

Optimizing the Benefits of Self-Monitoring Among Patients With Cancer

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Purpose/Objectives: To investigate oncology professionals' perspectives about, experience with, and envisioned feasibility of incorporating patient self-monitoring as a patient-centered practice.

Research Approach: An interpretive, descriptive study.

Setting: Four health systems and five cancer centers in three states.

Participants: 38 nurses, nurse practitioners, oncologists, physician assistants, and radiation therapists.

Methodologic Approach: Individual and focus group interviews.

Findings: Three themes were revealed: (a) the concept of self-monitoring is unarticulated and underused by healthcare providers, (b) taking a proactive approach with patients can help generate specific and accurate data for clinical decision making, and (c) self-monitoring by patients may result in challenges imposed by negativity.

Conclusions: This study uncovers the potential contribution of patient self-monitoring as a means of providing patient-generated data that informs clinical decision making, going beyond self-monitoring for self-management only. Because the term *self-monitoring* is not used by clinicians, adoption of an agreed-upon term is recommended as the first step toward developing and implementing a self-monitoring strategy. Findings support the need to reenvision patient education to ensure self-monitoring is clinically useful while preventing an excessive focus on the negative, which may contribute to patient anxiety.

Interpretation: The full potential for self-monitoring by patients is not entirely reached. Because nurses are charged with providing patient education, they are strategically positioned to adopt the term *self-monitoring* and integrate a self-monitoring strategy into patient-centered practice.

Self-monitoring comprises an “awareness of bodily symptoms, sensations, daily activities, and cognitive processes” and “measurements, recordings, or observations that inform cognition and provide information for independent action or consultation with care providers” (Wilde & Garvin, 2007, p. 344). This definition reveals key dimensions of self-awareness, observation, recording, knowledge, and reporting. Self-monitoring is proposed to contribute to self-management through improved symptom recognition and disease regulation (Wilde & Garvin, 2007).

Self-monitoring, or tracking, is becoming more popular in the general population. New technologies highlight the explosion of, and interest in, health-related self-monitoring. Use of the Internet and smartphone applications provide growing opportunities for consumers to track their health (Cha, 2015). People can track exercise, diet, and sleep and participate in online communities where they can track health conditions and share observations. Electronic personalized

health records (ePHRs) allow for data capture and storage of patient-generated health information, and may provide opportunities for patients to share self-monitoring observations with clinicians in person or via patient portals that tether ePHRs with electronic health records (Sujansky & Associates, 2013; Wald & McCormack, 2011).

Studies of patient and provider acceptance of patient portals provide mixed reviews, and their impact on patient outcomes within specific clinical applications is unknown (Irizarry, Dabbs, & Curran, 2015). Other research findings on the outcomes of using these technologies vary. For example, a study of dietary tracking used for weight loss concluded that mobile technology-facilitated tracking worked no better than handwritten efforts; however, the authors noted that using technology would save time (Arens-Volland, Spassova, & Bohn, 2015).

Regardless of the medium patients use to track their health, research supports clinician-guided patient self-monitoring, which has had positive clinical outcomes. This includes self-monitoring in conjunction with self-management of diabetes (American Diabetes Association [ADA], 2015), hypertension (ADA, 2015; Glynn, Murphy, Smith, Schroeder, & Fahey, 2010), weight loss (Burke, Wang, & Sevvick, 2011), and anti-coagulant therapy (ADA, 2015; Heneghan et al., 2006). Patient pain diaries also have been studied within the context of self-management and self-care in oncology. Pain diaries have been useful to patients (de Wit et al., 1999), providing a greater sense of control and a greater awareness of pain, and useful to caregivers (Schumacher et al., 2002). Use of pain diaries in association with education and clear recommendations of when to contact a prescriber has resulted in improvements in pain among patients with cancer (Vallières, Aubin, Blondeau, Simard, & Giguère, 2006). Similarly, the PRO-SELF[®] Pain Control Program, which combines instructions on how to complete a pain management diary with academic detailing and nurse coaching, has been shown to improve patient knowledge of and skills for pain management (Kim et al., 2004; Rustøen et al., 2012), as well as appropriate prescribing of analgesia (Miaskowski et al., 2004).

Patients with cancer have begun to examine other ways of self-monitoring, going beyond the use of pain diaries. In one study, patients beginning chemotherapy were randomized to use a daily calendar to track a variety of side effects and symptoms. They reported bringing the completed calendar to the clinic to help them remember events and to show their healthcare providers what was happening, with about 25% indicating they shared this information only with nurses (Hermansen-Kobulnicky, Wiederholt, & Chewning, 2004). A qualitative study examining

patient experiences with self-initiated self-monitoring revealed that participants' self-monitoring nurtured a greater sense of control and self-advocacy (Purtzer & Hermansen-Kobulnicky, 2013). The perspectives of oncology professionals on patient self-monitoring are clearly needed, as about 33% of patients with cancer potentially self-monitor their own volition (Hermansen-Kobulnicky, 2009; Hermansen-Kobulnicky et al., 2004), and opportunities have been documented to improve pain management and patient engagement via this intervention.

The perspectives of oncology professionals on patient self-monitoring are understudied. Oncology nurses have said that a symptom-reporting tool for patients to document at home is useful for treatment decisions (Tucci & Bartels, 1998). In addition, findings from a small pilot survey of oncology nurses revealed that respondents, on average, perceived that self-monitoring often helps them to efficiently obtain accurate information for symptom management. It also showed that respondents often to always agree that patient self-monitoring helps them to understand patients' perspective (Hermansen-Kobulnicky & Purtzer, 2014). Therefore, evidence points to the clinical usefulness of and an opportunity for recognizing individual patient needs, a prerequisite for patient-centered care. In addition, the continued and growing use of symptom-assessment tools to help patients improve their self-monitoring of symptoms is strong evidence of the need to gather more reliable and specific data for improved decision making (Nekolaichuk, Watanabe, & Beaumont, 2008; O'Sullivan, Dupuis, & Sung, 2015). Additional research on the perspectives of oncology nurses and other healthcare providers on patient self-monitoring is needed to more fully elucidate its application in cancer care.

Although patient self-monitoring has been incorporated into self-management practices on a limited basis (e.g., pain management) and studied from the patient and caregiver perspectives, to be optimized within cancer care, the perspectives of oncology professionals must be examined. The objectives of this study were to investigate oncology professional perspectives about, experience with, and envisioned feasibility of incorporating patient-generated self-monitoring as a patient-centered practice.

Methods

This is an interpretive, descriptive study. This research design is well-suited for disciplines like nursing, as it involves an applied qualitative approach at the "level of intimate individual experience" (Thorne, 2008, p. 31). Semistructured individual and focus group interviews were conducted with oncology

professionals. The sample consisted of nurses, nurse practitioners, oncologists, physician assistants, and radiation therapists in four health systems and five cancer centers located in three states. For recruitment purposes, key contacts (e.g., managers, directors) were identified at each cancer center. These contacts assisted with information dissemination in the recruitment and scheduling of participants. Convenience sampling was used based on practitioner availability and willingness. Contacts also provided entry for recruitment by strongly encouraging participation, disseminating study information approved by the institutional review board, and/or providing opportunities to sign up. Individual interviews with two oncologists and one nurse practitioner were conducted when focus groups were not logistically feasible. Honoraria were offered for participation (\$200 for oncologists and \$100 for others).

Data Collection

Thirty-eight oncology professionals participated in interviews. Nine focus group and three individual interviews were conducted in a three-month period. Individual interviews were conducted with clinicians who had private practices and whose participation in focus groups was limited because of distance. Team-based cancer care was noted as each focus group represented a significant portion of their team from a respective facility. No participant spoke of working in isolation but rather with professionals of other disciplines. Participants' professions were collected to describe the sample (see Table 1). Focus group participants used pseudonyms during data collection to protect confidentiality. Interview questions with content

TABLE 1. Professions of Study Participants (N = 38)

Profession	n
Administration	
Director of oncology services	1
Patient coordinator	1
Medicine	
Medical oncologist	3
Radiation oncologist	2
Physician assistant	2
Nursing	
Patient navigator	2
Nurse practitioner	2
Nurse researcher	3
Charge nurse or manager	3
Infusion nurse	11
Radiation nurse	3
Clinic nurse	1
Certified nurse assistant	1
Radiation therapy	
Radiation therapist	3

INTRODUCTORY SCRIPT

As you know, our topic is patient self-monitoring. By this I'm going to refer to a somewhat lengthy definition of self-monitoring that includes having an "awareness of bodily symptoms, sensations, daily activities, and cognitive processes," and conducting "measurements, recordings, or observations that inform cognition and provide information for independent action or consultation with care providers" (Wilde & Garvin, 2007, p. 344). This is the definition my collaborator and I have considered, but we want to know what self-monitoring means to you.

INTERVIEW QUESTIONS

- What is your experience with self-monitoring?
- What are the benefits of patient self-monitoring?
- What would enhance the benefits?
- What are the drawbacks of patient self-monitoring?
- What would lessen the drawbacks?
- What is the exchange like between you and your patients regarding self-monitoring?
- In an ideal world, what would a visit between you and a patient that somehow involved patient self-monitoring look like?
- What do you envision being the potential of self-monitoring?

FIGURE 1. Introductory Script and Interview Questions

domains and follow-up question probes were decided a priori, and questions addressed participants' definition of self-monitoring, experiences with patient self-monitoring, and future vision for self-monitoring (see Figure 1). Clarification questions were also asked as needed (Kvale, 1996).

Face-to-face interviews were conducted by the authors at the participants' healthcare facilities, and two interviews were conducted by telephone with prescribers who had private practices and whose locations and availability necessitated interview by telephone. Interviews were digitally recorded and transcribed verbatim, and transcripts were reviewed for accuracy. Institutional review board approval was obtained from the University of Wyoming prior to participant recruitment, and written consent of participants was sought prior to the interviews.

Data Analysis

The unit of analysis for the individual and focus group interviews was the individual and group, respectively. The basis of analysis included verbatim transcripts, interview observations, and debriefing notes. Analysis included reflexivity—that is, critical self-awareness during interviews and debriefings as part of the iterative process to interpret and revise (Ulin, Robinson, & Tolley, 2005). Harding's (2013) coding process, which offers a means to interpret data in an inductive manner resulting in thematic representation, provided guidance for analysis. Initial codes were identified upon reading the transcripts. Also,

key phrases were identified and notes were written. Codes were assigned to preliminary categories, and interrelatedness among categories was noted. Categories were revised through ongoing comparisons and contrasts, and themes and subthemes emerged through the interpretation of codes in each category. Microsoft Excel® spreadsheets were used to sort categories and related codes. As recommended by Thorne (2008), regular and intensive brainstorming sessions were used to move analysis beyond coding. These sessions were documented using analytic memos and notes, which served as an internal dialogue that facilitated the organizing and conceptualizing of the data (Thorne, 2008).

Findings

Three themes were revealed: (a) self-monitoring was found to be unarticulated and underused by healthcare providers; (b) participants described how taking a proactive approach with patients can help generate specific and accurate data for clinical decision making; and (c) participants acknowledged self-monitoring challenges related to negativity.

Theme I

Participants reported that they did not use the term *self-monitoring*; however, they welcomed a means to be more intentional in using it.

Now that we have a name for it, “self-monitoring” . . . an identified concept, you know, seriously, that . . . can make that become something that is instituted on a semiformal basis or something that we talk about.

Participants who did not use the word used alternative terms to describe patient self-monitoring, including but not limited to *paying attention*, *tracking*, and *journaling*. Using these terms increased self-awareness and/or generated needed patient information related to their cancer experience. As a group, participants described the term *self-monitoring* as awareness and the recording of thoughts, symptoms, and daily activities (Wilde & Garvin, 2007); however, individually, none reported using the term in this comprehensive way. Self-monitoring was explained as “a concept that’s used in other chronic diseases like diabetes, but not one that . . . we fully embrace in oncology.” One participant said,

I haven’t used that term, but it really got me thinking. . . . We talk about the potential side effects, the medications . . . to report these things if they occur, you know, so we encourage them to do that, but we don’t really talk specifically about recording anything.

Theme II

Taking a proactive rather than reactive approach was discussed by participants, who acknowledged the benefits of talking with patients regarding potential needs. This approach included three subthemes: (a) self-monitoring can inform clinician follow-up with patients, (b) specificity with self-monitoring is key in managing symptoms, and (c) self-monitoring improves accuracy of patient-generated clinical data.

Self-monitoring can inform clinician follow-up with patients: Participants reported asking patients to track their cancer experience in various ways, often with the intent of using the information on follow-up.

[I talk about] taking notes about the timing of things and bringing those back in . . . for a follow-up visit so that we know when things are likely to happen, and [we] maybe change our course of action so we can take more of a preventive approach rather than a reactive approach.

The perceived value of proactively discussing this practice with patients is clear. One participant stated, “When I’ve asked people to log things . . . it’s always helpful. You know, it makes all the difference in the world.” While some participants simply ask patients if they have been “observing any changes that [they] haven’t had prior,” without suggesting to keep any written record, others talk with patients more about keeping track at home.

I would say the majority of people don’t [self-monitor]. . . . So when patients are on . . . active treatment, we encourage them to keep a log . . . that helps us determine what time frame [they had] the symptoms. [Was] it related to the chemotherapy or . . . related to the cancer? . . . That way . . . we can try to make recommendations [like] when [is] the best time for [the] nausea med.

Specificity with self-monitoring is key in managing symptoms: Specific self-monitoring information patients bring to appointments is useful because it is, according to one participant, “concrete. It’s right there. It’s not vague.” Specific self-monitoring information helps healthcare providers identify patterns in patient symptoms, reduces uncertainty, and improves decision making.

It’s helpful to see trends and for the patient to be aware of what days things peaked . . . because there’s a lot of work-arounds we can do. . . . We’re pretty calendar-driven . . . [which is] most helpful . . . when we can really get a clear picture of what happened . . . and then address it for future cycles so they can manage those symptoms better before they hit so hard.

Participants stressed the need for specific information for symptom management, saying, “I always tell them to start monitoring after chemotherapy between day 7 and day 10, but they really need to be diligent about taking their temperature if they don’t do it any other time.” The interactive nature of using specific self-monitoring information for symptom management is evidenced by another participant who explained, “If I’m really working with someone to optimize medication, I’ll ask them to journal things and then bring it in to their next visit if I’m working with them on a particular symptom.”

Self-monitoring improves accuracy of patient-generated clinical data: Accuracy of patient self-reports can be compromised if they do not proactively record their cancer experience via self-monitoring.

I don’t know how [patients] would remember. I can’t remember somebody’s temperature 10 minutes later. . . . Well, sometimes, they may transpose. You know, you’re like, “It was 102,” instead of 100.2. . . . I mean, everybody does that, so just jot it down. It . . . it helps you.

One participant admitted, “I wonder a lot. Especially with the cognitive changes we see . . . [some patients] already have some age-related cognition issues.” Even without “chemobrain,” patients may find that relying on recall is difficult. It can also lead to inaccuracies.

Theme III

Although clinically useful, patient self-monitoring can present challenges to clinicians because of the inherent negativity patients feel with their cancer diagnoses. This is evidenced within three subthemes: (a) the dilemma of patient reaction to self-monitoring education, (b) the unintended result of problem-focused nursing assessment, and (c) the need to support normalcy within the symptom experience.

The dilemma of patient reaction to self-monitoring education: Participants spoke of their responsibility to offer anticipatory guidance regarding possible cancer- or treatment-related symptoms. They expressed concern about patients reacting with anxiety when they coupled this guidance with self-monitoring instruction.

We do a poor job at this point educating people on what to monitor because then . . . they develop such anxiety about changes in their body and how they’re feeling. It’s hard to dial that down sometimes and know what’s appropriate to call in about. “What am I worrying too much about? If I have pain, how long is it appropriate to wait before I let somebody know about it?”

Another participant indicated that she was reluctant to use self-monitoring tools as part of self-monitoring education because of her tendency to focus on negative side effects.

I’m not typically one to pass those [self-monitoring tools] out. . . . I want people to be aware of what’s happening and report side effects, but I don’t want them to feel like they have to be looking for them at all times and be in that mindset [of] “What’s wrong with me now? Oh, this! Oh, I’m getting nauseous.” [They] almost have too much anxiety about monitoring their side effects. Sometimes I think you can overreport if your mind is wrapped around having to check for this and check for this and am I feeling this?

Participants have observed that some patients display self-monitoring extremes and excessive focus.

Sometimes they monitor a little [too] closely . . . [go a] little overboard . . . but they’re scared. . . . They don’t know what’s appropriate and what isn’t.

One participant described how a patient “brought in a [stool] sample that he didn’t need to bring in. . . . It’s like they think the doctor wants to see everything. . . . [Others brought in] sputum in a jar or in a tissue.”

The unintended result of problem-focused nursing assessment: The negative nature of the cancer experience may unintentionally be reinforced by nurses during patient assessment. A nurse who is herself a cancer survivor indicated that she did not value self-monitoring because it continually reminded her of the disease.

They really pushed from the nursing standpoint of “How often did you take the nausea medicine?” “How much did you drink?” And I totally did not want to do that, because, to me, that just reminded me of how bad I felt. You know. It’s like when your hair falls out. It’s like in your face and makes it real. . . . It’s real enough as it is.

The need to support normalcy within the symptom experience: Participants wanted their patients to live as normal a life as possible. As one participant noted, “One of my patients told me, ‘Don’t let cancer define you’. . . . [Patients] really should be looking a lot at the big picture.” Another participant stated, “Sometimes [the patients] forget to come up for air and realize that they need to have some normalcy in their life.”

[Patients] get caught up on their 13 diarrheas and don’t focus on things outside of their treatment. . . . Well, not to blow off symptoms . . . when you have diarrhea, you don’t have a normal life. . . .

[Patients] get so focused worrying about the what-ifs, the worst-case scenarios, that sometimes they don't always look at keeping some balance and . . . some normalcy in their life.

One suggested means to facilitate normalcy is to acknowledge the positive and minimize excessive negativity. Participants encouraged patients to journal positive situations and related thoughts. "There's a lot of evidence out there that proves that journaling is very healthy, but I would ask that you make a point to include something positive every day. What was good about today?"

Sometimes it's so much [negativity] that you almost have to try to help them step back and say, "Okay, now maybe you could even put in something positive that happened during the day. Can you find something positive, even if it's about the weather or about someone, a neighbor who brought your family dinner?"

Discussion

This study examined oncology professionals' perspectives of, and experience with, self-monitoring among patients with cancer. Findings highlight oncology clinicians' use of a variety of ways to refer, in part, to Wilde and Garvin's (2007) dimensions of self-monitoring: self-awareness, observation, recording, knowledge, and reporting. For example, some participants reported asking patients to pay attention to their symptoms (self-awareness) to improve patient self-report, and yet they did not discuss keeping a written record. Even when participants used one or more of these strategies, they did not always proactively address them, leaving untapped benefits of self-monitoring, such as improving self-report of symptoms and quality of care.

When they were more proactive in encouraging patient self-monitoring, participants noted that it aided clinical decision making and provided greater accuracy and specificity for symptom management. These findings add to existing knowledge, as previous research has focused on the use of self-monitoring among patients with cancer as part of an intervention to improve the self-care and self-management primarily of pain (Kim et al., 2004; Miaskowski et al., 2004; Rustøen et al., 2012; Schumacher et al., 2002; Vallières et al., 2006; West et al., 2003). The authors' findings also are consistent with earlier research that examined the use of pain diaries and found that they were associated with more accurate self-reports (de Wit et al., 1999).

In the current study, the perceived clinical benefits of patient self-monitoring were juxtaposed with the

drawbacks of negativity. Paying closer attention to the cancer experience, with all its negative sequelae and emotions, contributed to anxiety in some patients. Indeed, a study in which patients with breast cancer were asked to journal their thoughts and feelings about cancer revealed more negative emotional content. Anxiety and/or depressive symptoms were expressed 6%–7% more after patients started journaling (Smith, Anderson-Hanley, Langrock, & Compas, 2005). Although a small (but significant) contributor in that study, this finding corroborated the lack of a clear, proactive approach among clinicians to harness rich and potentially more reliable information from patients. In contrast to this negative impact, Schumacher et al. (2002) found that keeping a pain diary was helpful to patients with cancer because it provided an improved awareness of anxiety and/or depression and a greater sense of control. Perhaps helping patients to strategically focus on a limited number of symptoms that are particularly bothersome and/or clinically relevant would help maximize the benefits of self-monitoring and minimize patient anxiety.

Participants spoke of the need for normalcy among patients who seem overly fixated on the negative. This desire for normalcy has been documented among patients who have expressed the desire to reclaim normalcy in their lives and social roles (Schapmire, Head, & Faul, 2012). Although few knew how to assist patients with this, recording positive things (cancer-related or not) was suggested as an antidote. Smith et al. (2005) found that the ratio of positive to negative journal entries did not explain any variance in anxiety and depression scores. Perhaps intentionally introducing the self-monitoring of positive life experiences along with negative symptoms would lead to a greater sense of normalcy for patients; however, future research is needed to ascertain the impact of this approach.

Although self-monitoring with extensive patient education has been shown to improve the patient experience of pain (Miaskowski et al., 2004; Vallières et al., 2006), the best approach to patient self-monitoring (whether strictly focused on symptoms or not) has yet to be established. This is also the case in patient self-monitoring outside of cancer. For example, a review of self-monitoring for weight loss concluded that significant and consistent weight loss was associated with more frequent self-monitoring of diet, physical activity, or weight, but the optimal intensity, frequency, and duration of self-monitoring was unknown (Burke et al., 2011). Future research is needed to discern the best way to optimize the positive impact of patient self-monitoring within the context of cancer care, while minimizing any anxiety brought on by focusing on the negative. Talking with patients and

oncology professionals would provide valuable opportunities to compare and contrast self-monitoring experiences, including the role anxiety plays in given patients.

Limitations

Participants were recruited based on availability and willingness to discuss patient self-monitoring as it applies to their practices. They were not limited to nursing; however, all were aware of patient self-monitoring and/or were, to some extent, involved in discussions with patients about the topic. This is notable and warrants a broader, interprofessional examination of this topic. Two of the cancer centers in this study employ a social worker and/or a pharmacist; however, none participated in this study and so their perspectives were not heard. Some focus groups contained individuals from a single profession (e.g., nursing, medicine), representing a portion of the team, whereas others represented the entire team. Although the interprofessional focus groups introduced opportunities for a rich discussion of varied perspectives, it precluded any comparison of these perspectives within the analysis. Finally, participants represented five different cancer centers in four health systems. New themes could be identified upon sampling additional facilities and other professionals who care for patients with cancer.

Implications for Nursing

With the growing use of oral chemotherapy agents and related safety and adherence concerns (Weingart et al., 2008), a self-monitoring strategy can help to address the American Society of Clinical Oncology/Oncology Nursing Society's chemotherapy administration safety standards regarding oral chemotherapy adherence and toxicity monitoring. Looking more broadly at all chemotherapy, Standard 18F states a need to document "patient feedback reflecting understanding and engagement" (Neuss et al., 2013, p. 231). One means of accomplishing this is using a self-monitoring strategy.

Adoption of an agreed-upon term and the related conceptualization must be the first steps in intentionally integrating patient self-monitoring into any practice. Facilitating discussions of the possibilities is a good place to start. The interviews themselves appeared to generate greater awareness of the potential for patient self-monitoring. In addition, focus group participants exchanged affirmations of applicability when asked to consider the future of patient self-monitoring within their practice sites. To move the adoption of the term forward within a practice site and more broadly within oncology, a highly respected,

Knowledge Translation

- Understanding the use of the multiple dimensions of self-monitoring and adopting the term *self-monitoring* will help clinicians more fully integrate self-monitoring strategies as a patient-centered practice.
- Patient self-monitoring provides oncology professionals with clinically useful information that informs cancer care.
- The quality of patient self-monitoring experiences may be improved by encouraging patients to find a sense of normalcy within their symptom experience.

influential leader should champion the need to use patient self-monitoring (Rogers, 1995).

A common understanding of self-monitoring preempts educational strategies for patients and clinicians on how to generate and use patient self-monitoring information. To adopt self-monitoring into practice, professionals need to not only be aware of the possibilities but be knowledgeable of the processes involved. A self-monitoring strategy encompassing clinician coaching and education, patient implementation of self-monitoring at home, and the intentional use of self-monitoring information by clinicians are needed. To develop this comprehensive strategy, clinicians need to answer questions within each facility regarding how patient self-monitoring should be integrated. For example, who is best suited to coach and educate patients on self-monitoring? When is the best time to have these conversations with patients? Who will intentionally engage patients in conversations about their self-monitoring? What patient-centered approaches should be implemented? To maximize patient follow-through, clinicians should start by integrating questions into patient assessment to identify self-monitoring preferences and needs (Purtzer & Hermansen-Kobulnicky, 2013).

Conclusion

Self-monitoring is reportedly underused, but, when used proactively for symptom management, has yielded many benefits. Drawbacks related to a negative focus are also identified by participants, suggesting that a clinician's role should include encouraging patients to find a sense of normalcy within their symptom experience.

This study uncovers the potential contribution of patient self-monitoring to provide access to accurate and specific patient-generated data that informs clinical decision making, going beyond self-monitoring for self-management alone. If clinicians do not use the term *self-monitoring*, they should adopt an agreed-upon term as the first step in developing and implementing

a self-monitoring strategy. Findings support the need to reenvision patient education efforts to ensure that self-monitoring is clinically useful while preventing excessive focus on negative experiences, which may contribute to patient anxiety. Future research should also examine how to best incorporate a self-monitoring strategy into an existing process of care to facilitate patient-centeredness.

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