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Existential uncertainty in the patient cancer experience: delimiting the concept

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Title:

Existential uncertainty in the patient cancer experience: delimiting the concept

Abstract:

Objective: To delimit the concept of existential uncertainty in the patient cancer experience from other, related aspects of uncertainty in the context of an existing framework of health-related uncertainty.

Methods: In-depth interviews were carried out with six people living with cancer, and analysed using theory-driven, concept-focused thematic analysis.

Results: Our analysis suggests that existential uncertainty is concerned with meaning rather than information; with the person rather than the disease; and with the fundamental nature of our human being-in-the-world rather than the more practical aspects of our relationships with others. Patient expressions of existential uncertainty may involve a non-scientific discourse of metaphor, analogy and imagination.

Significance of Results: It is important for professionals working in supportive oncology to have a conceptual understanding of uncertainty in order to choose how best to respond to patients' needs, as different interventions may be more or less appropriate to different aspects of patient uncertainty.

Keywords:

existential; uncertainty; cancer; meaning; concept

Introduction

Uncertainty is a prominent feature of the cancer experience that has an important existential dimension (Hench & Danielson, 2009). This is true of all stages of the cancer journey, from diagnosis and treatment to post-treatment and/or end-of-life (Ueland, Rørtveit, Dysvik & Furnes, 2020; Lagerdahl, Moynihan & Stollery, 2014; McKechnie, MacLeod & Keeling, 2007). Han, Klein and Arora (2011) suggest that existential uncertainty may be a greater concern for patients than what they call scientific aspects of uncertainty, i.e. uncertainty around diagnosis, prognosis, causal explanations and treatment, even though scientific aspects tend to dominate the research literature. If the care we offer cancer patients is to be truly patient centred, it behoves us to devote more attention to existential aspects of uncertainty and their implications for psychosocial oncology. But what do we really mean when we talk about existential uncertainty?

Although the term 'existential uncertainty' has long featured in the health literature (e.g. Adamson, 1997), including in the context of cancer (e.g. Karlsson, Friberg, Wallengren & Öhlén, 2014), we were unable to find a systematic conceptualisation of existential uncertainty prior to the recent publication of our concept analysis (Dwan & Willig, 2021). This analysis drew on existing research literature in the fields of health, uncertainty and existential therapy to develop a thoroughgoing and theoretically-informed definition of the concept. This analysis proposed four defining attributes of existential uncertainty: (i) it is an awareness of the undetermined but finite nature of one's own being-in-the-world; (ii) it is concerned with identity, meaning and choice; (iii) it is fundamental to what it means to be human and is therefore ineradicable from the human experience; and (iv) it is embodied at different levels of awareness (precognitive as well as cognitive).

The aim of this article is to go beyond this concept analysis by delimiting the concept of existential uncertainty – in other words, to propose how it might be distinguished from other aspects of health-related uncertainty. Such a study is necessary for two reasons:

Firstly, if existential uncertainty is fundamental to what it means to be human, as we propose, then it risks becoming an undifferentiated catch-all unless it is clearly delineated from other aspects of uncertainty. A lack of specificity would seriously limit the concept's clinical utility. For example, it has been suggested that when patients experience existential uncertainty, they find it harder to take in and process information, and can feel overwhelmed if additional or new information is provided (Penrod, 2007), but if professionals involved in cancer care cannot distinguish between different aspects of the uncertainty experienced by patients, they may respond to situations involving existential uncertainty in ways that are unhelpful or even harmful. A conceptual understanding of uncertainty is doubly important given that health-related uncertainty is shaped in part by patients' engagement with health care professionals (Petriceks & Schwartz, 2020; Epstein & Street, 2007).

Secondly, a feature of the existing literature is that either researchers contrast existential uncertainty with existential *certainty* (e.g. Røysland & Friberg, 2016; Karlsson et al., 2014), or they conceptualise existential uncertainty as one of many aspects of uncertainty, including informational (van den Bos, 2009), clinical (Adamson, 1997), reducible (McCormack et al., 2011) and aetiological (Cohen, 1993), without situating these within a coherent framework that specifies how in conceptual terms they might differ from one another.

In putting forward the case for a more systematic programme of research, Han et al. (2019) argue that the diversity and diffuseness of health-related uncertainty research have sown confusion and inefficiency: "Researchers talk past rather than with one another, and fail to reach a shared understanding of what is truly known and not known about the phenomenon." (p.1757) Uncertainty is a particularly prominent aspect of the cancer experience because of the life-threatening nature of the disease (Nissim et al., 2012). However, it has been suggested that health professionals working in cancer care may not feel adequately trained in exploring uncertainty, particularly uncertainty around the future course of the disease (National Institute

for Health and Care Excellence, 2004). The aim of this article is to present a corrective to the vagueness of conceptualisations of existential uncertainty in the existing literature. It is hoped that this might contribute to the development of a more systematic programme of research around health-related uncertainty and a more patient-centred practice among professionals working in supportive oncology, including palliative care.

Methods

Our study involved the analysis of in-depth interviews on the topic of uncertainty with people who had received a cancer diagnosis in the past five years. Theory-driven thematic analysis was used within a concept development framework (Schwartz-Barcott & Kim, 2000) to derive key attributes of different aspects of uncertainty experienced by people in the context of a cancer diagnosis. These attributes were then used as the basis for proposing distinctions between existential uncertainty and other aspects of uncertainty.

Theoretical framework

Given the fragmentary nature of much of the existing research on uncertainty (Han et al., 2019), we felt it was important to situate this study within an existing theoretical framework. We chose as our framework the conceptual taxonomy of varieties of uncertainty in health care put forward by Han et al. (2011). This taxonomy proposes eight aspects of uncertainty falling into three different categories (see Figure 1): the first category is scientific uncertainty, which encompasses uncertainty around diagnosis, prognosis, causal explanations and treatment; the second category is practical uncertainty, which encompasses uncertainty around structures of care and processes of care; and the third category is personal uncertainty, which encompasses psychosocial uncertainty and existential uncertainty.

We chose this taxonomy for three reasons. Firstly, it integrates principles and insights from earlier theoretical models in a comprehensive and systematic manner, so its purview is broad and inclusive. Secondly, it provides an a priori framework for distinguishing between existential

uncertainty and other (specified) aspects of uncertainty – in other words, there is an assumption that existential uncertainty can be meaningfully distinguished from other, related aspects of uncertainty, e.g. around prognosis. Finally, it has spawned a considerable programme of research (with 328 citations in the ten years since its publication, according to Scopus), so its use here is conducive to the development of insights that might have a greater impact on theory and practice than a more inductive approach would generate.

Participants

A purposive sample of six participants was recruited to the study. Participants were recruited online via Twitter. We decided to recruit outside of a health service setting to minimise the risk of inhibition that might arise if participants perceived a link between the research team and their medical team (Marks & Yardley, 2004). To be eligible for inclusion in the study, participants had to: (i) be in receipt of a cancer diagnosis within the last five years (to ensure the experience of diagnosis, treatment, etc. would be relatively fresh in participants' minds and therefore more easily accessible); (ii) be experiencing uncertainty (ascertained on a self-report basis: recruitment materials asked for people who were experiencing uncertainty around their cancer); and (iii) be willing to explore that uncertainty in the context of a semi-structured interview. Informed consent was obtained from participants electronically before the interview began. Ethical approval for this study was granted by the Psychology Research Ethics Committee at City, University of London (ETH1920-1358).

Of the six participants, three were male, two were female and one was non-binary. They ranged in age between 32 and 67. Two participants had been diagnosed with prostate cancer; one with bilateral breast cancer; one with bladder cancer; one with lung cancer; and one with chronic myeloid leukaemia. Time since diagnosis ranged from seven weeks to four years. All participants were based in the United Kingdom.

We acknowledge that this is a small sample, and make no claim as to its representativeness. We believe such a sample is nonetheless capable of generating valid theoretical insights. We make two main arguments in support of this contention. Firstly, this research assumes that uncertainty is a fundamental aspect of human being-in-the-world (Spinelli, 2015), which is to say uncertainty is distributed across all of humanity, so something meaningful about the concept of existential uncertainty can be derived from the testimony of a relatively small number of participants (Guest, Bunce & Johnson, 2006). Our assumption is that the concept of existential uncertainty transcends demographic and situation-specific variables, which is to say the concept is not different for men versus women, for people with breast cancer versus prostate cancer, etc.

Secondly, this research is conceptual rather than phenomenological in nature. It is therefore concerned with the meaning structure of uncertainty, which is assumed to be relatively stable, enduring and consistent across people (Dwan & Willig, 2021), not with the range of experiences which this structure might permit – the experiences of uncertainty among people living with cancer are expected to vary widely, and a phenomenological exploration of existential uncertainty would reasonably require a much larger sample size with more attention to sociodemographic variables, source of recruitment and considerations of cancer type and stage in order to generate valid conclusions about the experience of existential uncertainty.

Concepts are, by their nature, “dynamic, rather than static; ‘fuzzy’, rather than finite, absolute, and ‘crystal clear’; context dependent, rather than universal; and [...] possess[ing] some pragmatic utility or purpose, rather than an inherent ‘truth’” (Rodgers, 2000, p.77). Our aim here is not to offer a definitive conceptualisation of existential uncertainty, but rather to suggest a preliminary conceptualisation which might spark further developments of the concept in future research and/or provide a theoretically-informed conceptual basis on which to begin exploring the experience of existential uncertainty in greater depth. Schwartz-Barcott and Kim (2000), whose concept development framework we adapted for this study, suggest that the

analysis of in-depth interviews with three to six participants is satisfactory for conceptual work of the kind undertaken in this study.

Data collection and analysis

Interviews were carried out by the first author via Zoom and lasted 90 minutes. They began with an object elicitation exercise (Willig, 2017) in which participants were invited to talk about two objects that were linked in their mind with the uncertainty associated with their cancer experience. (Participants had been asked in a screening call to give some thought to this before the interview.) The aim here was to allow participants to frame the meaning that uncertainty had for them in their own terms before responding to more specific questions that sought to draw out the distinctions between the different aspects of their uncertainty – see Appendix 1.

The interviews were transcribed verbatim. The transcripts were then coded and grouped together (Crabtree & Miller, 1999) according to a coding manual based on the eight aspects of uncertainty specified in the Han et al. (2011) taxonomy (see Table 1) – in other words, passages from all six interviews concerned with a particular aspect of uncertainty were gathered together in one place. Themes were then derived by the first author from the gathered data for each aspect using the technique of immersion and crystallisation (Borkan, 1999), and checked with the second author. These themes form the basis of the findings we describe below.

Results

Our analysis of the interviews generated six attributes of existential uncertainty, as set out in Table 2. These are consistent with the defining attributes specified in our concept analysis derived from existing literature (Dwan & Willig, 2021). There is, however, a significant addition: questions of control and agency. In the passages coded as existential uncertainty, all

participants reported struggling with a lack of control that extended beyond the medical aspects of cancer. For example, one participant said:

'I suppose what it's taught me that there are things that I'll never ever be able to control, things that might have a huge impact on me, that I'll never be able to control, and you just have to live with that, and find a way to live with it, really, however hard that might be.'

What we present below is a necessarily brief account of how the concept of existential uncertainty entailed by these six attributes might be distinguished from three aspects of uncertainty within the taxonomy with which it shares conceptual terrain: uncertainty around treatment (shared concern with choice); uncertainty around prognosis (shared concern with the future); and psychosocial uncertainty (shared concern with patients' relational world).

Existential uncertainty vs treatment uncertainty

According to our analysis, treatment uncertainty involved: (i) a concern with side effects and quality of life; (ii) a concern with efficacy; and (iii) weighing up before deciding. One of the participants who was treated for prostate cancer referred to 'that pit-in-the-stomach feeling' he got when he was asked to choose between surgery and radiotherapy. His account of the exchange he had with his care team suggests a possible distinction between existential uncertainty and uncertainty around treatment:

'So, well, you're, you're the radiologist and the surgeon, why don't *you* know the right answer to this, surely? No, no, we can't tell you, you have to decide for yourself, we can't advise you on what your treatment should be, eh, cos they've both got different side effects and we don't know what's important for you.'

The 'pit-in-the-stomach feeling' was possibly associated with the need to reflect on what was *important* for him, i.e. the meaning of life, rather than uncertainty around the treatment itself. The radiologist and surgeon could reduce the uncertainty around treatment side effects by providing information and data, but they couldn't tell him what it would *mean* for him if he were to experience these side effects. Thus it might be said that while uncertainty around treatment implies a deficit of information or knowledge, existential uncertainty is a question of meaning.

Existential uncertainty vs prognostic uncertainty

Our analysis of the interview passages coded as prognostic uncertainty yielded three defining attributes: (i) time and death; (ii) variability and unpredictability (of test results); and (iii) direction and recurrence (i.e. concern about the direction of the disease trajectory or the possibility of its recurrence following treatment). The first attribute shares common ground with existential uncertainty, in particular with 'an undetermined future' and 'living with the spectre of dying'. So how are the two concepts different? One participant talked about his ambivalence around the question of how long he might have left to live:

'Cos that'll help me decide whether I take early pension and get the caravan or, you know, we sell up the house and downsize, em, or whatever we do with our lives. And from a practical side of things, that's what I should have known, but from an emotional side of things, I didn't really want to know or ask that question.'

This distinction between the practical and the emotional may point to a distinction between prognostic uncertainty and existential uncertainty: prognosis conveys information about the likely course of a disease, but as with treatment uncertainty, the information is not emotional per se – it is the meaning of the information for the individual that gives it an emotional and therefore embodied quality.

Another participant drew a distinction between the 'medical point of view' and the 'real point of view', whereby he pointed to the shortcomings of a medical discourse predicated on data, probabilities and typical cases, which does not necessarily capture the reality of the lived experience, in particular its existential dimensions. This distinction was echoed by the participant who was living with chronic myeloid leukaemia when they offered the following reflections on blood test results on the one hand and life's big questions on the other:

'...it's this idea of like the difference between my quantifiable evidence of your health and this metaphysical concept of your health.'

Existential uncertainty vs psychosocial uncertainty

The Han et al. (2011) taxonomy distinguishes between existential uncertainty and psychosocial uncertainty within the category of personal uncertainty. Our analysis yielded three attributes of psychosocial uncertainty: (i) practical/material concerns (e.g. employment, finance, housing, etc.); (ii) sociopolitical/sociocultural factors (e.g. fears around disruption to medical supplies associated with Brexit, social attitudes to sexual and gender minorities, etc.); and (iii) managing relationships (e.g. when/how to tell loved ones about the diagnosis, the impact of the cancer on loved ones, the need to manage other people's reactions to the cancer, etc.).

Given psychosocial uncertainty and existential uncertainty are both squarely focused on the person rather than the disease, it is more difficult to draw a neat distinction between them than between existential uncertainty and scientific or practical aspects of uncertainty. However, one distinction that can be substantiated from the data is that psychosocial uncertainty has a pragmatic, concrete dimension to it – the issue is readily identifiable (lack of money, poor housing, disruption to medical supplies, issues within particular relationships). By contrast, it is harder to pinpoint the specific problem when it comes to existential uncertainty, much less identify a solution – the future is undetermined no matter how hard we might try to forecast it,

most things are outside of our control however much we might try to control them, we are unavoidably embodied and on a journey towards death, etc. These are not problems to be solved, but rather what it means to live as a human being.

The intangible nature of existential uncertainty was most evident in the data generated by the object elicitation exercise. While some of the objects participants brought represented scientific aspects of uncertainty, e.g. a letter from the consultant, a bottle of pills, a PSA test record card, there were others where the uncertainty was less explicit and seemed to tap an existential dimension, e.g. music CDs, a cathedral choir, a photo of a participant at a political demonstration. In the case of the music CDs, the participant explained that music and emotion were deeply bound up with his sense of uncertainty:

'I've realised since I was diagnosed with the cancer that, em, something has changed inside of me emotionally and, em, there's so many songs there, I just burst into tears when they come on, it don't matter where I am, it just sort of hits, hits a nerve. Em, I don't particularly feel particularly sad when it happens, I just feel very sentimental and emotional. And it could be daft, I mean, I'm a rock music lover, but it could be, it could be Vera Lynn or it could be, you know, Land of Hope and Glory or something like that, it could be anything, you know, a Disney song, and I found, I found that sort of weird.'

It is perhaps significant that, although he is a rock music lover, two of the examples he namechecked were Vera Lynn and Land of Hope and Glory which, for many, capture something of the quintessence of the British spirit in the twentieth century, and therefore reflect an aspect of the British national identity. A case can be made too that the participant who chose a cathedral choir as one of her objects (both of her sons had attended a cathedral school and one had been a chorister) did so because of the cultural significance of the cathedral in her life, and the challenge that cancer posed to this significance.

Identity was also evident in the testimony of the participant who talked about her experience of attending a large march to protest the result of the Brexit referendum, which she said was the first time in almost a year that she didn't think about her cancer:

'I've never seen as many people as that, you couldn't see the end behind you, and you couldn't see the end in front of you, so you were just in this huge, huge body of people. You knew ultimately where you were going, but you couldn't see the end either way – that was incredible to me, all of these people, and all probably thinking the same way as I think, you know, em, and all the support, and it was very peaceful and you made, em, you made friends with the people around you, you know, there were kids on the march, there were people with their dogs, em, and there were people with musical instruments and they were singing as they were going along, eh, and it was just, I loved it, I loved the day [...] the feeling of being part of this thing, and maybe we will change something, maybe something will change – you know it hasn't changed, but you've just got that optimistic feeling as well, I suppose, that yeah, you know, we can do this.'

These examples may point to an association between existential uncertainty and the feeling of connection with (or disconnection from) something transcendent, but the important point is that while examples of psychosocial uncertainty were relatively clear, examples of existential uncertainty tended to be more opaque and difficult to articulate – they seemed to be getting at what it means to live as a human being at a more fundamental level, and were often expressed in non-scientific terms using the language of metaphor, analogy and imagination.

This is not to over-simplify things by suggesting an absolute distinction between psychosocial and existential uncertainty. Quite clearly, the practical challenges associated with psychosocial uncertainty are inextricably entwined with some of the deeper questions about human existence – for example, one participant talked about the fact that her son didn't tell

her about a medical issue he was experiencing for fear of worrying her, and this led her to question her identity as a mother:

‘...cos you don't stop being a mum, you're still worried about that, but he didn't want to worry me, and it kind of stops you...’

This demonstrates how a change in the dynamic of a relationship (psychosocial uncertainty) can lead to a questioning of identity at a deeper level (existential uncertainty).

Discussion

The findings outlined above support three ways in which existential uncertainty can be distinguished from other aspects of uncertainty in the patient cancer experience. Firstly, existential uncertainty is concerned with meaning rather than discoverable facts. This is consistent with Penrod's (2007) suggestion that introducing new information to a patient who is experiencing high levels of existential uncertainty may be counterproductive.

Secondly, existential uncertainty is focused on the person rather than the disease. Scientific aspects of uncertainty are predicated on the assumption that “conditions have identities independent of their existence in given patients” (Christakis, 2001, p.6), and are constituents of the “ideology of uncertainty reduction” (Babrow & Kline, 2000, p.1805) that characterises contemporary Western medicine. By contrast, existential uncertainty is predicated on the assumption that cancer cannot be divorced from the individual's holistic embodied experience. It is concerned with a search for meaning, and is not amenable to strategies that might seek to reduce it directly (e.g. with information).

Thirdly, existential uncertainty is concerned with the fundamental principle of relatedness that underpins human existence rather than relationships between bounded beings. The existential therapy literature offers support for such a distinction. Spinelli (2015) draws on

Heidegger's concept of being-in-the-world to distinguish between the relatedness that is a foundational precondition for the emergence of a self, and the relationships between bounded beings to which this relatedness gives rise. In other words, while psychosocial uncertainty is concerned with bounded beings and the relationships between them, existential uncertainty is concerned with the deeper level of relatedness, and therefore with the grounding on which these relationships depend for their continued existence. Another way of conceptualising this is that psychosocial uncertainty is ontic in nature, i.e. relates to "the specific individual ways in which each of us is in the world" (Cohn, 1997, p.3), while existential uncertainty is ontological in nature, i.e. concerned with "those intrinsic aspects of Being which are 'given' and unescapable" (ibid.).

Implications for practice

Given that uncertainty pervades the cancer experience, it is important for professionals involved in supportive oncology to consider how best to respond to patients' expressions of uncertainty. Although cancer patients will have many questions that can and should be answered, particularly around scientific and practical issues, there will inevitably be questions that cannot be answered, and it requires the judgment of the individual clinician to distinguish between these. If a patient is experiencing acute uncertainty about 'the future', for example, the analysis presented here provides a way of parsing this uncertainty before deciding how to respond: if the uncertainty is about prognosis or treatment outcomes, then an informational intervention may be indicated (Epstein & Street, 2007); if the issue is more social or practical, it may be that a solution-focused intervention may be most helpful (Neilson-Clayton & Brownlee, 2002); but if the uncertainty is existential in nature, an informational or solution-focused intervention would not be appropriate, whereas a meaning-oriented intervention might be beneficial (Frankl, 1988; Lee, 2008; Vehling & Philipp, 2017), for which there is growing evidence of efficacy in the cancer context (Breitbart et al., 2018; Bauereiß, Obermaier, Özünal & Baumeister, 2018).

Limitations

Conceptual research such as that described here is ultimately linguistic in nature (Walker & Avant, 2019) and is therefore susceptible to the imprecision and ambiguity of language itself, as some have pointed out (Beckwith, Dickinson & Kendall, 2008). It is important that the conceptualisation of existential uncertainty offered here be read as one of multiple possible conceptualisations, and – crucially – one that aims for utility rather than ‘truth’. In keeping with an evolutionary approach to concept analysis (Rodgers, 2000), our conceptualisation of existential uncertainty and its relationship with other aspects of uncertainty within the taxonomy are contextually bound, i.e. this conceptualisation reflects our social world in general, our health care systems in particular, and – most specifically – the structure of the Han et al. (2011) taxonomy. We chose to situate our analysis within this taxonomy because of its systematic approach to uncertainty in health care and its generation of increasing volumes of research. It is our hope that the elaboration of its constituent elements proposed here will be helpful to professionals working in palliative and supportive care as they respond to uncertainty in clinical encounters and to researchers seeking to elucidate further the nature of uncertainty in health care.

Future research might fruitfully extend the concept of existential uncertainty into contexts beyond cancer, especially where people receive a diagnosis that might pose a threat to their sense of themselves at a fundamental level, for example a diagnosis of HIV that can carry with it the threat of rejection and social alienation (Brashers, Neidig & Goldsmith, 2004), or a diagnosis of dementia that can carry with it the threat of psychological death (Blandin, 2016).

Conclusion

The Covid-19 pandemic has shown clearly that the uncertainties experienced by cancer patients can come from sources beyond the cancer itself (Leach et al., 2021), and that clinicians must develop their own language and framework for anticipating and addressing these uncertainties (Petriceks & Schwartz, 2020). Any such framework must be built on a clear

conceptual understanding of the different aspects of uncertainty that patients may experience. In this article, we have outlined some of the key distinctions between existential uncertainty and other aspects of uncertainty that are salient in the context of health care, including a focus on meaning rather than facts, the person rather than the disease, and the fundamental nature of our human being-in-the-world rather than the more practical aspects of our relationships with others. By delimiting the concept in this way, we hope to have added clarity to a conceptual framework that is relevant to clinical and research contexts alike.

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