

Applying User Engagement Models from Direct-to-Patient Online Services to Improve Patient Portal Design

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Abstract

As part of Electronic Health Records (EHR) systems, patient portals can be powerful tools for patient engagement. However, most portals do not currently incorporate patient-centered design to assist patients in understanding and managing their health outside of the clinic setting. In this paper, we employ a qualitative analysis of direct-to-patient web sites that serve patients as the primary stakeholders. The web sites we analyzed present information and depict patients in ways that confer agency, offering patients a number of ways to educate themselves and seek further services. Our analysis identifies crucial design elements of such web sites that could be implemented into current patient portals to increase patient empowerment in understanding and managing their care. Ultimately, the proposed model of “active patient engagement” can empower patients to learn about their health and engage more actively in medical discourse, potentially impacting health outcomes.

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1 Introduction

Sarah is a 57-year-old woman who lives alone. She has just returned home from a doctor's visit. Sarah already dislikes going to the doctor, and this afternoon, her visit was more stressful than usual because her doctor diagnosed her with hypertension. He prescribed medication to reduce the symptoms. Sarah was presented with a lot of information along with the prescription and, as usual, she felt rushed during the office visit. That evening, Sarah decides to log on to the online patient portal website, provided by her doctor's office, to find more information about her prescription and hypertension in general. Sarah gets annoyed sometimes trying to navigate the portal. When she can't find what she needs, she hesitates to message the doctor – he seems so busy! Sarah spends a lot of time clicking through menus on the portal site, but finds nothing that helps her learn or feel more comfortable about her condition. Sarah logs off, disappointed, and picks up the bottle of pills, eyeing the instructions printed on the label skeptically.

Increasingly, health care organizations strive to implement patient-centered care models, driven by understanding the patient point of view, and characterized by care that fosters “healing relationships” between clinicians and patients (Epstein et al., 2010). In this regard, the patient portal function of Electronic Health Records (EHR) systems represents an important facet of health care delivery (Centers for Medicare & Medicaid Services, 2012). Although patient portals have the potential to empower patients in understanding and managing their health care, portals do not currently incorporate a patient-centered user experience. This is partially due to the history of EHR implementation – specifically, such systems were originally designed to optimally support clinician workflow and facilitate accurate payments for services rendered (Eysenbach, 2000). Accordingly, EHR systems invariably “favor the interests of people with economic and political power” (Friedman and Kahn Jr., 2002, p. 1179). In the case of multi-payer, privatized health care delivery models, the stakeholders with power include payers and health care organizations (primarily through the Medicare payment system; Antos et al., 2012).

Prior studies of patient portal adoption have focused on privacy concerns (Angst and Agarwal, 2009), patient satisfaction (Sibona et al., 2011), and system trust (Gogan et al., 2009). Much less is known about designing interventions that honor patient agency and account for patient support systems and care activities outside of clinical settings. The opening vignette above, depicting Sarah's experience, provides one example of when a patient-centered configuration of a patient portal could lead to a more comfortable and engaged patient, potentially leading to better compliance with medication schedules and therefore a more favorable health outcome.

In this paper, we draw on lessons about patient user experiences from medical informatics to analyze existing practices of patient engagement demonstrated by direct-to-patient websites. By examining successful direct-to-patient web sites, we aim to derive a model of information organization and patient depiction that can be used to improve patient portals. Specifically, we approached our

analysis by asking following question: *How do organizations with successful direct-to-patient interfaces organize information and depict users/patients to facilitate patient engagement?*

In the following sections, we review literature from medical informatics that addresses the patient experience and the role of online portals in empowering patients. Then, we use an interpretive approach to examine cancer nonprofit education and resource support web sites for themes that encourage patient-centered agency and engagement. Following this, we suggest improvements to the patient portal experience. In doing so, we demonstrate that models of direct-to-patient services, which already function well, can inform patient portal designs—and facilitate cost-conscious and effective implementation of redesigned patient portals in health care organizations.

2 Literature Review

One barrier to applying patient-centered principles to the design of patient portals is the lack of integration of the patient as a direct stakeholder in health care organization information systems design (Eschler et al., 2015b). We believe that patient portals could successfully incorporate the values and needs of patients by presenting and organizing information in ways that support a positive, engaged patient self-image. To examine this issue, we consider the patient as an important, direct stakeholder to the EHR system, whose mode of access occurs via the patient portal (though we acknowledge that other indirect modalities, such as a phone call to a clinician's office, may also generate EHR input).

Our theoretical framing is partially derived from Kling et al. (1998), who defined social informatics as an approach that “examines the design, uses, and implications of information and communication technologies (ICTs) in ways that account for their interactions with institutional and cultural contexts” (p. 1047). The *institutional context* of the patient stakeholder in the health care organization is one of a “client,” but the patient can also be framed as the most crucial stakeholder, in that s/he benefits from ministrations of clinicians. In the Western *cultural context*, patients are often objects of medical care, since clinicians act upon them (Lee and Garvin, 2003). The patient-centered care model challenges this position.

To better understand how patient-centered care models might work in systems design, the medical informatics domain has explored possibilities for empowering patients through health information systems. For example, in focus groups involving users of patient portals, Donnelly et al. (2008) found that feeling empowered – which, in turn, bolstered a patient's identity as an able, engaged individual – motivated use of a patient portal and online information to manage health. This model challenges the traditional “sick-role” dyad of helpless patient/knowledgeable, powerful doctor (Suchman, 1965), transforming the relationship into a more cooperative, egalitarian one.

In a more comprehensive picture of patient engagement, Mathieson and Stam (1995) presented a model of patient understanding in medical discourse that illuminates how an empowering patient portal might function. First, the authors argued, a patient portal should provide resources for patients to learn about their condition. Second, the portal should help patients learn about the nature of medical discourse: for example, when it is appropriate to contact a clinician, and how the tools afforded by a portal support such contact. Third - and most importantly for engaging and empowering them – patients must decide how they fit into medical discourse. That is, what can the patient now do on his or her own to manage the condition? When patients decide to involve themselves in medical discourse, the patient portal can be a vital tool to help them do so.

The interplay between patients and information systems, such as the patient portal, is affected by a number of factors. Radley and Billig (1996) characterized patients' evolving health beliefs as a function of ongoing, constructed identity. In another way of viewing the interplay between health, the patient, and technology, Huvila et al. (2015) used the framing of “subject positions” to describe the relationship between patient attitudes and their use (or not) of patient-facing technology, such as portals. At the extreme, a patient may encounter aspects of information systems that prompt disengagement (Nach and Lejeune, 2010): for example, information may be presented in ways that refer only to a patient's “disease identity” (e.g., “Manage diabetes” or “Living with diabetes”).

Another example of system interaction that may prompt disengagement may be interacting with information organized or presented in unmeaningful ways (e.g., information taxonomy that over-utilizes medical terms, such as “Learn more about diabetes mellitus”). These experiences have the potential to contradict – or, worse, damage – the patient's self-image. While most theoretical contributions related to IT and identities exist in the organizational or professional context (Alvesson et al. 2008), identity and self-image are important aspects of individuals' social and cognitive processes when interacting with information systems across social contexts (Carter, 2013). As such, interfaces aimed at serving direct

stakeholders such as patients should aim to successfully support self-image and identity construction and maintenance.

Perhaps the ultimate irony of patient portals is that patients are invited to manage corporeal needs in a decidedly disembodied modality. Yet, online identities often embrace offline behavioral expectations (Schultze 2014). See Figure 1, for example: the care “dyad” of knowledgeable doctor/submissive patient is reflected in the login screen of a patient portal for a large, regional health care system. This symbolism reflects and reinforces power dynamics that exist in clinic visits, and is a tangible example of what Stein et al. (2013) referred to as “IT artifacts or their properties” that can impact users’ “self-narratives” (p. 171).



Figure 1: An example patient portal login screen with doctor/patient dyad depiction

In summary, the reflexive act of using the patient portal to manage health, and update or maintain a self-image as an “able” patient, is a real feedback mechanism that should be incorporated into the design of patient portals. The patient’s work in self-appraising health and ability is often achieved in interactions with his or her clinicians (Charmaz, 1983), and patient portals can also act as an extension of in-clinic relationships with medical professionals (Buetow, 2009). For these reasons, it is important to acknowledge the impact of information presentation and user/patient depictions on patient self-image.

3 Methods

Information and resource website home pages hosted by cancer nonprofit organizations were the population of interest for generating our data. We chose United States-based organizations to focus on a sample of organizations operating under more or less consistent cultural and institutional constraints, namely: prominent Western medicine influence, with a largely privatized health care model, in an English-speaking country that has strict medical privacy regulations. Although our dataset reflects services directed at health care stakeholders (cancer patients) who have extreme health information needs, we believe the intensity and frequency of health care information system use by this group can better inform user engagement for all patient-stakeholders.

3.1 Data Collection

In our sampling technique, we chose to begin scraping data by pulling the URL and a front page screenshot for all of the sites under “recommended resources” from a cancer forum’s (www.reddit.com/r/cancer) crowd-sourced list of online resource sites for patients. We grew the sample using link referrals to additional organizations from the initial sites, eventually amassing a total sample of 45 websites. Each unit (homepage) data scrape included the “About” text from site, to assist coders in understanding the organizational focus, as well as a screen shot of the homepage at the time of data collection, during March and April, 2015. Our sample included large, national organizations, as well as smaller, more regional organizations. Importantly, we stopped sampling data when we had reached theoretical saturation (as described by Eisenhardt and Graebner, 2007).

3.2 Data Analysis

We followed Urquhart et al.'s (2010) approach to grounded theory to identify themes in an iterative process of qualitative coding. First, we applied open coding to a subsample of the data from the organization websites (10 sites), to describe any potentially relevant aspect of information organization strategies (e.g., site taxonomies) or appearance (e.g., photographs of people used on the site). Second, to interpret the emerging themes from the open coding round, we grouped themes and codes and settled on a comprehensive code book, meeting frequently to ensure consistency in code application. Third, to construct the emerging theory, we studied incidence of codes, code co-occurrence, and studied the relationship between codes to iterate toward actionable design features for patient portals. All three authors then narrowed the list of codes to those that had the greatest overlap with our interest in information presentation and user/patient depictions, as specified in our research question. Once finalized, the codebook was applied by the two primary coders to the entire sample of 45 websites.

3.3 Findings

Our coding process included determining the organizational focus for each web site, consulting both the "About" page for each site, as well as the information presented on the home page. Age categories for the primary organizational stakeholders identified from our analysis are adapted from the National Cancer Institute's (2006) definitions of child (dependents under 15 years of age), young adult (aged 16 to 40), and adult (over 40) age groups. A fourth organizational focus was added to incorporate sites that served patients affected by a particular cancer diagnosis or pathology; we refer to these as "illness-specific" sites. Table 1 describes the sample in more depth.

Site ownership	<i>n</i>	%
Non-profit organization	44	98
Government organization	1	2
Total sites coded	45	100
Organizational focus*		
Illness-specific	23	51
Children (15 & under)	11	24
Young adults (16-39)	12	27
Adults (40+)	8	18

**does not add to 100% due to focus overlap*

Table 1: Description of sample

We identified four code families that were meant to capture different facets of the site's presentation of information:

- **Type of engagement** was coded using both menu taxonomy on the home page and the "About" text for the site. Examples of types include seeking financial support (i.e., fundraising), offering educational resources, or helping patients find support.
- **Organization of information** describes the taxonomy element types used in the main menus on the web site home page. For example, menu items such as "Just diagnosed," "Treatment options," and "Survivorship issues" would be coded as "Illness phase" organization of information.
- **Language characteristics** were coded for active versus object wording. For example, if the organization offers illness information through its blog, the information could be presented as a hyperlink called "Blog" (object wording) or "Read more about cervical cancer" (active wording).
- **Imagery elements** were coded to describe how patients/users were depicted on the site; we coded for "well" individuals (i.e., not in an obviously clinical environment) and for "sick" individuals (i.e., visible clues to illness: baldness or cannulas).

From these designations, we organized the top codes in each family by organizational focus (see Table 2).

Organizational focus	Type of engagement	Organization of information	Language characteristics	Imagery
Children	Seeking financial support (i.e., fundraising for organization)	Facts	Object wording	“Sick” individuals
Young Adults	Helping patient find support	Task	Action wording	“Well” individuals
Adults	Offering educational resources	Illness phase, facts*	Object wording	“Well” individuals
Illness specific	Offering educational resources	Facts	Object wording	“Well” individuals

**Most prevalent codes are tied in frequency in this instance*

Table 2: Code prevalence by organizational focus

3.3.1 Sites for childhood cancer patients

Sites focused on support for children exhibited noticeably different user experience and depictions of patients and families than the other types of sites. This finding is not necessarily surprising. Adults would likely be visiting the site on behalf of a child with cancer, or draw in other adults who may want to support a family with a sick child. Sites for children were distinguished by their primary engagement tactic (raising funds) and, in particular, the use of “sick” individual imagery on home pages. Although these sites were used in both the initial sample and to a lesser extent in the expanded sample, we find that this model of user experience is that of a user proxy, where children – the patients – are likely indirect stakeholders. For this reason, we concentrate on the findings related to sites for young adults and adults, who are more likely to engage in their own health care, and thereby, use information as direct stakeholders.

3.3.2 Sites for young adults and adults

In contrast to sites for childhood cancer patients, those serving young adults and adults were much more likely to use active wording to present information in top-level menus (e.g., “Click here to learn more” versus “Current research”). Additional examples of language used in menus are presented in Figure 2. We also found that, without exception, young adult and adult sites employed portraits of “well” individuals rather than images of patients experiencing obvious illness or side effects of treatment. This model of user experience reflects an image of the patient as an able, empowered individual, despite the fact that needs associated with cancer have brought a patient to the site.

In addition, young adult sites emphasized supporting the needs of young adult cancer patients, as previously identified by the National Cancer Institute (2006). These needs include: finding a peer to talk to, locating an employment attorney, or seeking financial help. In contrast, sites serving adults (age 40+) emphasize education about the illness. Organization of information supports these engagement types, with sites focused on young adults presenting information based on illness phase (“Newly diagnosed”) and task (“Find peer support”), while adult sites present information based on illness phase and facts about the illness (“Symptoms” or “Screening”).

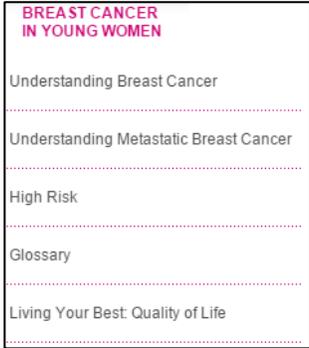
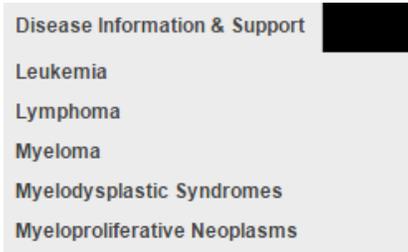
Language: Active wording <i>versus</i> object wording	
<p><u>Active wording</u> describes how interaction with the resources will help the patient when they take action (engage with the content) Source: https://www.youngsurvival.org</p>	<p><u>Object wording</u> is less descriptive and directs the user to types of information units available on the website Source: http://preventcancer.org</p>
	
Information organization: Illness type <i>versus</i> illness phase	
<p><u>Organization by illness type</u> gives information delineated by diagnosis or pathology Source: http://www.ils.org</p>	<p><u>Organization by illness phase</u> offers guidance at difference stages of the illness (e.g., diagnosis, treatment, survivorship) Source: http://www.pancan.org</p>
	

Figure 2: Examples of language and information presentation types

3.3.3 Illness-specific sites

Distinct from other types of organizations, illness-specific sites emphasized education about the specific illness, with a significant secondary type of engagement around funding research to seek new treatment. These sites used fewer “active” words and often designated illness facts by specific diagnosis, although we observed exceptions to this model. The primary benefit to including illness-specific sites in our sample – besides their tremendous presence in the cultural consciousness of cancer – is that these sites utilize an information model we see in young adult and adult sites, using illness facts to facilitate patient and caregiver education. Furthermore, we found that illness-specific sites particularly supported the imagery of the “well” individual in reflecting users of the site.

4 Discussion

By identifying clear practices of information organization and patient/user depiction used on the web sites coded, we are able to describe methods engaging patients that direct-to-patient support organizations already employ. In this section, we set forth models of engagement that (1) have been deployed in supporting patient needs in another context; (2) need not be re-invented, but can be adapted; and (3) benefit from honoring and reflecting an “able” patient image, as demonstrated by non-profits that work to meet patient needs. Our findings are meant to inform ongoing improvements of the patient portal experience offered by EHRs, to meet “Meaningful Use” requirements (Centers for Medicare & Medicaid Services, 2012), and to enhance patient-centered care (Epstein et al., 2010).

Overall, we identified six elements that composed a total “active patient engagement” model: use of multi-level navigation; information organized by illness facts, illness phase, or task; taxonomies that avoid medical terminology; using images of “well” individuals; using “active” wording in taxonomies; and emphasizing finding support, resources, or educational materials (see Table 3 for more detail in definitions). A majority of the sites (28 of 45) sampled used at least four of the active engagement elements; seven of the sites employed all six of the active engagement techniques; and 10 sites did not employ an obvious active patient engagement model at all.

Active engagement element	Definition
Uses multi-level navigation	User is able to hover over top menu to see sub-menu elements. This helps the user understand, at a glance, how concepts are presented on the site.
Organizes information by facts, illness phase, or task	Information is presented in terms of illness facts (symptoms, testing, treatment); illness phase (diagnosis, treatment, survivorship); or by task (find support; volunteer; listen to our podcast)
Avoids taxonomies using medical terminology	Menu elements do not overly rely on medical phrases that may make content difficult to understand; this includes abbreviations
Uses images of “well” individuals	Images that reflect patients who may use the site default to depicting people outside of a clinical setting
Uses “active” wording in taxonomy	Users are invited to act on the information and engage further with site content, and labels depict what the user will gain from interaction (“Learn more about metastatic breast cancer”; “Find a support group in your area”)
Emphasizes finding support, resources or education	The content is organized and presented in a way that trusts patients to empower themselves and honors their agency in informing themselves

Table 3: Detailed definitions of the six “active patient engagement” elements

Next, using the designations of websites given above, we present an exemplary case from our sample that is likely to encourage active, patient-centered engagement with the content and services provided.

4.1 Example: Effective, Patient-Centered Engagement

The LiveStrong Foundation (homepage at livestrong.org) demonstrates a model of user experience that presents information in a dynamic way, utilizing active engagement elements described above. First, the information is organized in two main top-level menus for patient or survivor visitors. One menu set gives information based on the patient or survivor’s illness phase (e.g., “Newly Diagnosed”). This is important because the effect of illness phase on the information needs of patients and survivors is a new, but potentially important, facet of information behavior in managing serious illness (Eschler et al., 2015a; Ziebland et al., 2004). The second navigation menu offers task-based navigation, such as supporting LiveStrong with fundraising activities or finding local programs to rehabilitate physical fitness.

These dual menus helpfully give two different “views” of the information: this expands the reach of the information presented, as illness phase presentation may resonate with some patients, while a task-based taxonomy may resonate with others. Both menus avoid medical terminology; in fact, specific diagnoses or prognoses are explicitly avoided. The navigation experience instead emphasizes the ability of LiveStrong to facilitate user activities or goals.

The depiction of patients/users is that of “well” individuals, which serves as a reinforcing image alongside the “active” language of the site and its navigation. The site’s design encourages patients to explore programs and services offered by LiveStrong. The depiction of “well” individuals supports a self-image of the active, able patient who can engage in his or her own care. If the objective of offering patients a “portal” into their EHRs is to activate patients’ involvement in managing health, then we argue that the LiveStrong model is an excellent one from a patient-centered design standpoint.

5 Implications

The contributions of this paper involve both theoretical and practical implications. First, we incorporate patients as primary stakeholders in health information systems, expanding on the notion of “user engagement” with the patient portal through qualitative analysis, which adds social and cultural context to factors involved in use (Kaplan and Maxwell, 2005). We draw in themes of information presentation and depiction of patient stakeholders as important aspects that an information system can incorporate to increase more traditionally measured engagement metrics (such as number of logins, time spent in information system, and tasks attempted versus completed).

This study also has practical implications for the implementation and/or redesign of patient-facing information systems. In addition to providing examples of engagement models, we are able to enumerate the benefits of improving patient engagement with the online portal to a health care organization and its stakeholders. We recall the Mathieson and Stam (1995) model of patient understanding in medical discourse, referenced above. The model has three steps that the patient carries out:

- a) Learning about his/her condition;
- b) Learning about the nature of medical discourse;
- c) Deciding how s/he fits into medical discourse.

User interaction that implements the “active patient engagement” model is designed to guide patients as to what they are able to do on a site. This empowers patients and helps them make decisions about when more information is needed or when professional intervention is required. This approach is implicitly patient-centered, conferring agency to the patient in managing health and clearly incorporating the patient into the care model as a direct stakeholder. This approach has led to organizational benefits, such as improving communication between patients and clinicians (Woods et al., 2013; Delbanco et al., 2012). Using the Mathieson and Stam (1995) model, Table 4 outlines differences between the current model of patient engagement, and the proposed “active patient engagement” model.

	1: Learning about his/her condition	2: Learning about the nature of medical discourse	3: Deciding how s/he fits into medical discourse.
Current patient portal model	Information about health conditions must be pieced together using elements of medical record; imagery used on the portal reinforces doctor/patient power dynamics from clinic	Patient struggles to understand and integrate prescribed or recommended care tasks in everyday life; carrying out communication tasks with health care professionals is not transparent and/or not supported well	Patient may eschew proactive communication, effectively “falling through the cracks” between clinic visits, rendering the patient portal less effective as a tool for patient-centered care
Proposed “Active patient engagement” portal model	Patient is able to learn about relevant health conditions because relevant information is presented effectively; patient imagery on the portal reflects an “active” and “able” role	Patient is better able to find information and complete tasks such as learning about relevant health topics; the portal facilitates transparent communication with health care professionals	Patient feels empowered to make decisions about communicating with health care professionals, and engages in proactive communication between clinic visits

Table 4: Current model versus “active patient engagement” model for the patient portal

In addition, we foresee benefits to other stakeholders in the health care organization. When patients are clear on their roles and abilities in managing their health conditions, clinicians’ workflow can be supported more effectively. Patients who are engaged and alert to their own conditions may be better able to seek help before a health condition escalates. Finally, conferring or reinforcing patient notions of responsibility may work to increase investment in and compliance with clinician-prescribed directives, such as medication routines and at-home care. To illustrate, we return to our opening vignette: Sarah wants to verify the dose and timing of her new prescription and find out more about hypertension. A more patient-centered experience has the opportunity to transform Sarah’s engagement in her own care. In an “Active patient engagement” version of the patient portal, Sarah encounters images that portray people, who may be her peers, in active, “well” configurations. For example, Sarah might see a scene of older

adults exercising, or cooking healthy food in a social setting. The imagery therefore has the potential to engage Sarah immediately and positively with the information system.

Further, when interacting with choices for finding content and navigating the site, it would be ideal for Sarah to have multiple options for viewing information. For example, the site could offer Sarah the ability to “learn more” about conditions she and her doctor had discussed that day (i.e., a task-based information organization strategy with an education focus: “Learn about high blood pressure”). All of these improvements to Sarah’s patient-stakeholder user experience are intended to support her role as a crucial stakeholder in her health, expressing a clear role for her in managing her health with the assistance of the health care organization’s resources and services.

6 Limitations

In this study, we analyze information presentation on nonprofit websites, developed by organizations that serve individuals with cancer. Our sample covers only populations that speak fluent English and have a U.S., evidence-based, medicine tradition; therefore, our findings may not generalize to cultural contexts that vary significantly from our population of interest. We have also necessarily “scaled up” our theoretical framing to apply to patient-centered applications for health (i.e., using information presentation in *one* health care context to inform another), thereby generalizing beyond our particular cases and their analyses (e.g., Urquhart et al., 2010). However, our findings are intended to characterize a model of active engagement of patients from information systems designed to provide direct-to-patient informational support, in order to improve another type of information system that, in its current form, insufficiently incorporates the needs of the patient stakeholder (the patient portal).

7 Conclusion

Patient portals do not currently address the informational needs of patients from the perspective of serving them as capable, engaged stakeholders. However, using a grounded theory approach to learn from websites of direct-to-patient cancer organizations that have demonstrated success in engaging patients online, we describe a model of “active patient engagement” that can be applied to improve the patient portal experience. This active patient engagement model employs “well,” capable imagery of its users, and offers dynamic, task-oriented choices in engaging with site content. We suggest that this model of engagement can be used to inform improvements in portals to enhance this important aspect of patient-centered care, helping patients like Sarah to feel empowered in managing chronic conditions and potentially improving health outcomes.

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