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Constructing Existential Uncertainty in the Cancer Context: A Deductive Thematic Analysis

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ABSTRACT



Notwithstanding ever-increasing reservoirs of scientific knowledge, uncertainty is a fundamental part of human existence that will never be eliminated. This paper focuses on the concept of existential uncertainty by exploring how people living with cancer construct their sense of the unknown. We interviewed six people who had received a cancer diagnosis in the last five years on the subject of their uncertainty, inviting them to talk about objects that were related to this uncertainty and to answer questions about their experience of uncertainty. A deductive thematic analysis of the interviews generated commonalities in the way they expressed the existential aspect of their uncertainty, namely: a struggle to put it into words; a resort to metaphorical modes of expression; and a sense that the process of doing so was somehow “weird.” We suggest that it is difficult for people to express their existential uncertainty directly and in the conventional terms of a medico-scientific discourse, and that they resort to alternative discourses that are more amenable to metaphor to do so. It is important for clinicians offering psychological support to be aware that clients may express uncertainty in this way so they can deepen rather than thwart their meaning-making process.

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This paper is part of a program of research that aims to develop a theoretically-informed conceptualization of existential uncertainty in the health care context, the lack of which is a weakness in the existing literature. On the basis of an analysis of interviews conducted with people who have received a cancer diagnosis, we suggest ways in which existential uncertainty might manifest in clinical encounters. The purpose of this is to enable clinicians to parse the uncertainty that is expressed in health care settings, and to respond in an appropriate manner. We chose cancer as our focus because the life-threatening nature of the disease makes uncertainty a particularly prominent aspect of the cancer experience (Nissim et al., 2012). We chose constructivism as the lens through which to explore this important issue because of its unique openness to, and embracing of, the unknown.

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Constructivism and uncertainty

Writing in the pages of this journal a decade ago, Mair (2012) set out his vision for constructivist psychology as a psychology “full of unknowns while making engagement with the unknown more possible than before” (p. 188). This vision was informed by Kelly’s (1977) conception of personal construct psychology as “the psychology of the unknown,” with a focus on the process of questioning rather than the accumulation of answers. Constructivist approaches to psychology provide an alternative to the modernist scientific paradigm, driven by positivist principles, which proceeds on the basis that if we ask the right questions and gather enough information to answer them accurately, we will eventually run out of questions to ask (Gordon, 2003).

The modernist quest for certainty is evident in clinical medicine (Gillett, 2004), which is driven by an “ideology of uncertainty reduction” (Babrow & Kline, 2000, p. 1805). This ignores the reality that while greater quantities of information can lead to increased knowledge and scientific breakthroughs, they also generate uncertainty and doubt because they inevitably raise further questions (Michael, 2000). Constructivism rejects the theoretical possibility of arriving at a “cognitive Eden’ in which we are forever secure, and where the terrain and rules of the game are stable and familiar” (Neimeyer, 2009, p. 11). Instead, it emphasizes the importance of engagement with the unknown, and meaning making in the face of uncertainty. This makes it a suitable lens through which to explore the questions that people ask in the aftermath of a cancer diagnosis, and the meaning structure of the uncertainty that might underpin them.

Uncertainty in health care

Health care is fertile ground for the exploration of uncertainty because of the fundamental connection between health and uncertainty. As Han et al. (2011) have written:

Uncertainty pervades and motivates every activity related to health care. At the most fundamental level, it is uncertainty of one form or another that fuels medical research, prompts patients to seek care, and stimulates medical intervention. The inability to abolish uncertainty, furthermore, promotes the perpetuation of these activities and creates difficult challenges for clinicians and patients. (p. 828)

But how might uncertainty in health care be usefully understood? Han and colleagues (2011) argue that the research around uncertainty in health care has traditionally been piecemeal and diffuse, and that this has hobbled our attempts to understand the phenomenon in a way that might lead to better outcomes for patients. They developed a conceptual taxonomy of uncertainty in health care to address the unsystematic nature of the existing research. This taxonomy distinguishes between scientific aspects of uncertainty (i.e., uncertainty around diagnosis, prognosis, causal explanations and treatment), practical aspects of uncertainty (i.e., uncertainty around structures of care and processes of care), and personal aspects of uncertainty (i.e., psychosocial uncertainty and existential uncertainty). It has spawned an impressive body of research, with well over 300 citations in the ten years since its publication.

Background to the current study

One of the features of the existing literature on uncertainty in health care is that the focus tends to fall much more heavily on scientific aspects of uncertainty than on personal aspects, in spite of the likelihood that personal aspects of uncertainty—including existential uncertainty—are of greater concern to patients (Han et al., 2011). In fact, we found from our initial engagement with the literature that the term “existential uncertainty” had never been properly defined or conceptualized, and different researchers were using it in ways that were idiosyncratic and inconsistent (Dwan & Willig, 2021). We therefore embarked on a program of research focused specifically on the concept of existential uncertainty in a bid to address this fundamental weakness in the literature. The overarching question driving this research was: how might existential uncertainty be usefully conceptualized?

We adapted the hybrid model of concept development (Schwartz-Barcott & Kim, 2000) to fit the specific question under investigation. The hybrid model is so named because it integrates insights from philosophy of science, sociology of theory construction and field research to combine analysis of a concept in existing theory with the collection and analysis of new empirical data. The hybrid model sets out three consecutive but overlapping and mutually influencing phases:

- Phase 1 – concept analysis
- Phase 2 – analysis of new empirical data
- Phase 3 – synthesis of first two phases

In Phase 1, we conducted an analysis of the use of the term existential uncertainty in existing literature across multiple disciplines as well as drawing on insights from the existential therapy literature and from uncertainty theory more broadly to establish a tentative definition of the concept. The outcome of this phase of the research, which has already been reported (Dwan & Willig, 2021), was a theoretically-informed conceptualization of existential uncertainty as an awareness of the undetermined but finite nature of a person’s own being-in-the-world, concerned primarily with identity, meaning, and choice; an awareness that is fundamental and ineradicable, and that manifests at different levels of consciousness.

In Phase 2, we conducted interviews with six people living with cancer to generate rich accounts of cancer-related uncertainty that might yield further insights into the meaning structure of uncertainty, including the nature of existential uncertainty and its relationship with other aspects of uncertainty in the cancer experience. The interviews were analyzed using deductive thematic analysis (see Methodology below), in which the eight aspects of uncertainty proposed in the Han et al. (2011) taxonomy were used as an a priori coding manual. The outcome of this phase of the research was a list of the defining attributes for each aspect of uncertainty (including existential uncertainty).

In Phase 3, we synthesized the findings from the first two phases in order to produce a revised conceptualization of existential uncertainty that was both grounded in theory and informed by (and consonant with) empirical accounts of the uncertainty

experienced by people living with cancer. In a recently published paper, we reported some of the results of Phases 2 and 3 (Dwan & Willig, 2023): we proposed six defining attributes of existential uncertainty (Table 1), as well as three key ways in which existential uncertainty might be distinguished from other related aspects of uncertainty, namely treatment uncertainty, prognostic uncertainty and psychosocial uncertainty. We argued that the main distinguishing features are existential uncertainty's concern with meaning rather than information; the person rather than the disease; and the fundamental nature of our human being-in-the-world rather than the more concrete aspects of our relationships with others.

The current study

In the course of our thematic analysis of the Phase 2 interviews, we noticed that while most of the themes we were drawing from the data coded as existential uncertainty pertained to the concept itself (i.e., its quality, its focus and its source—see Table 1), some pertained to the way in which participants sought to express this aspect of their uncertainty. We noted that examples of existential uncertainty tended to be more opaque and harder to pin down than examples of other aspects of uncertainty, “often expressed in non-scientific terms using the language of metaphor, analogy, and imagination” (Dwan & Willig, 2023, p. 251). What we present below is a more in-depth exploration of this point: we turn our attention to the ways in which people living with cancer might talk about the existential aspect of their uncertainty. We are concerned here with metacommunication—in other words, our focus is not primarily on *what* people might talk about when they talk about existential uncertainty (e.g. future, identity, meaning), but rather on *how* they go about talking about it.

It is important to be clear that this research is about the *concept* rather than the *experience* of existential uncertainty. While it draws on people's descriptions of their uncertainty experience, its aim is not to capture that experience. Its aim is to help clinicians to parse the uncertainty that is expressed in clinical encounters with people living with cancer, and to become more sensitive to its manifestations, including the indirect and allusive ways in which people might seek to articulate its existential aspect. However we hope that when researchers come to do phenomenological research on existential uncertainty in the future, our conceptualization of existential uncertainty and its modes of expression will ensure that research is underpinned by a clear and theoretically-informed understanding of the term.

Theoretical assumptions

Because our approach is deductive, it is important that we make explicit the theoretical assumptions on which the analysis reported below is based.

We subscribe in this study to a broad conceptualization of uncertainty as “the subjective perception of ignorance” (Han et al., 2011, p. 830), a metacognition involving (i) a knowledge deficit, i.e., what is unknown, and (ii) an awareness of this deficit, i.e., uncertainty. We will comment briefly on these in turn.

Table 1. The six defining attributes of existential uncertainty according to the analysis with illustrative examples from participant interviews, divided into three meta-theoretical categories.

Meta-theoretical category	Attribute	Examples
Quality: existential uncertainty is experienced as...	An intrusion into awareness	<p>"I'll be working away, and then I think, oh, I've got cancer, you know – it was me. And then I just carry on again, you know, it's that kind of intrusive thought, but it's just a minute"</p> <p>"there was no inkling that I was ill, or there was anything wrong with me and this is just like a bolt out of the blue"</p> <p>"that sinking feeling in your tummy"</p> <p>"you kind of feel like the pit of your stomach kind of go"</p> <p>"it just feels like a weight on your shoulders"</p>
	Embodied	
Focus: existential uncertainty is concerned with...	An undetermined future	<p>"you can't take how things are today, that that's how they're always going to be, and that's how you're always going to be able to behave"</p> <p>"my questions are based in the idea of a timeline that you obviously can't access, like, where are we going to go?"</p>
	Identity and meaning	<p>"that's sort of left me feeling with a sort of am I really still a man?"</p> <p>"let's try and do something good out of this, and not in a sense of some kind of moral duty, but just, just some way that helps me process everything that's happened and make you feel like there's a point to it, there's a purpose"</p>
Source: existential uncertainty is a consequence of...	Living with the specter of dying	<p>"[dying] seems more, it seems more concrete, more definite, I suppose, still can't, still can't actually say how definite because we don't know when it will be"</p> <p>"cancer is almost, this is going to sound really dark but it's the only way I can think about it right now, but especially with my kind of chronic cancer, it's just like a waiting room to death"</p>
	Questions of control and agency	<p>"cos there's nothing, nothing, there's nothing I can do about it"</p> <p>"we have three alcohol-free days, you know, a week, all the things you should do, we exercise, we walk, you can only do what you can do, and it's almost, we've done everything we can do, but yet this has happened"</p>

As regards what is unknown, we adopt an existential ontology (Hersch, 2015), which assumes the existence of a world characterized by “non-fixed phenomena whose significances and meanings are continuously in flux” (p. 111). Central to the idea of an existential ontology is that within the context created by existential “givens” such as death, isolation and meaninglessness (Yalom, 1980), the non-fixedness of phenomena results in unavoidable uncertainty (Spinelli, 2015). Uncertainty is often oriented toward the future, particularly in the case of cancer where people are understandably occupied with the question of disease progression. We assume that “the future is not already in existence waiting for scientific methods to reveal that future” (Staley, 2017, p. 41), but rather that the future exists in the present only as potential. This position is consistent with the emphasis on freedom (Yalom, 1980), choice and responsibility in existential theory (Spinelli, 2015)—the future is undetermined in the present, but is shaped by the choices we make among the possibilities afforded by the present.

We assume that uncertainty does not exist in any absolute or objective sense, but only as a function of our uniquely human being-in-the-world (Heidegger, 1996/1927). This requires that we see uncertainty in relational terms—in other words, not as existing *out there* in the world, nor as existing *inside our heads* as an “exclusively isolationist subjectivity” (Spinelli, 2015, p. 16), but as something we construct through our being-in-the-world-with-others (Cohn, 1997): we cannot determine or control

ahead of time what is going to happen since the future both implicates us and also extends beyond us and what is in our gift to control.

This study is concerned with what Daase and Kessler (2007) refer to as known unknowns (things we know we do not know), unknown unknowns (things we do not know we do not know), and unknown knowns (things we prefer not to know and turn away from). As people living with cancer “pass from a relatively stable, taken-for-granted, pre-illness world to a reconstituted uncertain world” (Cohen, 1993, p. 82), it is assumed that they become aware of things they previously preferred not to know and therefore kept out of awareness, such as the reality of life’s finitude. Drawing on the embodied phenomenology of Merleau-Ponty (1998/1962), we regard awareness as encompassing that which is intuitive, experiential and somatic as well as cognitive, rational and conceptual (Barbour, 2016; Peile, 1998). It is particularly important that a study focusing on cancer-related uncertainty be sensitive to embodied ways of knowing, since the cancer experience is somatic by definition.

One of our key epistemological assumptions is that the meaning we give to the uncertainty we experience as humans is an indirect, socially-constructed response to something real in the world, i.e., a response that is mediated through socially-available ways of constructing that “something real” in symbolic terms, such as language and culture (Babrow et al., 1998; Neimeyer, 2009; Willig, 2012). For example, a person living with cancer may choose from a range of different (potentially conflicting) discourses in their construction of uncertainty, including their oncologist’s estimate of the probability of treatment efficacy, the Western cultural conception of cancer as a battle to be won or lost, spiritual beliefs that might emphasize personal responsibility and divine determinism to differing degrees, etc. The socially-constructed nature of uncertainty is generally acknowledged in health care, where encounters between patients and clinicians are seen as shaping the uncertainty (Epstein & Street, 2007; Petriceks & Schwartz, 2020). This amounts to a social constructivist position, emphasizing the choice of the individual when it comes to selecting from socially-available options (Crotty, 1998). This is consistent with an existential ontology in that it balances the role of the particular social and material givens of existence with the assumption that the individual has agency and choice when it comes to the meaning-making endeavor (Burr, 2015). This also reflects the centrality of choice as a theme in existential theory, notably in the work of Viktor Frankl (2011), who regarded a human being as a *deciding* being. Our aim here is to say something useful about how people living with cancer might decide to express themselves when they attempt to make meaning out of their awareness of things that they do not (yet) know.

When it came to analyzing the interviews conducted for this study, we assumed that everything participants said was somehow relevant to uncertainty, even if this was not always immediately evident. We decided it was important to adopt this inclusive approach in order to capture the indirect ways in which people might make meaning out of their uncertainty experience. It is difficult to talk directly about uncertainty since uncertainty entails a not knowing, and it is surely easier to talk about knowing than not knowing. Our assumption was that *whatever* participants chose to say about their cancer experience in the context of an interview about uncertainty would connote something of their construction of uncertainty.

What we present here is an exploration of how people express themselves when they construct meaning out of their sense of the unknown, in particular its existential aspect. Existential uncertainty, like any concept, has pragmatic value in that it allows us to point to an important aspect of the human experience and explore the meaning structure underpinning it. In this sense it is a matter of epistemology rather than ontology. As Wilson (1963) reminds us, abstract nouns are not the names of abstract *things*, and existential uncertainty is not a thing so much as a tool for talking about an important aspect of what it means to be human.

Method

The results reported in this paper are based on interpretations derived from a deductive thematic analysis of interviews conducted with people living with cancer, as we now describe.

Recruitment to study

We used Twitter to recruit a sample of six participants to the study. Purposive sampling is typical in qualitative research of this kind. Furthermore, it was assumed that existential uncertainty is an intrinsic aspect of human existence and therefore universally distributed (see Theoretical assumptions above), which means a small sample size is sufficient to yield some understanding of it (Guest et al., 2006). We chose to recruit outside of a medical setting to mitigate the impact of a medical framing on participants' construction of their uncertainty experience—in other words, to frame the research in such a way that participants would feel free to articulate their uncertainty experience in whatever way they chose rather than risk priming them to articulate it in exclusively medical terms, as might have happened if the invitation to take part in the research had come *via* their medical team.

The only eligibility criteria were that participants should be over the age of 18, should have been diagnosed with cancer in the last five years (so that details of their initial diagnosis and treatment would be relatively fresh in their minds and therefore more easily accessible), and should describe themselves as living with uncertainty. The only exclusion criterion was that a person in acute distress should not take part for ethical reasons but should instead be signposted to an appropriate source of support—this was determined by means of a screening telephone call. This exclusionary criterion was not applied as nobody presented in a way that would indicate acute distress. All participants were based in the United Kingdom. They ranged in age from 32 to 67

Table 2. Demographic details for participants.

Participant	Age	Gender	Diagnosis received	Time since diagnosis
P1	62	Female	Breast cancer	2 years
P2	59	Female	Bladder cancer	7 weeks
P3	64	Male	Lung cancer	3 years
P4	32	Non-binary	Chronic myeloid leukemia	3 years
P5	61	Male	Prostate cancer	2 years
P6	67	Male	Prostate cancer	4 years

and had received one of a variety of cancer diagnoses (breast cancer, bladder cancer, lung cancer, chronic myeloid leukemia, prostate cancer). Time since diagnosis ranged from 7 weeks to 4 years. See [Table 2](#).

All participants gave informed consent prior to the interview. Ethical approval for the study was granted by the Psychology Research Ethics Committee at City, University of London (ETH1920-1358).

The interviews

Participants were invited to explore their experience of cancer-related uncertainty in an interview lasting up to 90 min. Interviews were carried out remotely *via* Zoom. The interview had two integrated components. First, there was an object elicitation exercise (Willig, 2017), in which participants identified and talked about two objects that were linked in their mind with their cancer-related uncertainty (participants were asked during the screening call to give some thought to this ahead of time). The aim here was to help participants focus their minds on the meaning of uncertainty in their lives, about which it might have been difficult to formulate thoughts spontaneously, and to allow them to frame their uncertainty experience in terms of this meaning rather than respond to our framing. Second, there was a semi-structured interview that involved a series of more focused questions that were designed to help participants describe different aspects of their uncertainty experience in greater detail (see [Appendix A](#) for the interview schedule).

The interviews were conducted by the first author and transcribed verbatim. They were then analyzed by the first author using a form of deductive thematic analysis set out by Crabtree and Miller (1999). This deductive approach to thematic analysis differs in its early steps from the step-by-step guide set out by Braun and Clarke (2006), in which initial codes are generated from the data itself. Because our research is concerned with the concept rather than the experience of existential uncertainty, we chose an approach that was developed specifically around the use of an a priori coding manual as a means of coding and organizing the data. What follows is a brief description of the steps we followed:

- Step 1 – Familiarization: the interview transcripts were read and re-read in their raw form in order to get a feel for the participants' stories. Initial impressions were noted.
- Step 2 – Coding: the interviews were then coded according to a coding manual comprising the following eight codes derived from the Han et al. (2011) taxonomy of uncertainty in health care: diagnostic uncertainty; prognostic uncertainty; uncertainty around causal explanations; treatment uncertainty; uncertainty around structures of care; uncertainty around processes of care; psychosocial uncertainty; existential uncertainty. In other words, we actively sought examples of these aspects of uncertainty in participants' accounts of their uncertainty experience. When it came to coding for existential uncertainty, we looked for one or more of the defining attributes of existential uncertainty as identified in the concept analysis we had already conducted (Dwan & Willig, 2021).

- Step 3 – Chunking: all instances of a given code were then “chunked” together. In other words, all participant statements that we deemed to be instances of existential uncertainty were gathered together as a subset of the interview data out of which themes could be generated – likewise for the other seven codes.
- Step 4 – Immersion/crystallization: this step involved repeated cycles of reading the subset of data relating to existential uncertainty and reflecting on it (immersion) until interpretations began to form (crystallization). This step was repeated for the other seven codes.
- Step 5 – Generation of themes: these crystallizations were then refined into themes. Candidate themes were named, reviewed by the second author and further refined. Final themes were decided upon for existential uncertainty, and considered in the context of the data set as a whole, i.e., the final themes for existential uncertainty were compared and contrasted with the themes for psychosocial uncertainty, prognostic uncertainty, treatment uncertainty, etc. to see where there might be shared conceptual terrain between aspects of uncertainty in the Han et al. (2011) taxonomy.

Results

Some of the results of this analysis have already been reported in a paper that describes how the concept of existential uncertainty might be delimited from other, related concepts (Dwan & Willig, 2023). What we describe below is the commonalities we observed in the way participants expressed themselves in passages coded as “existential uncertainty.” Although these commonalities are interrelated, for clarity we present them as three categories:

- Struggle to articulate
- Metaphor
- Weirdness

Struggle to articulate

Participants often seemed to struggle in passages coded as existential uncertainty to articulate directly something that seemed to resist such articulation. When P4 was asked what questions they most wanted answers to, if answers were available, they sighed and said:

I think the answers to the questions I want are just not answerable, but I’ll answer the question, but you know like it’s some semblance of precognition and the idea of like am I going to get better?

This participant gamely tried to answer the unanswerable by invoking *some semblance of precognition* and *the idea of like* whether they were going to get better. It is clear that these words are approximations, but fail to capture exactly or entirely what they are trying to express. The mention of precognition furthermore supports the idea that what participants were trying to express in passages coded as existential uncertainty was often preverbal—a felt sense rather than a fully elaborated idea.

A sense of grasping at something elusive distinguished passages coded as existential uncertainty from passages coded as other aspects of uncertainty. For example, P5 wondered whether he would ever lead a “normal life” again, struggling to elaborate on the “horrible feeling” associated with that question:

it's sort of, ugh, how do you describe, it's quite difficult to, to, to translate with... I'd use the word dread, but it, dread is far too big a word to describe the actual emotion, but it's that sort of empty, em, dismal is, is probably the, the, the emotion I'd say, it's sort of, it's a miserable thing.

He was clearly working quite hard here to verbalize the feeling, but no word seemed quite right—he said “sort of” three times and his diction was peppered with hesitation (“ugh,” “em”) and revisions (“dread” → “empty” → “dismal” → “miserable”) as he sought a satisfactory means of translating the feeling into a word.

When talking about the uncertainty he experienced in the period following initial diagnosis, P3 began talking about his dreams:

because me mind was so fuzzy, I couldn't even work out properly what tablets I needed to take and when, em, it was hell, it was hell, I was having nightmares and I was trying to explain it to me daughter and her other half, em, almost like they was lucid dreams where I was in 'em, and em, I was actually actioning what was happening with 'em, em, which was weird because I've never had any experience like that, em, and to be honest, ever since, I, like I dream every day, I dream often about the same thing, and I, I speak a lot in my sleep now, because I'm having conversations, em, and then I'd wake up and I'd still be talking, and I'd realise, what am I doing?

It is interesting that this participant found himself speaking a lot in his sleep after the diagnosis, which we interpreted as him struggling to articulate something that he could not articulate during waking hours. What is of greater interest for our purposes here, however, is that he chose to introduce his dreams into our conversation, given the dreams were not ostensibly about cancer—he said:

They're always, always about work, and more often than not, they're more about people questioning my ability to do things, I even have to prove meself that we're on target and stuff like that, always seem to be someone challenging me, so that I'm having to, you know, convince 'em that I am working hard.

We linked the dreams to his cancer-related uncertainty by the shared theme of having to prove oneself in the face of a challenge, but P3 did not make this connection himself. So why might he have brought his dreaming experience into the conversation at all? He must have felt at some level that his dreaming experience was relevant to the cancer-related uncertainty or else he wouldn't have started talking about it. We suggest that the fleeting and tantalizing quality of dreams is of a piece with the tentative and faltering modes of expression evidenced by the quotes above in which the *mot juste* is just out of reach. In other words, in passages coded as existential uncertainty (as distinct from passages coded as other aspects of uncertainty) participants frequently seemed to find conventional modes of expression wanting. It is in this context that participants turned to alternative modes of expression in an attempt to capture their sense of existential uncertainty.

Metaphor

We use metaphor in the broad sense of the word—a way of describing something using words that are imaginatively rather than literally linked with that thing—to encompass these alternative modes of expression. We will now give some representative examples of how participants used their imaginations to express their existential uncertainty when more direct and literal modes failed them.

P1 brought to the interview a photograph of herself at a march in protest at the outcome of the Brexit referendum (the popular vote that paved the way for the United Kingdom to leave the European Union). She became visibly emotional as she explained that the day of this march was the first time in almost a year that she didn't think about her cancer. In describing the day, she said:

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.

The picture painted by P1 likely allowed her to express something of the complexity of her experience of uncertainty that a more direct, literal description would have frustrated. Her account of the march touched on themes of common purpose and identity (“all probably thinking the same way as I think”), connection (“you made friends with the people around you”), journey (“you knew ultimately where you were going”), agency and purpose (“optimistic feeling [...] that yeah, you know, we can do this”) and transcendence of the isolated individual self (“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 [...] there were kids on the march, there were people with their dogs”). We understood the association made between the day at the march and P1's cancer experience as one of contrast—that while the previous year had been characterized by existential uncertainty and the sense of disconnection with which it is associated, she one day found herself on the march *not* experiencing this existential uncertainty.

P1's mention of singing and musical instruments is perhaps significant, as music was invoked by other participants too in passages coded as existential uncertainty. P3 brought a music CD to the interview, explaining that music and emotion were deeply bound up in 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.

Talking about his relationship with music and how it had changed since the diagnosis allowed him to express an aspect of his uncertainty that may have been impossible to express in a more direct manner. His choosing to mention Vera Lynn and Land of Hope and Glory (notwithstanding his sense of himself as a fan of rock music) may point to his identification with a shared cultural heritage, given their patriotic overtones, which echoes the transcendence of the individual self referred to above.

P2 chose a cathedral choir as one of her (imagined) objects in the object elicitation exercise—her sons were musical and had attended a cathedral school when they were teenagers and now one of them had a baby “who loves to make music” and P2 was wondering if she would live to see whether this grandchild might continue to develop this interest. She talked about the family’s association with the cathedral school as a happy one, and it is interesting to note the reference to a religio-cultural institution, which echoes the superindividual aspects of the examples cited above (cultural in the case of Vera Lynn and Land of Hope and Glory, socio-political in the case of the Brexit march).

Beyond music, participants used a variety of different analogies and comparisons to convey their meaning in metaphorical terms. P4 talked about the effect of knowing “what is probably going to be 90 per cent chance will be the thing” that kills them:

cancer is almost, this is going to sound really dark but it’s the only way I can think about it right now, but especially with my kind of chronic cancer, it’s just like a waiting room to death, like, not that I see the whole experience as that, but like, you’re constantly talking in an elongated construct that ends with the finite aspect of death, that’s what cancer is.

While P4 used the image of “a waiting room to death” to express their relationship with uncertainty, P2 compared her cancer-related uncertainty with the uncertainty she experienced when her husband, who served as a pilot in the military and was at one time deployed in Afghanistan, was on a mission and she didn’t know whether he would return safely.

P6 talked about how he and his friend, who was also living with cancer, used humor as a way of engaging with the uncertainty of their experience:

we sort of both deal with these things with the same thing, we turn it into a black humour. Eh, my tumour, my, you know, prostate cancer, had a name – I called it Donald. Because it was part of me and I thought, well, you know, he’s been a part of me, he’s going to have a name, it’s what I’m trying to get rid of, you know, and we, sort of, we deal with things with, eh, the humour, this black humour that, em, you know, sort of making jokes about it and that, and sort of some people think you can’t sort of do that, to which we say well it’s my body, it’s my cancer, I’ll do what I bloody well like with it, you know, this is how I deal with it, I don’t deal with it with tablets and things like that, you know, I deal with it with talking with friends and we deal with it with laughing and joking about it.

When this participant said ‘we *turn it into* a black humor’ and ‘I’ll *do* what I bloody well like with it’, he was making clear that this is not an act of mere description, but an act of construction—he is choosing what this experience is for him and humor gives him the means to do this.

While passages coded as other-than existential aspects of uncertainty (diagnostic uncertainty, prognostic uncertainty, treatment uncertainty, psychosocial uncertainty, etc.) tended to be expressed unproblematically in conventional and literal terms, passages coded as existential uncertainty ranged much more widely in their terms of reference, using metaphor as a way of substantiating an aspect of uncertainty that defies conventional expression. The implications of this for clinicians working with people in receipt of a cancer diagnosis are set out in the Discussion below.

Weirdness

One of the distinguishing features of passages coded as existential uncertainty was the repeated reference to weirdness. For example, P3 found it “daft” and “sort of weird” that he should emote in response to Vera Lynn or Land of Hope and Glory. Perhaps the triggering of emotion by unexpected types of music challenged his sense of himself as “a rock music lover.”

The challenge to identity presented by cancer was evident too in the testimony offered by P5, who had been diagnosed with prostate cancer:

I don't get erections naturally anymore, em, and that's sort of left me feeling with a sort of am I really still a man? It's a sort of weird thing, I hadn't, hadn't expected, em, so much of my sense of self to be attached to my penis, yeah? It's a sort of, it wasn't what I was expecting, I didn't, I didn't think, I didn't think I was that sort of man, yeah? But actually it's turned out to be a really big deal.

He goes on to describe his feelings around using a penis pump to maintain the health of the penis, asking:

Will I ever, you know, lead a, a normal life where I'm not doing this cos nobody else does this, you know, you might see it in the odd weird porn video, but it's not a thing that people do normally, it's not the, you know, it's a, it's an odd thing. Em, and em, and I think, you know, will I be ever, will I ever be rid of it, so I'm, I'm 61 now, em, and em, you know, I wonder, well if this goes on for five, five more years or, or, when do I just give up? It's sort of, it's, it's weird, it's sort of, it's, it's a horrible feeling, em, that just sits there.

In one passage, P4 talked about how the threat posed by cancer is different from the threat posed by an attack they had experienced in the past:

when I survived the hate crime, you know, I almost died, I had a collapsed lung, all that stuff, but that was a different thing because someone else had done it and it was a moment and it was done and then with this, it's just bad luck, it's just genetics, well actually it's not hereditary but it just, you know, happens in your body, and there's no blame or control to place on it, it's just something that exists and you kind of have to come to terms with, so I think in that way, that's been like a weird way to think about your mortality, that, you know, from previous experiences where you might have killed yourself or someone else was going to kill your self, now it's something deep in your body that you don't have control over that's trying to kill you, and inaction will kill you, you know it's kind of like the antithesis of what you would normally assume would happen. So that's kind of strange.

The suggestion here is that the cancer experience is harder to come to terms with because it challenges assumptions in a way that an attack from an external source

doesn't—that for this participant to regard the cancer as something deep in their body trying to kill them is “a weird way to think about your mortality” and “kind of strange.” They proceed to describe the bodily experience associated with “larger scope questions of, you know, am I going to be alright,” explaining:

it just feels like a weight on your shoulders, you know, it just feels like, I guess a really weird parallel to make would be like sometimes I'm just sat there in bed and I think about it or I'm trying to go to bed and I'm trying to think about it, it would feel like I assume – I've never been under one – but what those weighted blankets are like, you know, just that whole idea of just your whole body and you just lose this energy and you just have this kind of weight on top of you of like [sigh], where are we going, what are we doing, you know.

It is striking that this participant chose an experience they had never had (being under a weighted blanket) to convey their sense of existential uncertainty, but perhaps more striking that they described this choice as “a really weird parallel.” The idea that their own choice was a strange one was echoed by P2, who chose a cathedral choir as one of her objects in the object elicitation exercise—commenting on her choice of object, she said: “It seems a bit odd.”

In the examples listed above, the weirdness seems to be bound up with the participant's own process and mode of expression. To paraphrase: the cathedral choir was an odd choice *for me to make*; the weighted blanket is a weird parallel *for me to draw*; the idea of something deep in my body that is trying to kill me is a weird way *for me to think* about my mortality; *I experience* the horrible feeling as not just horrible, but also weird; I find *my response* to music weird now. The important point here is not simply that participants struggled to express what they felt in a way that captured it satisfactorily, but that the experience of attempting to do so felt somehow unfamiliar or alien to them—it seemed to present a challenge to their sense of themselves, and was therefore perceived as weird.

Discussion

Our analysis suggests that participants struggled to express the existential aspect of their cancer-related uncertainty in a way that they didn't struggle to express other aspects of their uncertainty; that in the face of this struggle, they turned to metaphor as a way of expressing their existential uncertainty indirectly, drawing on culture, analogy and humor to do so; and that this sometimes felt “weird” to them. We will now consider how these findings fit with the existing literature, what they might mean for clinical practice, and how they are limited by fundamental methodological constraints.

Existing literature

What was striking about the objects brought by participants to the interview is that objects where the link with cancer was not immediately evident (the cathedral choir, the music CDs, the photo of the Brexit march) yielded richer testimony in terms of existential uncertainty than objects where the link with cancer was more immediately

obvious (a doctor's letter, a bottle of pills, a PSA test record card), which were more likely to generate testimony that we coded as one of the scientific aspects of uncertainty (prognostic uncertainty, treatment uncertainty, etc.). One way of making sense of this is that participants who brought objects where the link with cancer was opaque were tapping into an aspect of their uncertainty that could not be directly expressed using the same language as the more concrete aspects of their uncertainty. They had to reach beyond the medico-scientific discourse of the health care system, and it is this reaching beyond conventional modes of expression that constitutes the struggle to articulate.

There is both empirical and theoretical support for this interpretation. On the empirical level, our analysis is consistent with previous findings that people living with cancer turn to the non-medical discourses of literature (Friberg & Öhlen, 2007) and nature (Karlsson et al., 2014) as a way of engaging with their existential uncertainty. As to why they might turn to such non-medical discourses, there is theoretical support for the idea that existential uncertainty cannot be expressed directly. We have argued that existential uncertainty is ontological rather than ontic in nature (Dwan & Willig, 2023), which is to say that it is concerned with the unescapable givens of human existence (such as the fact that we will die) rather than the specifics of our individual existence (such as how or when we will die). Existential uncertainty is so deeply embedded in what it is to be human that it cannot be isolated as a specific question about a specific thing in the way that other aspects of uncertainty can, and this makes it difficult to talk about in conventional terms. It eludes direct or literal articulation in much the same way as Spinelli (2015) argues that while we can talk about "relationship" in direct terms, the limitations of language prevent us from talking in direct terms about the fundamental existential principle of "relatedness," which is the foundational precondition on which "relationship" relies—and this nudges us in the direction of analogy. Existential uncertainty and relatedness are what Gergen (2018) might call "territories beyond elementary articulation" (p. 709).

Addressing the topic of human understanding from the point of view of personal construct psychology, Mair (2016) writes: "It is difficult enough when what you are trying to understand is quite limited, like why your friend sounded so upset when you spoke to him on the phone recently. It's much more difficult when you are not quite sure what it is that you are struggling to give some form to, to grasp and express." (p. 499) This fits well with the participant accounts; it was easier for participants to express their uncertainty around diagnosis, prognosis, treatment, relationships with family and friends, etc. than it was for them to come to terms with existential uncertainty, which defies satisfactory verbal articulation. It is not always possible to articulate fully what we sense or feel in direct experience; hence the struggle.

Finding themselves unable to express their existential uncertainty in the conventional terms of the medico-scientific discourse that dominates Western constructions of cancer and ill health, participants turned to metaphor as a way of expressing indirectly what they were feeling. Terror management theory offers support for our analysis here when it makes the connection between abstract concepts such as soul, status and time (which feature in cultural worldviews that defend against death), and metaphor: "A central way in which people impose structured meaning on vague or elusive concepts is to conceptualize them metaphorically in terms of other kinds of experiences or objects

that are more concrete and clearly delineated in their experience.” (Landau et al., 2010, p. 209)

Mair (2012) insists on the importance of metaphor, imagination and different modes of storytelling including poetry and art in conveying deeper meanings, suggesting that we need to broaden our conception of language itself:

[L]anguage is not just in words and sentences, however important these are. It is to do with all the ways in which we body forth and convey meaning between and among ourselves. Language is in dress and design, in buildings and organizations, in music and gesture, in the silence between words and the stillness between movements. (p. 197)

This is echoed in Gergen’s (2018) argument that a dialogue between psychology and the arts is a way of bridging the gap between the structural limitations of language and the complex meanings that we as humans might wish to convey. Such complex meanings may originate as a bodily felt sense—we experience uncertainty but we struggle to say what exactly it is we are uncertain about. This is consistent with the emerging understanding of uncertainty as manifesting not only at a conscious level but also at preconscious or unconscious levels (Anderson et al., 2019). According to our analysis, people may be surprised or even disconcerted by their attempts to transform their bodily felt sense into a verbal elaboration. The sense participants had that their departure from the conventional terms of the medico-scientific discourse was somehow weird plausibly speaks to Heidegger’s concept of the uncanny, wherein human existence outstrips our capacity to understand and we feel like strangers to ourselves (Withy, 2015).

Implications for clinical practice

The findings of this study should be seen in the context of an increasing body of literature pointing to the efficacy of meaning-based approaches to therapy for people living with cancer (Bauereiß et al., 2018; Breitbart et al., 2018).

Bohart (1995) argues that “people’s concepts and intentions can guide their perceptual search so that they focus on some patterns of meaning to the exclusion of others, and thereby they construct or, more accurately, configure the realities they live in” (p. 321). We suggest that a conceptual understanding of existential uncertainty may guide therapists by sensitizing them to important moments in the therapeutic encounter when clients are expressing something significant but elusory about their uncertainty. This is important if, as our analysis suggests, expressions of existential uncertainty may not manifest in a direct or obvious way and may, therefore, be easily missed. This analysis provides a way for therapists to parse a client’s testimony that is sensitive to more subtle or latent expressions of uncertainty and a rationale for responding in a certain way. This can be broken down into two steps.

The first step is to attend to aspects of the client’s process that may point to existential uncertainty—in other words to recognize the proposed harbingers of existential uncertainty: a struggle to articulate, the use of metaphor and a client’s sense of “weirdness.” The importance of attention is highlighted by Neimeyer (2009) when he writes of constructivist psychotherapy: “If therapy is understood as a form of rhetoric, this is, an artful use of language to achieve practical ends, it is clear that an *attention to*

and use of poetic and figurative speech plays an important part in the process” (p. 77, emphasis added).

Concepts can help guide this attention, leading to “new or more finely ordered meaning patterns” (Bohart, 1995, p. 320). The second step is to respond to these harbingers in a way that deepens the meaning-making process for the client. A constructivist position, supported by evidence from the health literature that uncertainty is socially constructed in clinical encounters (Epstein & Street, 2007; Petriceks & Schwartz, 2020), suggests that a therapist’s response to a client’s expression of uncertainty does not merely elicit further expression of a preexisting uncertainty buried “within” the client, but rather co-constructs the uncertainty in an iterative, intersubjective process. It is for this reason that therapists must have a facility with a broad range of different discourses on which clients might draw when trying to express the existential aspect of their uncertainty, whether they be scientific, artistic, literary, musical, spiritual, religious, etc. A therapist’s response to an expression of existential uncertainty that speaks the client’s chosen language, however “weird” it may seem to them, is more likely to deepen that client’s meaning-making process than a response that seeks to clarify in a more literal or rational manner the ontic aspects of a client’s personal uncertainty, or the scientific or practical aspects, which may instead thwart the meaning-making process (Bohart & Tallman, 1999).

Limitations and suggestions for future research

We have highlighted the shortcomings of language when it comes to expressing existential uncertainty, and we acknowledge that such shortcomings exert themselves in this research, particularly given its focus on verbal expression and its concern with the (linguistic) concept of existential uncertainty. As Gergen (2018) points out: “To describe the world essentially requires embracing a system of signs that are in place prior to observation. Regardless of observation, knowledge claims fall victim to the system of language.” (p. 698) This implies a circularity in the use of language that is particularly difficult to escape in psychology—in order to label a psychological phenomenon, we must have some prior conceptual notion of what the label represents, which is confirmed by the labeling itself. This circularity is an issue here insofar as our analysis is based on passages of participant testimony coded as existential uncertainty, which required some prior notion of what “existential uncertainty” might mean in order to be coded as such. This notion was informed by our analysis of the concept as it has been used in existing literature (Dwan & Willig, 2021), so the risk is that the analysis presented here might simply confirm the previous analysis. We were sensitive to this possibility and made a conscious effort to remain open to aspects of participant testimony that did not fit in an obvious or literal way the defining attributes of existential uncertainty identified in the previous analysis. We did this by adopting an inclusive approach to coding (see Method) and resisting any urge to foreclose the possibilities presented by passages where the link with uncertainty was opaque (e.g. the participant talking about naming his tumor Donald).

This does not change the reality that we cannot get “under the net” of language, to borrow a phrase from Iris Murdoch (2002/1954)—not with words, at any rate. We limited ourselves in this study to people’s use of words (or attempted use of words)

to construct their sense of the unknown, specifically its existential aspect. We acknowledge that words may not always be the best way to express existential uncertainty—it is interesting to consider whether existential uncertainty might be more satisfactorily expressed in the non-verbal modes of expression favored by therapeutic approaches such as person-centred expressive arts therapy that bypass to some extent the limitations of language (Rogers, 2013). Future research might explore how people express existential uncertainty in such modes and what this could tell us about the meaning structure of uncertainty.

Future research might also shine a light on how existential uncertainty might manifest in contexts beyond cancer. For example, it would be interesting to explore how the threat of *physical* death associated with cancer might compare with the threat of psychological death (a threat to the self) associated with dementia (Blandin, 2016) or the threat of social alienation (a threat to identity) associated with a diagnosis such as HIV (Brashers et al., 2004).

Concepts are best seen as provisional, fuzzy and dynamic, always evolving according to context and knowledge (Rodgers, 2000). The research presented here is best seen as a preliminary exploration of a concept—an empirically supported theoretical foundation on which future research might fruitfully build and on which clinicians might draw when formulating and responding to client expressions of uncertainty in health care settings where so much is unknown. This is very much in keeping with the case Kelly (1977) makes for personal construct psychology being seen as a “psychology of the unknown”:

What we do then is not so much to go about sifting out nuggets of truth to add to our treasure chest, as it is to invent new constructions to place upon the events of the universe in which we have engaged ourselves. The constructions are admittedly inadequate – the history of scientific thought should, if nothing else, lead us to regard them so. But, even though they are inadequate expressions of what we will eventually conclude, they do provide practical ground for more intimate involvement, for more alert anticipation, for more courageous commitment, and, eventually, for the very reconstructions which will supplant them. (p. 10)

Conclusion

If Fromm (1949) is right that “the quest for certainty blocks the search for meaning” (p. 45), then a meaningful life demands that we supplement the modernist drive to reduce uncertainty ever further with a constructive way of engaging with the irreducible uncertainty of existence that always remains. In this paper, we have proposed a way for researchers and clinicians to make sense of how people construct the unknown after a cancer diagnosis—the struggle involved, the turning to metaphorical modes of expression, and the sense of weirdness that permeates the process. We hope that our analysis provides a firm base from which future research may continue to explore the ways in which people make meaning out of their existential uncertainty, in health care settings and beyond. We also hope that the analysis might be helpful to clinicians in guiding their attention to the existential aspect of their clients’ uncertainty and the subtle ways in which it might manifest in the therapeutic encounter.

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