

Tagging Patient Responsibilities

(All quoted text is quoted from Maia Jacobs' ["A Cancer Journey Framework: Guiding the Design of Holistic Health Technology"](#). All text quotes from CaringBridge journals are paraphrased.)

"The challenge with understanding cancer journeys is that few papers discuss the full scope of patients' experiences." There are many factors relevant to a patient's experience of their cancer journey!

What are "responsibilities"?

The cancer journey framework was organized into three categories. "The '**responsibilities**' category highlights the multiple tasks that are placed on patients during each of the cancer journey phases." The responsibilities span both social and logistical factors.

We take the Jacobs framing to heart and define responsibilities exclusively as "tasks", i.e. small units of work that are purposeful and goal-oriented. For example, a patient worrying about an upcoming treatment would not be doing a task, but a patient mentally organizing information to decrease their stress would be doing a task (note the communicated purpose).

Core Guidance

Tag a particular phase if the patient *mentions* or *acknowledges* a particular responsibility in their journal post.

Key tensions:

- *Past action vs Near-present action vs Future action*

Does it matter if a responsibility is far in the past? We have decided that it does not matter, as it is still *salient* to the patient now or they wouldn't have included it in the journal post.

Does it matter if a responsibility is merely *anticipated*? Generally, it does not matter.

Anticipation is a component of labor associated with the responsibility. Note, however, that *medical* anticipation is typically Preparation rather than or in addition to something else.

"I've been told it'll go good week/bad week so I'll be monitoring my level of nausea as we go" is Preparation but NOT Symptom Tracking (see Symptom Tracking guidance below).

- *Imputing motives to the journal author*

A decision: The text of the journal can only be tagged for a responsibility if it expresses that responsibility at the surface level. In other words, no "mind reading" the patient, even if the inference seems straightforward. Particularly for social factors like 'Managing clinical transitions' and 'Coordinating support', this decision complicates the tagging process. See the related discussion of 'Gratitude' below.

A related question: does the act of posting constitute labor that ought to be classified as a responsibility in this framework? Per the 'Core Guidance' above, I've decided it does not. First, it requires too much "mind reading" of the patient's motivations for posting. Secondly, it conflates the communication act (writing) with the signal we are trying to infer (responsibilities that are salient to the patient). Having said that, we allow for one exception: the 'Sharing medical information' responsibility (see 'Support Management' below). We take essentially all medical details presented in a journal to be evidence for 'Sharing medical information'.

- *Gratitude*

Usually, expressions of gratitude do *not* rise to the level of a responsibility. In general, we need a stronger signal to suggest that the patient experienced a labor requirement. For example, "Thanks for the spa giftcard Angie, it is very much appreciated!" does not provide sufficient evidence that any 'Coordinating support' behavior took place. Similarly, "Thanks for all the prayers and kind notes" is too vague, as is 'I started crying from reading all of your very sweet notes.'.

Each of the responsibilities below includes a high-level description along with quotes from the Jacobs paper, as well as high-level guidance about when to apply a particular responsibility tag to a journal.

Patient responsibilities and their description in Jacobs et al. 2016:

- **Communicating the disease to others:** responsibility for communicating the disease to others. This responsibility is mostly about initial informing; see 'Support Management' below. "Telling children about the diagnosis was particularly difficult for our participants. ... trying to stay positive during this particular discussion. Telling children... was a very important educational moment".

Guidance: The patient clarifying decisions and health condition to others. This includes sharing about the diagnosis to new people, potentially at any time (e.g. a teacher mentions the challenge of sharing her cancer with her students months after the initial diagnosis); however, it also includes justifying patient decisions (as opposed to "Sharing medical information" which is purely informational). For example, the patient may write about the difficulty of communicating with his extended family about the decision to enter hospice care.

- **Information filtering and organization:** "the need to find and filter health information to help them better understand their particular diagnoses and treatment plans. ... participants cautioned against looking online. ... patients are responsible for not only finding medical information but filtering the information as well."

Guidance: Any discussion of information seeking or organization. This includes soliciting information from medical professionals. Also includes specifically requesting information or referrals. Sharing medical information, even if it *seems* like its the result of the patient's own research, does not qualify unless the patient states that they organized the info or it's clear

from context that they did so, e.g. the info is stated to be from multiple sources or appointments. Just listing a treatment plan is not necessarily Info Filtering and Organization (although it is Sharing Medical Info) unless it's clear that the patient organized it. Note that this responsibility includes non-medical information, e.g. organizing info about upcoming family visits, or seeking info about insurance coverage of a proposed treatment.

- **Clinical decisions:** "Patients must make a number of significant decisions, choosing between various surgeries (mastectomy, lumpectomy), treatments (chemotherapy, radiation), and selecting doctors."

Guidance: The patient discusses a clinical decision made BY THE PATIENT. This happens surprisingly little; most decisions are not discussed with alternatives e.g. "I'll be doing chemo" (more common, not 'Clinical Decisions') vs "I discussed options with my doctor and I'll be doing chemo first" (less common, evinces 'Clinical Decisions')

- **Preparation:** The need to prepare for upcoming treatments. "Most participants would read about upcoming treatments and organize their calendar with appointment information. A few participants also wrote down questions to ask doctors prior to appointments, and talked to survivors who completed similar treatments about their experiences."

Guidance: Preparation includes non-medical prep for anticipated consequences of treatment, including specific treatments, symptoms, and side-effects. (Anticipated consequences can include scheduling future treatments, experiencing future symptoms, etc.) For example, stockpiling food or finances in anticipation of stopping work, or getting a wig fitting. It's okay if the action is merely anticipated i.e. it is possible the event will occur, but hasn't occurred yet and might not. Preparation generally does not include the 'counting' of treatments, e.g. '2 weeks left of chemo!', unless it is associated with a tangible indicator of preparation for the upcoming treatments. Preparation can include explicitly-acknowledged mental preparation, e.g. via vacations or long-weekends at a family member's house. Can also include spiritual preparation, although the patient ought to be mentioning the spiritual act (e.g. prayer) specifically in conjunction with some future event/occurrence. Further examples: "chemo teach" sessions, counseling/therapy, writing a will, prep for unknown future treatment for a diabetes diagnosis, etc.

- **Symptom tracking:** aka "Symptom management". Tracking symptoms "so physicians understand how patients are reacting to their treatments". "Participants discussed a range of physical side effects such as pain, bruising, nausea, losing fingernails and hair, and fatigue. Participants frequently discussed the need to actively manage side effects by keeping nurses informed."

Guidance: The patient is EXPERIENCING SYMPTOMS AND SIDE-EFFECTS and taking steps to manage them, either through behavioral change or through tracking info for sharing with medical professionals. Mentioning tiredness is probably not enough evidence for this responsibility, but *noticing* tiredness probably is. Generally, the symptom tracking responsibility includes: (1) experiencing NEW symptoms or a CHANGE in symptoms and (2) TRACKING the symptoms or COMMUNICATING symptoms to medical professionals. TRACKING generally refers to self-tracking (i.e. personally doing the noticing/recording) AND systematic action on the part of the patient. One aspect of being "systematic" is

making explicit comparisons, e.g. between symptoms before and after starting drug, or between today and yesterday; generally noticing general trends like "I've been more irritable" does not identify specific points of comparison for

- **Support management:** Sharing information about current treatment and seeking help. "Support management also becomes a necessity, as patients must share their health information and updates with their support network. Participants did this in a variety of ways. One participant shared that she delegated responsibilities, asking one person to drive her to and from chemo, and another to help specifically with domestic chores." We break down support management into two further responsibilities, listed below, and 'Support management' as a responsibility should not be used while tagging. We created these sub-responsibilities to try to peak at coordination of support in a way that isn't totally eclipsed by the primary use of CaringBridge journals (which is sharing medical information with family and friends).
- **Coordinating support:** A component of support management.
Guidance: Requests for support, time spent coordinating support, and frustrations about difficulties communicating and/or getting help. Includes requests for prayer support e.g. "keep me in your prayers", as well as requests for information. Currently, we don't consider the receiving of gifts to constitute coordinating support.
- **Sharing medical information:** A component of support management.
Guidance: Basically any medical info being shared at all. Includes (1) appointments, (2) treatments, (3) medical decisions, (4) testing, (5) test results. Includes info about past and future events. Many CaringBridge posts are written to do just this.
- **Compliance:** Compliance to treatments, "one of the most important responsibilities placed on patients in order to ensure effective treatment."
Guidance: Any attendance of a clinical appointment or the administration of treatment is Compliance. Includes *missed* treatment, such as forgetting a medication (or running out) or skipping an appointment. Compliance is about a patient's TREATMENT ADHERENCE and RECEIVING TREATMENT. For example, complaints about following a treatment fall under the compliance responsibility. Compare with "Symptom Tracking", which is about experiencing symptoms but NOT treatment. Compliance includes both "I have to go to chemo for the next four weeks" as well as "I finished my second round of chemo four days ago", and it even includes "I finally received the results of the test."
- **Managing clinical transitions:** The importance of dealing with stress as treatments change. Participants discussed "the importance of managing clinical transitions as participants completed surgery, began various treatments, and transitioned into post-treatment survivorship. Many participants talked about feeling the most anxious during these transitions", with these transitions "marked by uncertainty".
Guidance: The patient indicates (1) a change in treatment/condition COUPLED WITH (2) any kind of expression of need or organization for any logistical activity. Basically, the need for a future task or to meet a new need that is arising or becoming salient because of a change in treatment or symptoms. For example, "I'm checking out of the hospital and going

home, but I need to find part-time home care." Previously this category included stress and other forms of emotional expression related to a change in condition, but now it is exclusively task-oriented; an expression of emotion is irrelevant to the presence of this responsibility. Haircuts (during chemo, in anticipation of hair loss) are an interesting example because they are USUALLY Managing Clinical Transitions and frequently also Preparation. (The same is true for "chemo teaches".) Note: Many patients describe transitions, but not as specifically as this responsibility definition requires. In particular, they'll mention (1) but not (2). A trickier example: "My family member is preparing me meals so I have the energy to go to the hospital." is NOT Managing Clinical Transitions as there is no evidence the patient identified this need or organized it, as opposed to receiving the meals as a [helpful] gift.

- **Financial management:** Additional time and stress managing finances related to the financial costs of cancer care. "While some participants admitted that they chose to ignore the bills in order to emotionally cope with the financial burden, others stated that they dealt with the burden by looking for grants and other financial resources, or asking for help from family and friends. For example, one participant shared that her family members bought her groceries during active treatment so that she could pay her medical bills."

Guidance: This includes things like explicitly asking for donations, linking to a GoFundMe page, or the patient discussing the coordination of instrumental support with people in their life. Note that this generally does not include gratitude, per the discussion above! This responsibility also does not include receiving meals and money without an indicator that it was solicited by the patient, even if a comment like "thanks, this was very helpful" is added. Generally, it seems like much of the financial management responsibility is either happening "behind the scenes" or it is being offloaded to a non-medical caregiver.

- **Continued monitoring:** Testing "to monitor for cancer recurrences. Continued treatments, such as hormone therapy may also be used during this phase."

Guidance: Continued monitoring is about testing when acute treatment is not being discussed in the same journal. Any mention of current or ongoing treatment means that continued monitoring is not present. Note that, despite the quote in the Jacobs paper about continued treatments like hormone therapy, this category does NOT include any forms of additional treatment; it refers exclusively to testing, and especially testing to monitor for cancer recurrence. (I made this decision because the category is otherwise too arbitrary and impossible to tag, and it lets us focus specifically on "monitoring for recurrence" behavior.)

- **Giving back to the community:** Labor done to benefit the broader community, e.g. awareness or fundraising for others. "Participants felt a need to volunteer or share their knowledge with others once they completed treatment."

Guidance: LABOR DONE for the community or an EXPRESSED DESIRE to give back to the cancer/survivorship community. This does not include very general giving back e.g. being a nice person. This includes attempts to support CaringBridge or other organizations that supported the patient during the cancer journey.

- **Health behavior changes:** Changes to personal health behavior that are *not* related to

treatment. Almost definitionally, I would not expect to see this responsibility during acute treatment. Others "felt obligated to take better care of their physical wellbeing". "Health behavior changes included going to their general physicians more, keeping up to date with health checkups, and being more vigilant with their diets." May include changes to lifestyle of family and friends as well.

Guidance: A conscious change i.e. a DECISION made by the PATIENT. Health behavior change is any conscious change to health behavior that is NOT (1) directly due to symptoms or symptom management -- for example, tiredness causing the patient to seek an earlier bedtime -- and NOT (2) prescribed by a medical professional. This includes, for example, seeking homeopathic or folk remedies (but only if not directly related to treatment! Otherwise, it is likely 'Symptom tracking'.)

Tag "None" when there is no mention of a patient responsibility. (In other words, if you would tag no responsibilities on a journal post, instead use the "None" tag.)