

“How I kept track of it of course was my business”: Cancer patient self-monitoring as self-stylized work

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ABSTRACT

Objectives: Self-monitoring behaviors of cancer patients benefit patients, caregivers, and providers, and yet the phenomenon of self-monitoring from the cancer-patient perspective has not been studied. We examined cancer patients' self-monitoring preferences and practices, focusing on the meaning of self-monitoring within the cancer experience.

Methods: Semi-structured interviews were conducted among adult cancer patients who had been seen at least once at a rural United States cancer center. Questions sought out the meaning of self-monitoring and its practical aspects. Qualitative data were analyzed by adapting the four-stepped method by Giorgi for empirical phenomenological analysis.

Results: Twenty participants were interviewed (11 women and 9 men). Transcribed interviews revealed that cancer patient self-monitoring is self-stylized work that ranges from simple to complex, while being both idiosyncratic and routine. Participants reported using tools with systems for use that fit their distinctive lives for the purpose of understanding and using information they deemed to be important in their cancer care. Three conceptual categories were discerned from the data that help to elucidate this self-stylized work as fitting their individual priorities and preferences, reflecting their identities, and being born of their work lives.

Significance of results: Findings highlight patients' unique self-monitoring preferences and practices, calling into question the assumption that the sole use of standardized tools are the most effective approach to engaging patients in this practice. Self-monitoring efforts can be validated when providers welcome or adapt to patients' self-stylized tools and systems. Doing so may present opportunity for improved communications and patient-centered care.

KEYWORDS: Self-monitoring, Occupation, Preference, Cancer, Symptom monitoring, Self-management

INTRODUCTION

Recent reports from the World Health Organization (WHO) acknowledge the value of promoting and using the expertise patients have in their own illness experience (World Health Organization, 2004; 2011). One way to enable patients to contribute their expertise to better manage their diseases and associated risks is through the supportive-care strategy of self-monitoring (World Health Organization, 2004). While cancer patients desire large amounts of

“external” information (i.e., obtained outside of themselves) such as wanting to know about the impact of treatment (Skalla et al., 2004), knowledge is also found in attending to the “internal” information patients generate through their everyday living with illness and treatment (Hermansen-Kobulnicky, 2009; Hermansen-Kobulnicky, Weiderholt & Chewning, 2004). Self-monitoring is proposed to be a key way for patients to become more aware of valuable idiosyncratic data to inform problem-solving and decision-making (Chewning & Sleath, 1996; Hermansen-Kobulnicky et al., 2004), and self-management (Wilde & Garvin, 2007). Whether intervention-based or anecdotal, published uses of self-monitoring tools in oncology are standardized with minimal

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recognition of individual preferences for, and practices of, self-monitoring. Because of this, little is known of how cancer patients may self-monitor without professional intervention and the influence of the professional's agenda.

Self-monitoring in health care has been defined to encompass an individual's awareness of their own thought processes, activities and physical symptoms and the measuring, observing, recording and tracking of such phenomena (Wilde & Garvin, 2007). Up to one-third of cancer patients may self-monitor of their own volition (Hermansen-Kobulnicky, 2009; Hermansen-Kobulnicky et al., 2004). Research findings and published anecdotal evidence suggest cancer patient self-monitoring efforts are useful to patients, their caregivers and health care providers with benefits including: a heightened awareness of symptoms and an enhanced sense of control (Schumacher et al., 2002), valuable data for clinical problem-solving (de Wit et al., 1999; Maunsell et al., 2000; Hermansen-Kobulnicky et al., 2004), improved patient recall and enhanced patient coping (de Wit et al., 1999), improved symptom management (Hoekstra et al., 2006; Vallières et al., 2006), and improved communication with providers (Hermansen-Kobulnicky et al., 2004; Schumacher et al., 2002; Tucci & Bartels, 1998).

In spite of the apparent benefits of self-monitoring, the phenomenon of cancer patient self-monitoring from the patient perspective has been studied very little (Wilde & Garvin, 2007). We examined cancer patients' self-monitoring preferences and practices, focusing on the personal meaning of self-monitoring within the lived cancer experience. Study findings can offer valuable insights that facilitate sustainable self-monitoring practices, potentially improving existing patient care models.

METHODS

Design and Study Participants

Qualitative interview data were collected as part of a multi-method investigation that also included a mailed survey (Hermansen-Kobulnicky, 2009). Face-to-face, semi-structured interviews were conducted at a rural, United States cancer center affiliated with a local hospital. University and local hospital Institutional Review Boards approved the research protocol. Participants were adults aged 18 or older seen at least once at the cancer center for diagnosis, treatment, a second opinion or follow-up care in the previous 18 months. Exclusion criteria were not having a previous or current cancer diagnosis and being unavailable for interview.

Participants were identified via a postcard included in an anonymous mailed survey, as part of the multi-method study. The self-addressed postcard served as a means to contact the PI if interested in being interviewed about self-monitoring. The PI contacted those who mailed postcards to confirm eligibility and interest and to arrange for an interview. Of 231 postcards mailed with the survey, 54 postcards were returned to the PI (23.4% response) and 40 individuals were successfully contacted. Of those contacted, 20 were not scheduled to complete an interview due to logistical difficulties or disinterest.

The research team conducted one interview per participant with all interviews occurring at the cancer center except for one conducted via telephone. Participants were offered \$15 for their time. Interviews were digitally audio-recorded and transcribed for analysis. Data reported were de-identified to maintain participant confidentiality.

Data Collection and Analysis

Four main interview questions were asked: (1) Tell me about your experience with keeping written track of your health; (2) What sorts of things do you write down? (3) How do you record things? and (4) What keeps you (kept you) writing things down? Questions 1 and 4 pertained to the meaning of self-monitoring and questions 2 and 3 addressed the practice of self-monitoring. Follow-up probes were asked as needed to foster in-depth descriptions. Throughout the interviews, checks regarding the meaning were made as a means of validation (Kvale, 1996). In addition to the interviews, data from medical records were gathered to describe the sample.

Qualitative data were analyzed by adapting the four-stepped method by Giorgi (1985) for empirical phenomenological analysis. First, interview transcripts were read to get a sense of the whole narrative. Next, transcripts were read and re-read again to identify context-laden meaning units. These meaning units were then reviewed and efforts were made to express the psychological insights they contained, first using the language of the participants followed by a conceptualization in the language of the researcher in attempt to capture the essence of the meaning. Last, statements were synthesized into a shorter, consistent descriptive statement to capture the meaning of the lived experience. The method was conducted by one research team member who brought a pharmacy and behavioral science perspective with interpretation affirmed by a second researcher with a nursing and educational psychology background. In addition, a senior qualitative researcher was consulted early in the analysis. The study was approached as a means to identify with

participants without presuppositions (Moustakas, 1994) and to describe the lived experience of self-monitoring within the cancer experience.

RESULTS

Nine men and 11 women aged 19 to 84 years completed interviews that ranged in length from 35 to 55 minutes. Due to the rural nature of the data collection, details are withheld or slightly changed where needed, while staying true to the meaning of the text, in attempt to protect participants' anonymity. Cancer diagnoses included eight breast cancers, four prostate cancers, six non-Hodgkin lymphomas, one Hodgkin lymphoma, and one malignant brain tumor. Participants reported various treatment combinations including chemotherapy, radiation, and/or surgery and all had completed treatment. In the first two interviews, participants' occupations seemed relevant to their self-monitoring practices, and so occupations were sought in the questioning if it was not revealed unsolicited. Occupations (with some retirees) included: engineer, librarian, historian, journalist, professor, secretary, school bus driver, college student, program manager, tradesman, medical assistant, rancher, research scientist, small business owner, and wife/homemaker.

Transcripts revealed that cancer patient self-monitoring is self-stylized work that is both idiosyncratic and routine, ranging from simple to complex, and purposely shared or not shared with others. The self-monitoring work reported involved tools and the systems or processes surrounding their use that were a good fit for their distinctive lives. Tools already in use prior to cancer diagnoses were redirected to cancer applications for understanding and using the information they deemed to be important, in ways that suited them best. New tools introduced by others were adapted and systems were developed for use. Three conceptual categories related to this self-stylized work to self-monitor and manage information were discovered from delving deep into the how and why of self-monitoring the cancer experience. This self-stylized work is detailed here in that it: (1) Fits One's Priorities and Preferences, (2) Reflects One's Identity, and (3) is Born of One's Work Life.

Self-Stylized Work

Fits One's Priorities and Preferences

Tools and systems were developed or adapted to fit participant priorities and preferences. Some reported monitoring health or exercise-related phenomena such as diet or running while others recorded major and minor life events such as trips taken

and daily "to do" lists, prior to monitoring cancer phenomena such as health status and responses to treatment. A few participants reported adapting tools imposed on them by health care providers upon the cancer diagnosis. The systems developed go beyond the seemingly straightforward systematic recording of phenomena to include the process of incorporating the tool use into one's daily living. Here, one cancer patient describes tracking what was important to him as well as the system surrounding it.

... I filled out a rather silly form about urination ... on every occasion that I see a doctor ... [in contrast] I kept track of bowel movements to find out what effect that was having because I was concerned about that ... I kept it up for months 'cause I wanted to see what was happening (Interview 2).

This individual kept track of his bowels for himself, not his providers, and he persisted even after his treatment was completed. The system this former Air Force officer developed followed from his usual routine of building model airplanes at his desk in the basement. By incorporating self-monitoring into his daily routine, he did what was important to him in a meaningful environment.

The folder [with his tracking data] was in ... the laundry room on top of the chest of drawers containing model planes. So I just kept it down there with my other stuff ... Well I would climb down there. Most of the time I was painting plane models ... It was just part of the routine I suppose. And I was just curious as to what was going to happen and how I was responding to it all [his past radiation treatments] (Interview 2).

Another patient explained how upon being diagnosed with cancer, keeping a large binder was a high priority, "And to me that was one of the most crucial things to do, was to have some place to start putting things" (Interview 1). She also attempted to journal, but found through trial and error what fit her needs best.

I'm very bad on pen and paper. I'm big on the computer. And so I started emails to people to talk about what I was going through ... and then I would sort of cut and paste ... and add pages [to my binder] ... I tried ... to do a book of writing and it's not me. I got not very far and then I sort of just, you know, quit on that (Interview 1).

Two women who received a booklet from cancer care professionals responded very differently to it,

revealing different priorities and preferences for tracking. One used the booklet to keep records of “everything” including treatment, labs, and questions for her physician, yet she also went beyond it, adapting her system to her own priorities. Citing a nurse’s suggestion and her family’s prodding, she kept a special journal “with a really nice pen” in order “to share feelings that I had within myself” (Interview 18). While she was not “that type” to write about her feelings, she described how “you feel those lonely times, those scared times . . . [and] you wrote those down. You share those with your book.” The other woman did not use the booklet that included “little forms that you could fill out for different symptoms” stating, “I did not care for that method.” Instead, she “would sit down and . . . just using a little scrap piece of paper . . . [she would] try to write a quick note . . . to remember to ask the big stuff” (Interview 3). Interestingly, during the interview this same woman said she wished she would have kept a journal to help her remember and to help her “figure out what was going on.” Although she considered journaling when only two treatments remained, and opted not to, thinking, “Why bother now?” she admitted wishing she would have begun at that time because “when treatments stopped and all the drugs stopped that was my hardest time . . . physically . . . and mentally too” (Interview 3).

Some participants preferred to have something they could easily carry with them and elaborated upon the system aspect of using a seemingly simple, portable tool. One woman noted a small notebook would fit in her purse, clarifying “so I have it with me all the time” (Interview 9). Another participant kept a breast pocket-sized notebook. He used it to daily track his cancer experience during his 6-weeks of radiation treatments noting, “I just had [my little notebook] on the TV stand when I got home and was watching the news or something I would just jot it down, just whatever I remember.” He would transfer the written information to his computer, “at the end of the day, I sit down and look at my e-mail and then go back . . . it reminds me of how it went” (Interview 8).

While self-monitoring was preferred by most, for two participants tracking cancer-related information was neither a priority nor a preference. One participant instead valued discussions with family and church friends, and noted, “Nothing really appeals to me about writing just because I hate to write . . . I cannot put my thoughts down on paper. I can verbalize things a lot more . . . It’s been that way most of my life” (Interview 7). This same participant kept written track of her blood pressure the day before her doctor appointments and kept a folder with her personal health information, carrying it to appoint-

ments to avoid having to write her health history yet again.

Reflects One’s Identity

Self-monitoring that reflects one’s identity refers to personal characteristics and a sense of self that are mirrored in the tracking tools and systems used. For example, one participant described herself as “obsessive-compulsive” (Interview 1). Her self-monitoring system was very methodical and organized, embodying who she is. When describing her tool, she explained, “My brains are right in that book [a binder with A to Z tabs].” She described a routine of using an under-used room in her home where she regularly sat at a table where she kept her binder in or on top of a designated bag with her “current planner” so she had it all ready for every clinic appointment.

Another participant, an engineer, explained how he kept track of his cancer-related symptoms with graphs and plots.

. . . they said, ‘keep track of it.’ Well okay. I kept track of it. And how I kept track of it, of course, was my business. And this was for my personal use of ‘how am I gonna keep all of this stuff straight?’ . . . It just was a routine that just matched my personality, I guess (Interview 6).

A rancher reflected her identity in her self-monitoring style as follows:

My people are ranch people . . . My mother and most ranch wives . . . keep their ranch records every day. Sort of a diary form . . . This [is] a daily record . . . I have done it [kept a journal] off and on most of my life (Interview 13).

Related to self-identity, these self-stylized tools were very personal in nature as evidenced by the naming of them, for example, “Bobbie’s Bible” (a three-ring binder), “My Little Pink Notebook” (a notebook), and “Naomi’s Care” (a spiral notebook).

Symptom monitoring appears to be done without knowledge that others might be inclined to do so as well; it is believed to be odd or unusual behavior that is unappreciated by others, reflecting one’s self-concept. One woman recorded her side effects and symptoms on a calendar she strategically added to her cancer clinic binder (Interview 5). She regularly brought her calendar and the binder to her appointments to show the nurses her experiences and noted, “They probably thought I was a little strange.” Interestingly, her remarks are juxtaposed later with her description of the nurses telling her “to watch

and see how I felt” because they “wanted to know what was going to work for me so that I . . . wouldn’t feel bad.” Another participant had kept 15 years of daily journals, tracking her health and exercise. She shared this information with her doctors that eventually aided in her diagnosis and yet she admitted, “I felt like I was treated kind of like a hypochondriac” (Interview 20).

Born of One’s Work Life

Self-stylized self-monitoring tools and systems were not novel to the cancer experience. Many were developed to manage information at work or in the home where the tools and/or the systems had been refined and the value proven. One retired secretary stated:

I had a bulletin board [at work] . . . and it was becoming more helter-skelter . . . It’s not efficient and so, that’s when I, early on, decided that I needed to have a [four-inch] binder . . . And so I decided to just get A through Z [tabs] and keep it standing on my desk so that almost any question [could be found in it]. It was fast and it was right there and it ended up saving my life a gazillion times . . . Once I started [with cancer] . . . and I haven’t used an A through Z book in years and years . . . but immediately it came back, like this is going to be the only way to do this or I’m getting so inundated with crap (Interview 1).

Some participants described using simple organizational tools and systems at home (such as filing cabinets and related filing systems), but more of these originated with their work-life. Examples of the latter include a novice historian who kept a daily “historical record,” a program director who used a detailed calendar as done at work, two ranch wives who kept a detailed diary as was kept on their ranches, an engineer who used spiral notebooks to journal the subjective and Excel spreadsheets to chart the objective experiences, and a writer who used file folders and file boxes. According to the writer:

I probably keep records of things in a similar way. If I’m working on an article for one of the projects . . . I keep a file . . . In fact my book [a current project] is in a box . . . All the research is in a box (Interview 15).

A retired tradesman explained the notebook and system he used to keep track of his daily progress during treatments as being parallel to how he had kept track of important information needed for work. “When I was out on the job and I needed material for the next day or something I had to jot that down so I would remember . . . You have to use a notebook.”

Another example is found with a school-bus driver who indicated that she kept records in a notebook that included student and parent contact information, and student health information. She adapted a similar notebook as a diary of cancer experiences and feelings (Interview 18). Neither the tradesman nor the bus driver shared this information with their providers, deciding to keep it to themselves.

DISCUSSION

In this study, participants described tools and systems for self-monitoring of information associated with their cancer experiences. These tools and systems were self-stylized and reflected participants’ priorities and preferences, self-identity and work lives. Priorities for self-monitoring ranged from not wanting to write down their cancer experiences, yet wishing they had later, to starting on the day of diagnosis, recognizing its value from the onset. Self-monitoring tool preferences described included files and filing systems, small and large notebooks, computerized spreadsheets and documents, large binders and calendars. For many, the tools used were developed and found valuable at work, and then applied to the cancer experience as a natural progression of who they are and how they do things. For some, standardized tools were used and adapted to better fit their needs.

Study results demonstrate a relationship between one’s work, self-identity, and the self-monitoring response to the cancer experience. In another study, returning to work was a means of regaining a sense of normalcy for men with prostate cancer (McCaughan & McKenna, 2007). Consistent with, yet expanding upon this, a recent meta-synthesis found that work among cancer patients enhances self-esteem and serves as an outward sign of one’s health, talents, and abilities (Wells et al., 2012). Cancer patients would be better served if they were helped to identify and achieve work-related goals more broadly rather than just helped with returning to work (Wells et al., 2012). We propose that cancer patients who bring a strategy from work to their cancer experience in the form of a tool and/or a system for keeping track of information may help themselves retain a needed link to work and achieve a work-related goal of managing information well. Future research could examine how self-monitoring that is born of one’s work life could help men and women regain a sense of normalcy or support a positive self-identity before they are able to return to work.

A recent study found that patients experience new anxieties about work life as well as physical health, and emotional wellbeing that extend beyond active

cancer treatment (Husson, Mols & van de Poll-Franse, 2011). These findings support the need to further examine the role of self-monitoring beyond active treatment to facilitate awareness and understanding of new anxieties, and to discover one's new "normal" in one's personal and work lives. Although the literature emphasizes self-monitoring during *active* treatment, it's possible that quality-of-life and patient-provider communication would be improved through self-monitoring during the transition *beyond* treatment. Encouraging cancer survivors to self-monitor and to share self-monitoring data with providers may be one approach to constructively address the feelings of abandonment, confusion, and vulnerability resulting from a communication gap during this transition (Thorne & Stajduhar, 2012). Future research is needed to investigate the potential for self-monitoring throughout the cancer continuum.

Moreover, consideration should be given to recognize cancer patients' expertise as partners throughout this cancer-care continuum. Providers can do so by inquiring of patients' prior or existing self-monitoring experiences and preferences, realizing these may relate to their work and their self-identities, and be easily translatable. Doing so offers opportunity to support ongoing efforts and to encourage application of any self-monitoring tendencies, preferences and priorities. It also may help them feel accepted for who they are and what they have taken time to do, legitimizing their role as partners in their care. In addition, while a health care professional may provide or suggest a tool to use for self-monitoring, acknowledging to patients that they can tailor such a tool to their priorities and preferences may assist in achieving both the professional and the patient agendas simultaneously.

An important caveat to recognizing cancer patient self-monitoring is realizing the self-stylized nature of this phenomenon. Our findings show that while some patients use different ways to refer to their self-monitoring, others do not volunteer this behavior at all. This may be because they do not fully recognize its benefits to providers or they fear being labeled or demeaned for undertaking such "unusual" behavior. Determining how to best assess, appreciate and apply patients' self-monitoring behaviors requires future research. Also important is that some individuals regret not having kept written track of their cancer experiences. Discovering helpful ways and times to discuss this with patients may help those who do not self-monitor to consider the behavior as a valuable response to their cancer experience. It may be helpful to offer standardized options to patients as examples or templates as a starting point for discussion.

Our findings point to a possible disconnect that could be prompted by the lack of provider receptivity interpreted by participants. Acknowledging self-monitoring behaviors and welcoming the information generated has the potential to improve communications between patients and providers (Hermansen-Kobulnicky et al., 2004; Schumacher et al., 2002; Tucci & Bartels, 1998). It is notable that some participants in this study chose not to share their self-monitoring efforts, and the associated information gained about their cancer experience, with their providers.

Data were collected prior to the recent spike in popularity of self-tracking using Internet websites and Smartphone applications and most participants used minimal technology. The popular media speaks of a "Quantified Self-Revolution" that includes "self-tracking" of health-related phenomena for the purpose of problem-solving (Hill, 2011; "Counting Every Moment," 2012). Websites offer free opportunities to track health-related experiences, to share information by contributing to an ever-growing online database, and to learn from others who track. In addition, technologies are being developed and tested to better capture and integrate self-monitoring and on-site self-report data for use by the healthcare team (Berry et al., 2011; Wald & McCormack, 2011). Future research is likely to find individuals using more technology, yet the self-stylized work of self-monitoring would suggest technology use would not be used or accepted universally.

LIMITATIONS

Interviewees were chosen based on availability and willingness to discuss self-monitoring practices and are not necessarily representative of the population of cancer patients. While gender and age was well represented in the sample, participants' race and ethnicity were not reported. Time since diagnosis and time since treatment completion also were not collected. These demographic and clinical variables did not emerge from the participant perspectives. Future research using larger sample sizes and purposeful sampling on these variables may lend additional insights. Most participants conducted some level of self-monitoring and for one self-monitoring patient, a spouse assisted in the monitoring. Future research is needed to more fully elucidate the perspectives of non-monitoring patients and caregivers.

CONCLUSION

This study uniquely contributes the patient perspective, focusing on self-monitoring within the cancer experience. Findings highlight patients' idiosyncratic self-monitoring preferences and practices, calling

into question the assumption that the sole use of standardized tools are the most effective approach to engaging patients in this practice. Welcoming and adapting to the self-stylized tools and systems preferred and used by patients provides opportunity for health care professionals to validate patients' self-monitoring efforts and improve communication with providers.

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