offered. As expected, providers that followed their patients longer had more opportunities to monitor worry and were more likely to endorse addressing a woman’s worry about recurrence concerns in detail themselves. Over 90% of medical oncologists followed their patients more than 3 years, but we found differences by specialty even on multivariable analysis that controlled for duration of follow-up, so we believe these differences in addressing worry merit attention. Differences in the nature of training, normative disciplinary expectations surrounding patient care and follow-up, and personality types of typical surgeons versus oncologists may also be important. For example, medical oncologists may be more comfortable with both patient counseling and pharmacologic interventions than surgeons. Greater understanding of the influence of physicians’ personal qualities, goals, and/or external circumstances that can impact interactions with cancer patients is needed [36,52]. In addition, more empirical studies are needed to assess the relative benefit of interventions to reduce worry and in what circumstances one strategy may be more beneficial than another (online versus cognitive behavioral approaches versus support groups) [8,53].

Our study has a number of strengths, including a relatively high response rate from a national sample of medical oncologists and surgeons who were selected solely on the basis of having seen at least one new breast cancer case in the preceding year. Limitations include self-report about confidence and that behavior reported could be subject to bias relating to recall, or social desirability. In addition, the nine strategies assessed for managing worry about recurrence were not exhaustive and, for example, did not capture referrals to mental health professionals such as a nurse practitioner or psychiatrist. Further studies should focus on a more in-depth examination of various strategies and referral patterns and how they may differ by access and health system factors. Although not within the scope of this study, it would be useful to determine if surgeons and oncologists are aware of resources and support services available at their institutions or within their communities, and the extent to which they utilize these resources.

In summary, given the Institute of Medicine’s recognition that psychosocial care is integral to quality survivorship care [13] further attention needs to be devoted to assessing psychological well-being, recognizing women in distress, and managing women with excessive worry about recurrence. Strategies to manage distress need to be more carefully evaluated across diverse populations and time since diagnosis. Survivorship care plans could provide a vehicle for communication between care providers and the patient [53]. Models of care coordination [54] must be developed and assessed to increase the likelihood that psychological distress such as worry about recurrence is being recognized and addressed.

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Conflict of interest

There is no conflict of interest noted among any of the corresponding authors.

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