

Original Article

Relating to the Experience of Contingency in Patients With Advanced Cancer: An Interview Study in U.S. Patients

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Abstract

Context. Being diagnosed with incurable cancer can be a life-changing experience, evoking different spiritual questions and needs. Confronting a serious life-threatening event occurs not only often unexpected but also can disrupt a person's self-image and ideals of their personhood. This confrontation makes it difficult for people to integrate it into their personal life story—otherwise referred to as an experience of contingency.

Objectives. Different modes of relating to the contingent life event of having cancer have been studied in a Dutch patient population. Here we present an interview study in an U.S. population with advanced cancer patients.

Methods. We included eight American patients with advanced cancer from the George Washington University Cancer Center. All patients were interviewed twice discussing their life events and life goals using a semistructured interview model. All interviews were transcribed and analyzed focusing on how patients described the way they related to the experience of having advanced cancer. The constant comparative method with a directed content analysis approach was used to code the themes in the interviews.

Results. The analyses show that the four modes of relating to contingency that we found in the Dutch study population can also be found in an American advanced cancer patient population. Differences were found in the extended way American patients described the fourth mode of “receiving.”

Conclusion. This study ensures a broader and deeper understanding of relating to the experience of contingency in having incurable cancer, which is crucial in developing accurate spiritual care in the palliative phase of patients. *J Pain Symptom Manage* 2017;■:■-■. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Experiences of contingency, advanced cancer, spirituality, interview study, American cancer patients

Introduction*Contingency*

Being diagnosed with incurable cancer can be a life-changing experience evoking different existential questions and specific spiritual needs, which confronts patients with uncertainty and a dependency on chance, a challenge that we define as contingency. A

contingent life event confronts a person with a turn of fate that changes that person's life drastically; it affects one's personal life goals adversely and cannot naturally be integrated into one's story of life and, thereby, elicits a quest for meaning.¹⁻⁴ In experiencing contingency, there is the possibility to attribute meaning to the situation one is faced with.

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Modes of Relating to Contingency

Based on the contingency theory introduced by the German philosopher Wuchterl⁵ where he describes forms of denying, acknowledging, and encountering contingency, we were able to distinguish four modes of relating to the experience of contingency in having cancer: denying, acknowledging, accepting, and receiving.⁶ In denying contingency, patients do not want to relate to the life event and aim to live their lives as normal as possible. In acknowledging contingency, patients accept the impact of the event on their lives and start asking questions. In the mode of accepting, patients are more ready to accept the consequences and start to integrate the life event into their lives. In the receiving mode, patients talk about seeing new possibilities and living a more conscious life. These modes were validated in 45 advanced Dutch cancer patients.⁶

Spirituality and Religion

However, these findings were limited by their specific national and cultural context. In the U.S., 89% of people believe in a higher being and religious attendance has stayed at levels far higher than that that prevails in most of Europe.^{7–10} We define spirituality as follows: “the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”¹¹ Religion also involves beliefs, practices, and rituals and is rooted in an established tradition that arises out of a group of people with common beliefs and practices concerning the sacred.¹²

Spiritual Care

Studies have shown that 87% of patients consider spirituality to be important in their lives, but at the same time, many patients have unmet spiritual needs.¹³ Preeminent consensus panels include spiritual care as one of eight clinical practice guidelines in palliative care settings.^{14,15} Studies had shown an association with patients’ spirituality and health care outcomes, especially quality of life for patients across the trajectory of cancer care.¹⁶ A spiritual care for a cancer patient and family education intervention showed improved quality of life, and less depression and anxiety.¹⁷ Spiritual care is defined as assisting patients to find meaning, hope, and strength^{13,18,19} and can be provided in various forms. Interventions focused on meaning making have been demonstrated to be especially helpful in advanced cancer patients.^{20,21} We have developed a semistructured interview model to elucidate interpretations of life events and their integration into life stories.²² This model is based on literature on meaning making, narrative

reconstruction of experiences of contingency, and ultimate life goals.^{5,23–25}

Aim of the Study

Here we aimed to perform an extension of our model by categorizing how patients respond to the contingent experience of having advanced cancer. We set out to assess whether the four modes observed in a Dutch patient population can also be found in an American patient population. Our research question was as follows: How do American advanced cancer patients relate to the experiences of contingency in having advanced cancer?

Methods

Inclusion Criteria

Patients aged ≥ 18 years with advanced cancer not amenable to curative treatment were eligible for inclusion. Exclusion criteria were considered a Karnofsky Performance Status of < 60 , insufficient command of the English language, and current psychiatric diseases based on the medical record.

Study Protocol

Eligible patients were invited by their treating physician (C. P.) or social worker (J. B.) who explained the study and asked for their consent. Patients were recruited from the Supportive and Palliative Care Clinic of the George Washington University Cancer Center. After signing a written informed consent, a baseline assessment took place to provide background information on the participants including an evaluation of Spiritual Well-Being (SWB) measured by the FACIT-Sp.^{26,27} Within one week after the baseline assessment, patients had two, in one case just one, structured conversations with the researcher (R. K.). After the interviews, the patients received an evaluation form to rate their satisfaction relating to the study on a scale from 1 (not satisfied) to 5 (satisfied).

Interview Model

The interviews were conducted by the researcher (R. K.) and lasted between 45 and 75 minutes. Four patients were interviewed in the George Washington University Cancer Center before or after an administered treatment, two patients were interviewed at the office of the George Washington Institute for Spirituality and Health, and one patient was interviewed at home. The interviewer (R. K.) was very familiar with the interview model, as she developed the interview model and trained spiritual care professionals to work with it.^{22,28} The model consists of a semistructured interview model and is supported by an e-application running on an iPad. Patients were asked to

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