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# Existential uncertainty in health care: A concept analysis

Conor Dwan BA (Classics), MSt, MSc, DPsych candidate  |  
Carla Willig BSc, MPhil, MSc, PhD 

Department of Psychology, City, University of London, London, UK

## Correspondence

Conor Dwan, Department of Psychology, City, University of London, Northampton Square, London EC1V 0HB, UK.  
Email: conor.dwan@city.ac.uk

## Abstract

**Rationale, aims and objectives:** According to an influential taxonomy of varieties of uncertainty in health care, existential uncertainty is a key aspect of uncertainty for patients. Although the term “existential uncertainty” appears across a number of disciplines in the research literature, its use is diffuse and inconsistent. To date there has not been a systematic attempt to define it. The aim of this study is to generate a theoretically-informed conceptualisation of existential uncertainty within the context of an established taxonomy.

**Method:** Existential uncertainty was subjected to a concept analysis, which drew on existing uses of the term across multiple disciplines as well as insights from uncertainty theory more broadly and from the existential therapy literature to generate a tentative definition of the concept. Antecedents, consequences, and empirical referents of existential uncertainty were also identified. A model case was described as well as a borderline case and a related case in order to illustrate and delineate the concept.

**Results:** Existential uncertainty is conceptualised as an awareness of the undetermined but finite nature of one's own being-in-the-world, concerned primarily with identity, meaning, and choice. This awareness is fundamental and ineradicable, and manifests at different levels of consciousness.

**Conclusion:** Humans rely on identity, worldview, and a sense of meaning in life as ways of managing the ineradicable uncertainty of our being-in-the-world, and these can be challenged by a serious diagnosis. It is important that medical professionals acknowledge issues around existential uncertainty as well as issues around scientific uncertainty, and recognise when patients might be struggling with these. Further research is required to identify ways of measuring existential uncertainty and to develop appropriate interventions, but it is hoped that this conceptualisation provides a useful first step towards that goal.

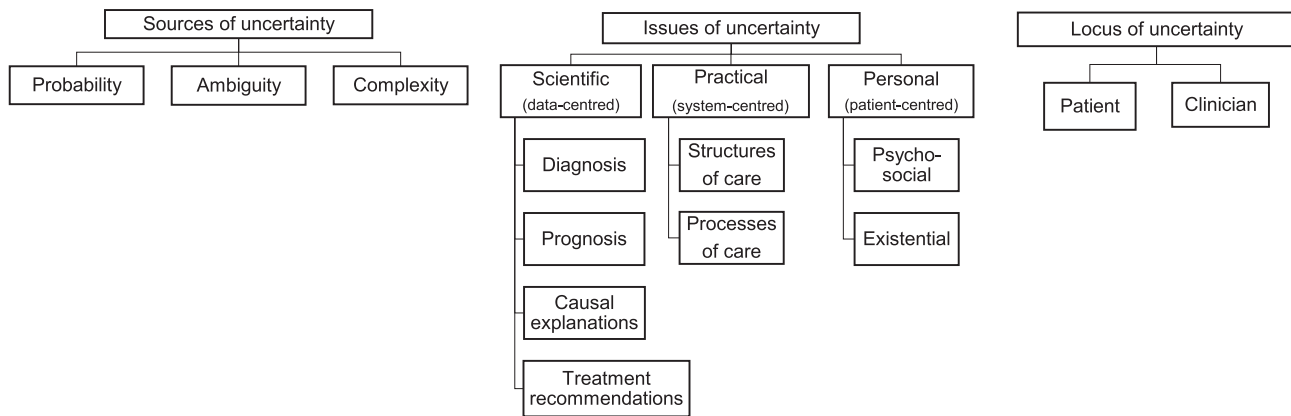
## 1 | INTRODUCTION

Uncertainty is an intrinsic aspect of human existence.<sup>1</sup> It is salient when we are faced with a serious threat to our health,<sup>2</sup> and its impact on health outcomes can be negative.<sup>3</sup> Although there have been many attempts to understand uncertainty in the health domain, the idiosyncratic manner in

which this research initially evolved has resulted in “[a] plethora of disconnected – and either redundant or unnoticed – findings, concepts, and theories.”<sup>4(p1757)</sup> It was in an attempt to establish a more systematic and coherent framework for conceptualizing health-related uncertainty that Han and colleagues developed a taxonomy of the different types of uncertainty in health care.<sup>2</sup>

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**FIGURE 1** The three dimensions of the Han et al taxonomy of varieties of uncertainty in health care,<sup>2</sup> in which existential uncertainty is classified as an issue of personal uncertainty

Integrating concepts and insights from earlier models of uncertainty, this taxonomy describes three dimensions (Figure 1): sources of uncertainty (probability, ambiguity, complexity); issues of uncertainty, which are classified as scientific (diagnosis, prognosis, causal explanations, treatment recommendations), practical (structures of care, processes of care), or personal (psycho-social, existential); and locus of uncertainty (patient, clinician). For such a taxonomy to have research and clinical utility, it is crucial that there be agreement on what the constituent concepts refer to.<sup>4</sup>

Issues of scientific uncertainty are more heavily represented in the research literature than issues of personal uncertainty, in spite of the possibility that existential uncertainty is of greater concern to patients than issues of scientific uncertainty.<sup>2</sup> To our knowledge, there has never been a systematic attempt to define existential uncertainty. Although the term appears in the health research literature and beyond, it often does so without an explicit definition.<sup>5-9</sup> The descriptions that do exist suggest that different researchers have different conceptualisations in mind: it is described variously as “that form of uncertainty which is experienced privately by the individual patient upon the realisation that the future life of his or her mind, body, and self is in jeopardy,”<sup>10(p134)</sup> “uncertainty about the availability of a relational exchange necessary for psychological survival,”<sup>11(p502)</sup> and “the varieties of uncertainty that are entailed by the finite limitations of our epistemic standpoint.”<sup>12(p383)</sup>

A lack of consistency in the meaning of basic concepts within the taxonomy may hobble future research in this field. The taxonomy is providing the basis for an ever-increasing number of research articles and editorials, including in the pages of this journal,<sup>13,14</sup> where Han and Djulbegovic assert the need to “continue to chip away at the problem and develop consensus on [...] a coherent and useful theoretical account of the types of uncertainty in clinical practice.”<sup>14(p183)</sup> The analysis of existential uncertainty that follows is a contribution to this aim.

## 2 | METHOD

Concept analysis is a widely used methodology for bringing clarity to poorly defined or delineated concepts,<sup>15</sup> and therefore well suited to

the aims of this study. It involves eight steps (presented here in the order in which they appear in the remainder of this article): (1) select a concept; (2) determine aim of the analysis; (3) identify existing uses of the concept; (4) determine defining attributes; (5) identify antecedents and consequences; (6) define empirical referents; (7) identify model case of the concept; (8) and identify other cases (borderline case, related case) to help delineate the concept of interest.

The concept selected for analysis was existential uncertainty. The purpose of the analysis was to generate a theoretically-informed conceptualisation of existential uncertainty within the context of the Han et al taxonomy.<sup>2</sup>

### 2.1 | Search strategy

A preliminary search did not locate any systematic attempt to define existential uncertainty, so it was necessary for this concept analysis to go beyond synthesizing existing uses, and to seek a firm theoretical base on which the concept could stand. There were three strands in the search strategy used to source relevant literature:

The first focused on existential uncertainty per se. Searches were conducted in Academic Search Complete, CINAHL Complete, MEDLINE Complete, APA PsychInfo and Scopus using the terms (i) “existential uncertainty,” (ii) “personal uncertainty” AND “existential,” and (iii) “existential doubt” as keywords from database inception to the time of the search (July 2020). The chosen databases were selected to capture research from as broad a range of disciplines as possible. Forty-two articles and book chapters remained after the removal of duplicates and results that were deemed not directly relevant. Citations of relevant material within these 42 items yielded a further seven articles.

The second strand focused on uncertainty theory more broadly to ensure that insights from the literature on the overarching category of uncertainty could be integrated with accounts of existential uncertainty. The aim was not to do a systematic review of all theories of uncertainty, but rather to take account of the theoretical underpinning of the taxonomy proposed by Han and colleagues<sup>2</sup> and the research this taxonomy has spawned. This was justified on the basis



that the taxonomy integrates principles from earlier approaches rather than representing a radical departure from those approaches. The references in the paper that originally proposed the taxonomy<sup>2</sup> were reviewed, as well as the 264 pieces of research that cited the paper between its publication and the time of the search (source: Scopus).

The third strand focused on existential theory. Given the failure to locate any rigorous, theoretically-derived definition of the term “existential” in the uncertainty literature, we decided to turn to the existential therapy literature for insights into the meaning of the word and the relevance of its theoretical underpinnings to uncertainty. Existential therapy encompasses a broad range of perspectives, with theoretical inconsistencies between different traditions,<sup>16</sup> so for the sake of epistemological coherence, we chose to focus on what might be regarded as the manifesto works of three of the most influential English-language researchers from the existential-phenomenological tradition: Hans Cohn,<sup>17</sup> Emmy van Deurzen<sup>18</sup> and Ernesto Spinelli.<sup>1</sup> This tradition was chosen because it is more closely aligned with existential philosophy than the existential-humanistic tradition developed by influential thinkers such as Rollo May and Irvin Yalom, whose writings draw on humanistic and pragmatic philosophies in such a way as to change the meanings of certain core existential principles.<sup>16,19</sup>

## 2.2 | Existing uses of the concept

Existential uncertainty is frequently described in the literature as an awareness.<sup>6,10,20-23</sup> When it comes to specifying what constitutes this awareness, conceptualisations range from conscious elaboration<sup>24</sup> to “precognitive sensations (eg, a feeling in your gut that this is right).”<sup>20(p663)</sup> Van den Bos refers to personal uncertainty as “a hot-cognitive social psychological process [...] [which] more often than not involves visceral and intuitive (instead of more reasoned and rationalistic) reactions.”<sup>25(p198)</sup>

Existential uncertainty is often associated with a threat to survival. For some researchers,<sup>26,27</sup> this threat is generated by the inevitability of physical death and the possibility of annihilation. For others, existential uncertainty is less about death per se and more about living in the shadow of death - this balancing of life and death is described as the “unbearable doubt about one’s going-on-being”<sup>28(p392)</sup> or “the uncertainty of [...] how life will be before death.”<sup>6(p2)</sup>

Existential uncertainty is also concerned with temporality. Adamson refers to existential uncertainty as “the individual’s awareness that his or her future is open and undetermined.”<sup>10(p134)</sup> Cohen writes that “[p]resent time becomes discontinuous with past and future time,”<sup>29(p83)</sup> while Penrod refers to “the shifting temporality of uncertainty,” describing it as “a present-oriented state that is influenced by perceptions of the past and future.”<sup>20(p663)</sup>

Existential uncertainty is described as a private, individual experience as well as an intrinsically relational phenomenon. This tension is captured by the idea that existential uncertainty is “experienced privately by the individual patient” in the context of a “medical encounter,”<sup>10(p134)</sup> which implies a relational aspect. Seppola-Edvardsen et al suggest that “managing this form of existential

uncertainty is inherently a social process.”<sup>30(p367)</sup> The relationality of existential uncertainty is fundamental to conceptualisations in the disciplines of politics, economics and sociology - young people in the midst of political conflict are said to “perceive the need to internalize a master narrative of collective identity that provides a sense of security and solidarity in the midst of existential uncertainty.”<sup>31(p173)</sup>

People are said to minimize their existential uncertainty by investing in a cultural worldview as a source of meaning in the face of mortality.<sup>32</sup> A distinction is often made between this type of uncertainty and uncertainty that is clinical,<sup>10</sup> informational<sup>25</sup> or scientific.<sup>33</sup> Miké asserts that “the question of meaning, the greatest mystery, is beyond the scope of science.”<sup>33(p357)</sup> Furtak points to instances of existential uncertainty where “the kind of knowledge that we *can* gain does not remove the fundamental uncertainty of our predicament,”<sup>12(p383)</sup> while Cohen refers to the “countless unanswerable questions and fears”<sup>29(p84)</sup> experienced by the parents of a child diagnosed with cancer.

What this research points to is the inadequacy of an exclusively scientific discourse when it comes to existential uncertainty. Friberg and Öhlen refer to the limitations imposed by the “strict frames of the medical discourse” in the palliative cancer setting, and suggest that “another discourse has to be adopted which involves openness towards existential dimensions.”<sup>34(p225)</sup> Suggested alternatives to a scientific discourse include nature,<sup>6</sup> literature<sup>34</sup> and religion.<sup>33,35-37</sup>

Issues of limitations and choice feature prominently in the literature. While death is often considered the most fundamental limitation of human existence, Furtak associates existential uncertainty with “the finite limitations of our epistemic standpoint.”<sup>12(p383)</sup> Our cognitive limitations combined with certain death make choices particularly difficult given we cannot choose everything and frequently must choose without knowing all we might want to know. And yet Adamson argues that “the individual’s freely chosen actions”<sup>10(p135)</sup> are the key to resolving existential uncertainty.

## 2.3 | Theoretical insights

What does it mean to say something is “existential”? Even in the literature on existential therapy, there is “a rather imprecise and almost colloquial use of words like ‘existential.’”<sup>17(pvi)</sup> The Oxford English Dictionary distinguishes between a general use - “of or relating to existence” - and a more technical use - “of, relating to, or concerned with individual human existence [...]; having, or prompted by, a keen awareness of individual freedom and responsibility.”<sup>38</sup>

Existential uncertainty falls into the technical category, encapsulating not just uncertainty *about* one’s existence, but also uncertainty *due to* the particular nature of one’s existence: Heidegger’s being-in-the-world.<sup>16,17</sup> The interrelationship between existence as the source of our uncertainty and as the object of our uncertainty is reflected in Cohn’s distinction between ontic issues, which relate to “the specific individual ways in which each of us is in the world,”<sup>17(p3)</sup> and ontological issues, which are concerned with “those intrinsic aspects of Being

which are 'given' and unescapable."<sup>(ibid.)</sup> In a similar vein, Spinelli argues that it is necessary in existential therapy "to step beyond – or beneath – thematic existence concerns themselves"<sup>1(p10)</sup> such as death, meaning and isolation, and attend to the fundamental principles that make such concerns unavoidable, which he identifies as existential relatedness, uncertainty and existential anxiety.

A prominent feature of Spinelli's theoretical framework<sup>1</sup> that has parallels in the literature on existential uncertainty is the concept of the worldview - "the set of fundamental beliefs about self, others, and the world on which the individual seeks to base her life choices and actions."<sup>39(p162)</sup> This is mirrored by the concept of the worldview proffered by terror management theorists: "People normally minimize existential uncertainty by investing in their cultural worldview's bases for viewing life as significant. However, people remain existentially uncertain to varying degrees because they can never be certain that the mainstream cultural worldview is absolutely true."<sup>32(p131)</sup>

Drawing on van Deurzen's existential framework,<sup>18</sup> Gulbrandsen and colleagues propose that in the health context, attention needs to be paid to uncertainty around bodily needs, sense of belonging, views about self, and meaning.<sup>40</sup> In medicine, bodily needs are understandably prioritized, and it is in this domain that an "ideology of uncertainty reduction"<sup>41(p1805)</sup> has come to dominate the approach to uncertainty in health care. The fundamental problem with this approach is "the assumption that the successful management of uncertainty [...] consists of knowledge or care processes related to the provision or acquisition of information alone."<sup>2(p836)</sup> Earlier models of uncertainty<sup>42,43</sup> regard uncertainty as a cognitive state that results from an inability to define an event or to predict an outcome accurately. This is inadequate when it comes to existential uncertainty if the source of existential uncertainty is human existence rather than a specific event. The conceptualisation of uncertainty as "a cognitive perceptual state that ranges from a feeling of just less than surety to vagueness"<sup>44(p18)</sup> opens up the possibility that uncertainty can manifest as a feeling and not just as a cognitive state. This is supported by a recent review of the evidence linking uncertainty and affect, in which it is accepted that "awareness of ignorance may occur at a pre-conscious or unconscious level."<sup>45(p2)</sup> While more research is needed in this area, the principle that uncertainty can exist at different levels of awareness provides some theoretical justification for focusing on precognitive sensations as well as cognitive evidence, and for looking beyond a scientific discourse when addressing concerns around belonging and meaning.<sup>30,34</sup>

### 3 | RESULTS

#### 3.1 | Defining attributes

On the basis of the commonalities between existing conceptualisations identified above and the theoretical insights that substantiate them, we propose the following four defining attributes of existential uncertainty, the first two of which are concerned with its focus, while the third and fourth relate to its qualitative properties:

#### 3.1.1 | Awareness of the undetermined but finite nature of one's own being-in-the-world

Existential uncertainty encompasses an awareness that our future is open and unknowable,<sup>1</sup> and an awareness that certain death awaits us, even if we prefer not to embrace this awareness in our day-to-day living.<sup>26</sup> The fact that our existence is undetermined (uncertain) but finite (certain) means that we live with a constant threat to the survival of our own particular being-in-the-world that goes beyond the physical to the social, personal, and spiritual domains. Existential uncertainty is concerned with the question of how to live in the shadow of this threat. It is informed by perceptions of past and future time, but is oriented towards the choices we make in the present. It is sparked by the question: how do I live when my survival is constantly under threat?

#### 3.1.2 | Concerned with identity, meaning, and choice

Our being-in-the-world is so profoundly relational in nature that existential uncertainty is not an uncertainty about the survival of an individual self set apart from the world, but rather an uncertainty bearing on the relational systems of which we are a part.<sup>1,21</sup> This means that existential uncertainty is about psychological as well as physical survival. This may be obscured by the fact that the majority of the health literature that invokes the concept is focused on conditions closely associated with physical death (cancer, chest pain), but it is plausible that existential uncertainty features in other conditions (such as dementia) that may be more closely associated with psychological death.<sup>46</sup> Discussions of identity in the literature emphasize the importance of social systems when it comes to the worldview that underpins our individual and collective identities. Our worldview helps to give life meaning, but when it is threatened by circumstances, we are reminded that "lurking just beneath the surface of our efforts to cling to whatever meaning and personal value we can is a deep-seated uncertainty stemming from the cognizance of the possibility that our lives are devoid of meaning."<sup>26(p198)</sup> Ultimately we must choose how to live our lives, and though we may be guided by a particular worldview, no worldview is absolute or unassailable. The question is: what does it mean to live *as me* in the world?

#### 3.1.3 | Fundamental, ineradicable, and always available to awareness

We experience existential uncertainty because of our being-in-the-world. It is fundamental to what it means to be a human being, and cannot be eradicated from the human experience. While existential uncertainty can be made salient by events, it is not created by them. We may experience acute existential uncertainty following a shock diagnosis or dire prognosis, but this type of uncertainty is not conjured from a vacuum - shock events merely bring to awareness

something that was being kept temporarily out of direct awareness: that our existence is undetermined and finite. Sometimes we struggle to regain our prior equilibrium following a shock event, and we must grapple with the implications of our new awareness: what does it mean to live with unanswerable questions?

### 3.1.4 | Manifesting at different levels of awareness

Whereas most types of uncertainty are conceptualized as conscious, cognitive phenomena,<sup>45</sup> existential uncertainty can manifest at different levels of awareness, ranging from bodily sensations<sup>20,25</sup> to cognitive elaboration.<sup>24,29</sup> Existential uncertainty is not “informational” and may be more effectively addressed by drawing on a range of different discourses, from philosophy, religion and spirituality to art, literature and the natural world, than by relying solely on a medical or scientific discourse. It is less about what people know and more about how they know it. As one person living with cancer in the palliative phase put it: “Other people know that they will die; the fact that we will die is the only thing we know, it's just that I know it in a different way.”<sup>6(p5)</sup>

### 3.2 | Antecedents and consequences

The antecedents of existential uncertainty are those conditions that are necessary in order for a person to experience it. Ultimately the only condition necessary is human existence, but for the concept to have practical utility, it is important to specify in more concrete terms the medical circumstances under which it emerges. In the health context, it emerges in response to an event or experience that has the capability to make salient the undetermined but finite nature of individual human existence, for example unusual somatic sensations<sup>7,8</sup> or the receipt of a diagnosis, test result or prognosis that carry a reminder of the vulnerability of human existence.<sup>40</sup> It is plausible to suggest that this would be particularly relevant to diagnoses such as cancer<sup>6</sup> or to experiences such as unexplained chest pain<sup>8</sup> that may carry with them the perceived threat of physical death. It may also emerge in response to the perception, conscious or subliminal, of a threat to one's worldview,<sup>26,32</sup> including sense of identity. This may be relevant to diagnoses such as dementia that carry with them the threat of psychological death,<sup>46</sup> or diagnoses such as HIV that carry with them the threat of rejection and social alienation (and therefore a threat to one's identity).<sup>47</sup> These suggestions are inevitably speculative until we have a firmer understanding of existential uncertainty.

The main consequence of existential uncertainty is anxiety,<sup>1</sup> as “certain belief in life's significance serves as a shield against anxiety-arousing thoughts of death.”<sup>32(p132)</sup> Other consequences of existential uncertainty are a sense of vulnerability,<sup>5,8,40</sup> and an attempt to incorporate the threatening event or experience into a recalibrated worldview.<sup>1,6,22</sup> If it is not successful, it may lead to disorganization and despair.<sup>29,43</sup>

### 3.3 | Empirical referents

Empirical referents are “classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself.”<sup>15(p179)</sup> There are two possible ways of detecting the defining attributes of existential uncertainty.<sup>48,49</sup> One is by asking a person who is experiencing uncertainty questions corresponding to the defining attributes. If the person does not feel confident about their future, struggles to see themselves in that future, seeks answers to what are unanswerable questions, and experiences the uncertainty somatically, then they are likely to be experiencing existential uncertainty. A second way is by observing their interactions with their medical team. If they present in a way that tallies with the defining attributes, for example, if they are persistently dissatisfied with the answers to their questions, this may be because they are experiencing existential uncertainty which, as discussed above, is distinct from informational uncertainty - no amount of information the medical team can offer will assuage the existential uncertainty.

### 3.4 | Model case

Cases are used in concept analysis as a way of pointing to concrete examples of the concept that help to clarify what it is, and is not. The cases outlined in the following sections are manifestations of different types of uncertainty in the cancer experience of one woman, Kate Carr, as described in her account of her breast cancer experience.<sup>50</sup>

The model case is “a pure case of the concept, a paradigmatic example.”<sup>15(p174)</sup> The following passage describes an exchange Kate had with her oncologist when she had finished treatment.

“So what do I do now then?” I said

“Sorry?” he said, worrying his stethoscope, the high priest in his all-knowing white coat, but with only the truth of *uncertainty* to offer a supplicant like me. No easy way out for him, no pat little tales of everlasting life.

“What do I do now?” I said again.

He looked at me, sort of. “Well,” he said. “We'll make an appointment for you to come back in three months.”

“No. I mean, what do I do?”

He glanced out of the window. “Do? You don't need to do anything.”

“But what's going to happen to me?”

He looked at me, carefully this time. “I don't know.”



“Am I going to be all right?” It was my turn to look away.

“I don't know. You've had all the treatment, and now we just have to wait and see what happens.”

I knew this already, of course. But I wanted a different answer. There were two other possible answers and I wanted to hear one of them now. I knew I wouldn't though – couldn't, the facts got in the way – and that I would spend the rest of my life preparing and waiting to hear the other.<sup>50(p106)</sup>

There is evidence in this short exchange of all of the defining attributes of existential uncertainty. Asking whether she was going to be all right shows an awareness of the undetermined nature of her being-in-the-world, while the reference to “the rest of my life” indicates an awareness of life's finitude. Implicit in her desire to know what to “do” (repeated three times) is the idea that she has a *choice* as to what to do, but does not know how to choose because her worldview has been so undermined. This is supported by her reference elsewhere to the confusion she felt – “my every step dogged by nagging doubts about my life which, however much it looked the same, did not feel the same”<sup>50(p94)</sup> – suggesting a loss of meaning. Her desire to hear the doctor tell her something she knew he never could convey the non-informational quality of existential uncertainty – there was no answer the doctor could have given that would have satisfied Kate. She “knew this already,” and perhaps the fact that Kate averted her gaze indicates a precognitive awareness that his answer was not going to dispel the uncertainty she was feeling. The fact that this is an exchange between Kate and her oncologist captures the intrinsically relational aspect of the concept.

### 3.5 | Borderline case

A borderline case is one in which some or all of the defining attributes of the concept are present but which is also somehow different from the concept.

The other suggestion the counsellor made was that I did not have to organise every last second of my family's life during my hospital stay. I had been trying to do this with lists and plans. It was another way of pretending that I had control over my situation, but it was also a genuine worry. I was and am the organiser in our family. Simon has always done most of the cooking and food shopping, but I have always held that particular bigger picture in my head, organising the children, Kerry, Siony, the house, school, our finances, everything from clean sheets to nit remedies and new shoes. I would be out of action for at least a month. What would happen to my little family without me? I

became obsessed with this, and behind this question always lurked the other question. *What would happen to my little family if I died?* My cancer was gradually and inexorably taking me away from my family, my absences becoming even longer, and the stem cell treatment was starting to feel like a practice run for my permanent absence.<sup>50(p58-9)</sup>

This is a borderline case between existential uncertainty and the adjacent concept of psycho-social uncertainty in the taxonomy.<sup>2</sup> Kate is clearly aware of the threat to her survival, both physically and in terms of her identity as “the organiser in our family.” The uncertainty seems to be manifesting at different levels of awareness too, with one question *lurking* behind another. The one defining attribute that is arguably missing from this scenario is the “fundamental and ineradicable” quality of existential uncertainty. In the earlier part of the excerpt, her uncertainties are practical and she deals with them with “lists and plans.” Furthermore they are more focused on others than on her own being-in-the-world, which arguably makes them psycho-social rather than existential. This is not necessarily a clean distinction, however, and in the latter part of the excerpt, as she considers her temporary absence as a trial run for her permanent absence, she may be describing existential uncertainty.

What this case illustrates is the difficulty in drawing clear distinctions between different types of uncertainty. The important thing in clinical terms is to remain sensitive to the boundaries between concepts, hazy as they may be, as this should inform the response – an informational response (perhaps advice on coping) might be appropriate to psycho-social uncertainty, whereas a meaning-based intervention might be more suited to existential uncertainty.<sup>51</sup>

### 3.6 | Related case

A related case is one that does not contain all of the defining attributes of the concept in question, but that is somehow connected to it. Uncertainty around prognosis, which is defined as “a prediction of the probable course and outcome of a disease,”<sup>38</sup> is similar to existential uncertainty in that it is concerned with the unknown future. In the following exchange, Kate asks her doctor about the ability of “cancer diets” to affect the course of the disease.

“I have a lot of patients on these diets,” he said. “They seem to find them helpful.”

“Oh. So you think I should go on one of these diets?”

“Do you want to?”

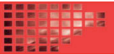
“No.”

“Well, don't then.”

“But if it would help...”

“I said my patients find them helpful. I, personally, have never seen these diets have any effect on outcome.”

*Outcome, that little word that stands in for survival.*<sup>50(p75)</sup>



The final line in this excerpt encapsulates a key difference between prognostic uncertainty and existential uncertainty - prognostic uncertainty is a form of scientific uncertainty concerned with the outcome of a disease and, in time, the accuracy of a prognosis can be determined. Kate's eventual death made it possible to judge the accuracy of her prognosis, eliminating the uncertainty. As existential uncertainty is concerned with meaning in life, it is not amenable to a discourse predicated on outcome or accuracy.

### 3.7 | Conceptualisation

Existential uncertainty is an awareness that my being-in-the-world is undetermined but finite. This entails living life in the shadow of an ever-present threat to my survival. I can mitigate the impact of this threat by choosing to develop an individual identity, align myself with a collective identity, and invest in a worldview that seems to imbue life with meaning. However existential uncertainty is fundamental to what it means to be human and therefore ineradicable. It is always available to my awareness, even if I may not always choose to embrace it within my awareness. Its manifestations can range from precognitive bodily sensations to full cognitive elaboration. It becomes salient at times of change or upheaval, and can be overwhelming when identities and worldviews are threatened by challenging experiences. It is at times such as these that I am reminded of the possibility that life has no meaning, and of the impossibility of a final and complete answer to the question: how am I to live my life?

## 4 | DISCUSSION

The conceptualisation of existential uncertainty yielded by this analysis highlights two important aspects of the taxonomy. Firstly, the emphasis on existential uncertainty as an intrinsic part of human existence rather than a type of uncertainty that is specific to a health "event" distinguishes it from other issues of uncertainty in the taxonomy, such as diagnosis, treatment options, and processes of care. In other words, although many people who encounter health problems do so without any significant experience of health-related uncertainty (as captured by the taxonomy's scientific and practical issues), it is hard to imagine any adult encountering health issues without some experience (however minor) of personal uncertainty - a doubt about relationships, identity or meaning in life. If clinicians fail to take account of the type of uncertainty that is shaped by patients' personal histories and broader circumstances, they risk failing to understand why patients might continue to report distressing levels of uncertainty even after their medical and practical questions have been answered with the best available information. Future research might investigate how existential uncertainty relates to the broader concept of uncertainty tolerance.<sup>52</sup>

Secondly, and relatedly, although existential uncertainty is classified within the taxonomy as an issue of uncertainty, the

conceptualisation makes clear that our being-in-the-world is not only an object of uncertainty for us, but also a source of uncertainty. This is not explicitly acknowledged in the taxonomy, where the three sources of uncertainty are identified as probability, ambiguity, and complexity. Probability, defined as "a phenomenon's indeterminacy,"<sup>2(p833)</sup> is the closest source of uncertainty in the taxonomy to existence itself, but fails to capture the fundamental and ineradicable quality of the uncertainty generated by our human existence. We concede that not much would be gained by adding "existence" as a fourth source of uncertainty in the taxonomy, particularly given the taxonomy is designed to achieve "some reasonable middle-ground level of abstraction,"<sup>14(p185)</sup> which can be adjusted according to the comprehensiveness and specificity required by the context in which it is being used. However, it is important to emphasize that uncertainty in the health domain cannot be divorced from the uncertainties that exist in other domains of people's lives, all of which are underpinned by the fundamental uncertainty of human existence.

## 5 | LIMITATIONS

Though well established and widely used, the concept analysis methodology is not without its critics,<sup>53</sup> who argue that it lacks depth, rigour, and replicability. We would argue that the concept analysis described above fulfils its aim of establishing a theoretically-informed conceptualisation of existential uncertainty. No claim is made for it being the only possible conceptualisation or even the most "correct" conceptualisation - indeed concepts should be seen as "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.'"<sup>54(p77)</sup> In this case, it is hoped that the establishment of an explicit and rigorous conceptualisation of existential uncertainty will give future research a firm basis from which to continue investigating its nature and effects, including its relationship with other types of uncertainty within the taxonomy.

## 6 | CONCLUSION

We offer the conceptualisation above as a tentative definition of health-related existential uncertainty, which emphasizes the importance of identity and worldview in managing the fundamental, ineradicable uncertainty of our being-in-the-world, and the challenge that a serious diagnosis can pose to our sense of ourselves and our sense of meaning in life. It is hoped that this conceptualisation will spark discussion and continued research that might further our understanding of the personal issues of uncertainty, which have in the past been overshadowed by the endeavour to understand the more scientific issues of uncertainty.

### CONFLICT OF INTEREST

The authors declare no conflicts of interest.



## DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

## ETHICS STATEMENT

This study has been approved by City, University of London Department of Psychology Research Ethics Committee (ETH1920-1358).

## ORCID

Conor Dwan  <https://orcid.org/0000-0002-6759-0821>

Carla Willig  <https://orcid.org/0000-0001-9804-9141>

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