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What does the word healing mean to you? Perceptions of patients with life-limiting illness

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Abstract

Introduction. There is a growing consensus that patient-centered care is more effective in treating patients than a strictly biomedical model, where there are known challenges to involving the patient in assessments, treatment goals, and determining preferred outcomes.

Objectives. The current study seeks to integrate patient values and perspectives by exploring how people diagnosed with a life-limiting disease define healing in their own words.

Methods. As a part of a larger study that included cognitive interviewing, we asked the question “what does the word healing mean to you?” Data were collected during face-to-face interviews with patients from three metropolitan healthcare facilities.

Results. Thirty participants responded to the question “what does healing mean to you?” Seven themes were identified through the data analysis. These themes include acceptance, feeling better, pain, social support, process, religion/spirituality, and make whole. The feeling better, pain, and process themes have subthemes.

Significance of results. Probing to understand patient perspectives and how to provide a holistic approach to care is essential to patient treatment. Patients defined healing in a broader way than how it is typically defined in literature. The patients’ definitions provide greater insight into perceptions and expectations regarding the healing process.

Introduction

Patient-centered healthcare typically refers to providing care consistent with patients’ values, needs, and desires, which is achieved when clinicians involve patients in treatment discussions and decisions (Institute of Medicine, 2001). The Revised Patient-Centered Clinical Method (PCCM) is comprised of four components: (1) understanding patients’ experiences with health and disease through exploration; (2) understanding them from a holistic framework; (3) improving the patient–provider relationship; and (4) having mutual understanding (de Oliveira et al., 2019). Patient-centered care has been shown to promote better health outcomes, greater patient satisfaction, and reduced health costs (Stewart et al., 2013). The components of the Revised PCCM inherently include the psycho-social-spiritual aspects of a patient into the care provided (de Oliveira et al., 2019).

Although there is growing consensus that patient-centered care is preferred and is more effective in treating patients than a strictly biomedical model, there are known challenges to involving the patient in assessments, treatment goals, and determining preferred outcomes. Specifically, healthcare providers and the institutions where the care is provided are grounded in the medical model, resulting in assessments and treatment plans being completed without the patient necessarily understanding them, being informed about them, or agreeing to them (Nickel et al., 2018). An essential component of patient-centered care is shared decision-making, which is not always possible or expected within the medical model of care. Shared decision-making allows for the patient’s perspective to be an integral part of the process. For this to occur, one means of understanding the patient’s perspective is to learn what “healing” means to them. Additionally, the patient needs to provide direct input into the assessment process and treatment planning, resulting in a co-created plan by both provider and patient.

In the Western healthcare system, healing typically refers to curing disease or restoring health in people considered to be medically ill (Levin, 2017). Egnew presents whole person healing to be the “physical, mental, social, and spiritual processes of recovery, repair, renewal,

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and transformation that increase wholeness” (Egnew, 2005). “Whole person healing” and “holistic healing” are often used interchangeably with whole-person healing (Kaptchuk and Eisenberg, 2001). The goal of both terms is to have a consistent and agreed-upon perspective of health that can lead to an overall improvement in quality of life for people with life-limiting diseases, which is consistent with patient-centered care as it is conceptualized in the revised PCCM (Ingram, 2014).

Some schools of thought outside the medical model approach the assessment of healing through categorization. For instance, anthropologists describe healing as an active response to distress and categorize the approach to healing, diagnosis, and treatment as either scientific and non-religious or nonmedical, unscientific, and religious (Egnew, 2005). Although approaches vary, there is a common core of components to healing such as the perceived meaning of the illness, a determination to improve, trust in the treatment method, expectations for treatment success, and an overarching sense of emotional healing with the manifestation of compassion (Kawachi *et al.*, 1999; Kaptchuk and Eisenberg, 2001; Jonas and Chez, 2004; Sloan *et al.*, 2017). Interestingly, healing has been linked with the concept of hope in that both constructs can be seen as dynamic and intersecting experiences; the transition from hopelessness to hope may be a critical step in the healing journey for a person to regain a sense of purpose and meaning (Eustache *et al.*, 2014). Healthcare providers generally focus on acute care and cure (Egnew, 2005), which discourages discussions of patients’ personal experiences with health, disease, and healthcare systems. The goal of palliative care is to lessen suffering in people with serious and progressive illnesses, including the primary patient’s caregivers (Cunningham and Groninger, 2019). Suffering is viewed as the physical, psychological, social, or existential/spiritual aspects of the experience of illness (World Health Organization, 2002). A palliative care interdisciplinary team includes a nurse, social worker, chaplain, and physician, at a minimum. Each team member views the patient’s health through a discipline-specific lens and contributes their perspective to create an integrated assessment that always focuses on the patient rather than the disease.

According to Cunningham and Groninger (2019), the goal of the palliative care team, in collaboration with the patient and family caregivers, is to develop goals of care in the context of treating a medical condition. This leads to a co-constructed understanding of treating the disease, including at the end of life. These goals of care can include the extension of life, symptom relief, regaining normal functioning, improving functioning, and the withdrawal of life-sustaining technologies. Using the model of palliative care earlier in the disease trajectory, rather than at end of life, can be the starting point for increased patient participation in decision making.

An individual’s culture influences all aspects of their understanding, acceptance, and responses to illness and treatment causing each patient to have their own definition of healing. While some healthcare providers may be amenable to having conversations that include the three domains of psychosocial care (patients’ psychological, spiritual, or religious views) as a part of the treatment discussion, others are uncomfortable, uninterested, or feel pressured for time (McCord *et al.*, 2004; Best *et al.*, 2015; de Oliveira *et al.*, 2019). Including these psychosocial components in healthcare into conversations are important for all patients, especially those diagnosed with life-limiting illnesses (McCord *et al.*, 2004; Best *et al.*, 2015). These three psychosocial domains also have a role in how people define healing for

themselves. Thus, it is paramount that healthcare providers learn what is central to patients’ healing perspectives, as this may impact their attitudes toward treatment. Moreover, patients feel their perspective is valued when affirmed by their doctor (Grant *et al.*, 2004). Through other explorations of healing, one study also examined how environmental settings such as a hospital room may enhance or detract from the healing experience (MacAllister *et al.*, 2016), further suggesting that the constructs of healing may be modifiable.

The purpose of this study is to explore how people diagnosed with a life-limiting disease define healing in their own words. More importantly, our goal is to highlight the need to ask about the patient’s own definition of healing, and using their input in the treatment plan, thus creating a mutual understanding that ultimately leads to better patient–provider relationships.

Methods

The current study, nested within a larger study, utilized qualitative data collected during face-to-face interviews with patients diagnosed with various serious illness from three metropolitan healthcare facilities: The National Institutes of Health (NIH) Clinical Center in Bethesda, Maryland, the Johns Hopkins Medicine Suburban Hospital in Bethesda, Maryland, and the Mobile Medical Care (Mobile Med), a community clinic located in Rockville, Maryland. The NIH Institutional Review Boards and appropriate research governing bodies approved the study.

The purpose of the larger study was to conduct contemporary validity testing, specifically cognitive interviewing, of the Healing Experience in All Life Stressors (HEALS) measure. At that time, HEALS was a 54-item, self-administered scale that measures psychosocial and spiritual healing. The development of the HEALS and classic reliability and validity testing have been previously reported (Sloan *et al.*, 2017; Ameli *et al.*, 2018).

As a part of the larger study, all participants were asked four open-ended questions that were created by the research team to evaluate factors that may contribute to the healing and illness experience. The question “what does the word ‘healing’ mean to you?” is the focus of this study and was the first question that was presented to the participants. The other three questions have been described elsewhere (Li *et al.*, 2017). Two investigators, who were not involved in patient care, a post-doctoral social worker trained in clinical research and a third-year medical student with training in health sciences conducted all the interviews. Each received training in cognitive interviewing, including the writing of the semi-structured script. Willis (2005) identifies concurrent probing as an acceptable approach for content validation. Probes were developed for some of the HEALS items and described elsewhere (Li *et al.*, 2017).

The interviews took place between February and June 2016. Using a purposive sampling approach, eligibility criteria included the individual’s ability to speak and understand English, being at least 18 years old, and being seen by a palliative care provider at one of the three sites. Patients with brain metastases were excluded from the study due to the symptoms associated with developing progressive neurologic dysfunction, which interferes with cognitive processes.

Analysis

All interviews were audio-taped and transcribed verbatim. Content analysis was used to analyze the data to identify

categories and themes. To minimize bias, the process used included having two authors (DS and EM) individually review the transcripts and identify the words, sentences, and descriptors that indicated healing. The next step was to combine the two lists and review them for similarities and differences. The differences were discussed until the authors agreed. The co-created list was reviewed by a third author (AB), who finalized the categories and themes. The finalized themes were then sent to two other authors (KB and MW), blinded to all previous analyses, to code data phrases based on the themes. The final step included the researchers collaborating to come to a consensus regarding the categories and themes. The senior author (AB) resolved discrepancies in the interpretation and selection of final coding.

Respondents

Fifty-six potential participants were approached based on convenience sampling, with 30 (54%) participants providing informed consent. We determined that having 30 participants was adequate for cognitive interviewing, where it is suggested that a range of 5–15 interviews is common (Dabney and Tzeng, 2013; Li et al., 2017). Eighty percent of participants were recruited from the NIH. The sample consisted of a middle-aged “plus” population with 66% above the age of 46 years, predominantly male (54%), white (54%), married (47%), and formally educated, with 77% having some college education to postgraduate degrees. Sixty percent of participants were unemployed, which is common with the presence of life-limiting illness (see Table 1).

Results

Seven themes were identified through the data analysis of the question, “what does ‘healing’ mean to you?” These themes include acceptance, feeling better, pain, process, religion, social support, and wholeness. The feeling better, pain, and process themes have subthemes. Each of the themes and subthemes is presented below, including quotes that lead to the identification.

Acceptance: Acceptance refers to an individual letting go of resistance to their diagnosis, impending death, or situation and looking for meaning in the face of illness. The act of acceptance also implies ceasing judgment toward oneself and embracing difficult situations rather than fighting against them with mental, emotional, physical, or spiritual energy that would otherwise distract from the healing process. Responses in this theme included “letting go,” “accepting new ways of thinking,” “not being judgmental of myself,” “being comfortable through difficulties,” and “accepting the fact there is no cure” for their disease.

Feeling Better: The second theme is feeling better, which was described by participants as “getting better” without further specificity. Examples of responses in this category include “feeling better,” “feeling like I did before I got here,” and “to make better.” The three subthemes, feeling better — mind, body, and better than before, were identified based on specificity from the participants.

Feeling Better-Mind: Some patients spoke of healing as improvement in their emotional, mental, or psychological experience. These explanations were often paired with physical healing as well. These responses included “feeling better ... emotionally” and “to regain strength physically or emotionally.”

Feeling Better-Body: Responses expressing this theme typically discussed a desire for the participant’s physical body to feel better. This included expressing longing for regained functionality,

Table 1. Demographic characteristics of participants (N = 30)

Characteristics	n (%)
Location	
NIH	24 (80%)
MobileMed	4 (13%)
Suburban	2 (7%)
Age (years)	
18–25	2 (7%)
26–35	6 (20%)
36–45	2 (7%)
46–55	6 (20%)
56–65	8 (26%)
66–75	5 (17%)
>76	1 (3%)
Sex	
Female	13 (43%)
Male	16 (54%)
Transgender	1 (3%)
Race	
White/Caucasian	16 (54%)
Latino/Latina	3 (10%)
Black/African American	10 (33%)
Refused	1 (3%)
Education	
Some High School	4 (13%)
High school grad	3 (10%)
Some College	8 (27%)
College graduate	6 (20%)
Postgraduate	9 (30%)
Employment	
Employed	10 (33%)
Student	2 (7%)
Unemployed	5 (17%)
Disabled	7 (23%)
Retired	6 (20%)
Marital Status	
Married	12 (40%)
Never married	8 (26%)
Separated	2 (7%)
Divorced	6 (20%)
Widowed	2 (7%)

performing physical activities, or working in their yard again, such as “feeling better physically.”

Better than Before: Occasionally, patients would describe healing in comparison to their state upon entering the hospital or care

facility. This distinction is different from the other subcategories of “feeling better” because of the emphasis on improvement from an earlier state without a specific reference to mind or body. Some participants also defined healing as improving beyond the last time they saw themselves as being healthy. Responses showing this theme included “feeling like I did before I got here” and “feeling better than when I came in.”

Pain: A theme throughout the patients’ responses was regarding pain. Based on patient responses, pain could refer to physical, mental, or emotional experiences. Within the overarching theme of pain, three subthemes were identified:

Less Pain-General: This theme describes healing as reduced pain but did not provide additional specificity as to the type of pain indicated. One response that illustrated this subtheme was, “if you have pain, less physical pain means you’re healing. You can have mental pain too.”

No Pain-General: A few patients defined healing as having no pain. This theme is distinct from less pain-general because these responses were characterized by the complete ending of pain rather than a decrease. These responses included those who defined healing as having “no pain” or “no suffering.”

No Pain-Mental: This theme for healing is expressed as having no emotional pain, mental pain, or distress. This category seemed to come up due to shifting social roles, where it became difficult to become a patient rather than continue as a caregiver for family members. One factor that may contribute to patients’ mental pain is the omission of explicit training on emotional support techniques for physicians, leading healthcare professionals to overlook emotional components of healing. The response expressing this theme stated healing as “no distress.”

Social Support: Some patients referred to healing as having support from friends and family. These responses did not include any discussion of symptoms or illness. One participant in this category defined healing as “family, friends, [and] caregivers give me the support I need.” Within the overall theme of social support, one common idea of “compassion” was also found. One patient defined healing through one’s attempts to help other people, which helps the patient improve. Healing, in this case, comes from actively improving the state of others in one’s environment rather than starting with the self. This patient defined healing by stating that “helping other people helps me heal.”

Process: Several patients described healing as an ongoing process that takes time, practice, and effort. Although these participants may have discussed differences between physical and mental pain, they are categorically separate due to their perspective of healing as ongoing rather than something with clearly defined boundaries. Several responses expressing this theme included, “There is no cure for my disease, so I have to enjoy this life. I have to practice making myself happy,” “making progress,” “moving from a state that’s not so great leading to a better state, whether physical or mental,” “getting healthy,” and “correcting your body.” One subtheme found within “process” was that of medical treatment.

Medical Treatment: In some cases, patients spoke of healing as obtaining medical treatment. All patients were on extensive medical treatments and may have been influenced by the disease-centered care typically discussed by traditional healthcare professionals. These participants described healing as “getting help through medicine or treatment to cure problems” or simply as “medical treatment.”

Religion/spirituality: Some patients viewed healing as the work of a higher power, specifically God. In these instances, healing was

seen as less of a process and more as a sudden release from illness. Healing definitions for this theme included God freeing them from disease, as well as religious healings on television where someone “puts their hands on you and tells you you’re cured.”

Make Whole: A few patients described healing as occurring when something lost or broken has been replaced or fixed. These responses imply that healing involves reparation of physical disorders, increased function to where they were before the illness, or filling previously unmet needs. This theme was characterized through the responses of “to make whole” and “being fixed.”

Discussion

The themes identified from the responses to “what does ‘healing’ mean to you?” highlight that patients define healing in a broader way than how the term has been traditionally defined in the literature. The patients’ definitions provide greater insight into perceptions and expectations regarding the healing process.

In this time where patient-centered care is being used as an indicator of the quality of care provided, (Kuper et al., 2008; CMS, 2011) knowing what a patient means by healing can help lead to this outcome. For example, if a healthcare provider recognizes that a patient does not indicate acceptance as a part of the healing process, they may invite involvement of a social worker, especially if the patient shows a buildup of resentment, total pain, or resistance. Similarly, if a patient views healing as an actionable process, they may be more likely to adhere to treatment plans and allow the care team to have greater confidence in the patient to engage in treatment. Understanding how a patient defines healing could lead to the more efficient use of personnel resources within palliative care teams. If healing involves psychosocial issues, a social worker would be the designated provider. In a similar manner, if the issue is spiritual or existential, a chaplain would be the designated provider, and a physician or nurse would be integrated into the team if healing involves relief from physical symptomatology. Probing to understand a patient’s perspective of healing will provide an opportunity for all team members to engage with a patient in a meaningful way to gain clarity about patient treatment outcomes. For example, if a patient’s meaning of healing is acceptance, they may not be as distressed by news of poor prognosis or unfavorable treatment results.

Similar to other qualitative studies on patient-directed concepts of healing, our results show that patients with life-limiting illnesses do not necessarily equate healing with a cure or reversal of suffering (Gauthier, 2002; Eustache et al., 2014). Healing is seen as a process in which people learn to find meaning while living with, instead of dying from, an illness. Importantly, we show that clinicians can gather incredibly rich and valuable information about the patient as a person by asking a single question — “What does word healing mean to you?”

This study has several limitations. Some of the participants were being treated at NIH, meaning their treatment was through clinical trials, while others were treated with standard non-research care. As a part of a clinical trial, individuals may have greater confidence in success of treatment which may have influence their perspective of healing, increasing hope of recovery. Additionally, data were not collected on disease diagnosis, which could limit generalizability.

Given that the larger study is centered on cognitive interviewing to develop a psycho-social-spiritual healing instrument, it is unclear if theoretical saturation was reached with predetermined sample of 30 interviews. Saturation is the appreciation in

qualitative investigations that sampling stops when a thorough understanding of the phenomenon under study has been reached (Kuper et al., 2008a). Although interviews were discontinued due to the primary study accrual, investigators feel confident that the sample is saturated as interviews with new participants toward the end of the interview series no longer elicited themes not already raised by previous participants meeting the necessary metric (Kuper et al., 2008b).

Last, using a categorical system in the analysis as the terms used by the patients are subjective, such as social support, compassion, and feeling better mentally; how we categorized them into themes may not fit the patient's intended definition.

Overall, there is a need to expand the research to include how patients diagnosed with specific life-limiting diseases define healing for themselves. This current study emphasizes the various ways that patients define healing, which could inform intervention and assessment of coping with terminal disease. Future research may involve a longitudinal study to design to determine definition changes as individual navigate diagnosis to end of life. Another area of study could explore how one's definition of healing relates to their perception of being treated in a patient-centered manner. Finally, future programmatic studies could assess the use of a patient-centered approach on patient satisfaction.

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