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Constructing knowledge in the face of uncertainty: Perspectives from health care

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Portfolio submitted in partial fulfilment of the requirements for the Professional Doctorate in Counselling Psychology (DPsych)

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DECLARATION

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PREFACE

If uncertainty is an intrinsic feature of the human condition, as many existential thinkers argue, then how can we claim to know anything at all? The main theme running through this portfolio is uncertainty; specifically how, in the context of life's intrinsic uncertainty, we can construct – or co-construct – knowledge. Spinelli (2015) argues that certainty and uncertainty are inseparably interconnected. He articulates the tantalising and somewhat dizzying idea that "no certainty (including the certainty of uncertainty) can ever be wholly certain; there can only be uncertain certainties and uncertain uncertainties" (p.25). This is one of the fundamental assumptions underpinning my approach to living – that uncertainty pervades the human experience, but that when faced with difficult questions we must avoid throwing our hands up in the air and retreating to the certainty of uncertainty as much as we must avoid retreating to the sanctuary of any other certainty: in other words, that we must develop a way of knowing that is infused with – but not overwhelmed by – the uncertainty of our existence.

This portfolio represents my attempt to do just this – to engage deeply and meaningfully with uncertainty while constructing what I hope is valid and useful knowledge about its place in health care. The portfolio is comprised of three parts: the presentation of my thesis, which develops the concept of existential uncertainty in the context of people living with cancer (Part A); the presentation of a client study and process report in which I describe my work with a person who is living with HIV (Part B); and the presentation of an article published in the *Journal of Evaluation in Clinical Practice* in which I use the knowledge constructed in my thesis to begin a conversation with the research community about the nature of existential uncertainty (Part C). I will begin by offering some general comments on the approach I have adopted across the three parts of the portfolio, before reflecting briefly on how the different parts of the portfolio relate to each other and to the overarching theme.

General approach

Although many of the questions with which this portfolio engages are directly concerned with epistemology and ontology, and are therefore philosophical in nature, the portfolio itself is decidedly a work of psychology rather than philosophy. This is to say that I am interested in questions such as 'what can I know?' or 'who am I?' as they relate to the sub-discipline of applied psychology, not as starting points for a philosophical treatise on justified true belief or the finer points of existential metaphysics. Therefore, when I engage with the theoretical and conceptual questions underpinning this portfolio, I do so always with an eye to praxis – my aim is not so much to provide answers that would pass muster with a philosopher, but rather to explore how health care professionals might engage with these questions in a clinical context in a way that is practically useful.

My engagement with the topics addressed is pluralistic insofar as it does not subscribe exclusively to one epistemological framework. This is discussed further at the appropriate points (notably Part A, 2.1 and Part B, 1.1, 1.3), but two frameworks warrant mention at this stage due to their centrality to the enterprise: existentialism and constructivism. My approach to this piece of work is heavily influenced by the theoretical framework developed by Spinelli (2015), which posits uncertainty as one of the foundational principles of existential therapy: the assumption is that although death is an inevitability, when and how we die – and everything that happens in the meantime – remain uncertain. The human tendency to search for meaning must be seen within this context (Landau, Greenberg & Kosloff, 2010). The assumption I have adopted throughout the portfolio is that meaning is constructed (rather than discovered) in a social setting. As Neimeyer (2009) puts it:

> "Far from viewing the 'construction of reality' as a project undertaken by an isolated subjectivity, constructivism sees meaning making as relational, social and cultural to the core." (p.ix)

It is for this reason that the word 'perspectives' is included in the title of the portfolio, acknowledging as it does that when we look at something, we do so from a particular time and place – I have tried throughout the portfolio to make this explicit, whether it is my own perspective or that of other researchers or research participants (in Part A), or my client (in Part B). In other words, context is key.

The context in which I chose to situate this portfolio is health care: in Parts A and C, the focus is on people living with cancer; in Part B the focus is on a person living with HIV. My choice of health care reflects an interest stemming from my own personal experience of a health challenge, of which I give an account at the beginning of Part A. I also chose health care because of its fundamental connection with uncertainty. As Han, Klein and Arora (2011) argue:

> "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)

Although the topic of clinician uncertainty is a fascinating one worthy of research attention, I chose in the research components of this portfolio to focus on the uncertainty experienced by patients. However, this is not to suggest that clinician and patient uncertainty exist independently of one another – in the client study and process report I reflect on how my own uncertainties as a clinician interact with those of my client in a way that exemplifies the social constructivist nature of uncertainty. And, of course, whether one is being a clinician or a patient in a given encounter is largely a matter of happenstance – clinicians can be patients too. I have tried, as much as the strictures of language permit, not to express things in a way that implies exclusively isolationist subjectivities, but rather to see the concepts and challenges addressed in this portfolio more broadly as aspects of Heidegger's being-in-the-world (Cohn, 1997; Cooper, 2003).

Part A: Doctoral thesis

Existential uncertainty in health care: Developing the concept

The first part of the portfolio is concerned with developing the concept of existential uncertainty in the context of an established taxonomy of uncertainty in health care (Han et al., 2011). It does this by exploring two related questions: how might existential uncertainty be usefully conceptualised? And: how might the relationship between existential uncertainty and other aspects of uncertainty be understood in the experience of people living with cancer?

There are two points I would like to make here. The first is that this research is conceptual rather than phenomenological in nature, which is to say that I am interested in the concept of existential uncertainty rather than the experience of existential uncertainty (a point further discussed in Part A, 2.3.1, 3.2.1). I make this point to help orient readers because conceptual research methods such as the hybrid model of concept development (Schwartz-Barcott & Kim, 2000) used in the thesis are less closely associated with counselling psychology than, for instance, phenomenological research methods, and may therefore be less familiar to readers. With this in mind, I have tried to outline my methodology as clearly, thoroughly and concisely as possible (see Part A, 2.2).

The second point is that I conceive of the thesis as being driven by a series of conversations – conversations that I have had with my research supervisor, colleagues, friends and, most importantly, the participants who agreed to talk to me about their experiences of cancer-related uncertainty. This is very much in keeping with the constructivist approach mentioned above. In conceiving of it in this way, I drew inspiration from Mair's (2000) description of psychology as a discipline of discourse and of psychologists as professional conversationalists. Nor do the conversations end with the writing of the thesis – they flow into Parts B and C of the portfolio too, as I explain below.

Part B: Client study and process report

Co-constructing meaning with a gay man who is HIV positive

In Part B of the portfolio, I present a client study and process report in which I explore some of the issues and themes that emerged in my clinical work with a gay man living with HIV. Identity was one of the main themes that recurred in our sessions – he felt that he had spent so long concealing his sexuality from those around him that he had lost touch with who he really was: ‘who am I?’ he asked (see Part B, 3.2). My conversations with this client helped sensitise me to the importance of identity in the concept of existential uncertainty, which informed my thinking in the thesis, where I raise the possibility that a HIV diagnosis might be an antecedent of existential uncertainty since it carries with it the threat of rejection and social alienation, and therefore a threat to one's identity (see Part A, 3.1.5.1 and Part C, 4.2). This is just one example of how there was an ongoing ‘conversation’ between my research and my clinical work to mutual benefit.

I reflect in this part of the portfolio on some of the challenges I experienced as a clinician engaged in an endeavour of co-constructing meaning with a client in the face of existential uncertainty. The challenge, as I saw it, was to offer my client something useful (a different perspective, a framework for making sense of his experience) without imposing a meaning on his experience. The question I grapple with is whether as therapists we can ever be sure that we are not subtly imposing our own preferred meaning on our clients’ experiences, try as we might to avoid it. This, for me, is an illustration of uncertainty in the clinical encounter, and a question that continues to preoccupy me.

Part C: Published paper

Existential uncertainty in health care: A concept analysis

The final part of the portfolio represents the beginning of a wider conversation with the research community on the subject of existential uncertainty. Part of the reason for aligning the thesis with an established taxonomy of uncertainty in health care (Han et al., 2011) was because I wanted to contribute to an existing conversation – I thought that this stood a greater chance of generating an impact in terms of research and practice than adopting a less theory-driven approach. I decided to develop one phase of the research – the initial concept analysis of existential uncertainty (see Part A, 3.1) – into an article, which I submitted to the *Journal of Evaluation in Clinical Practice*, an international journal of public health policy and health services research.

I chose this journal for two reasons. Firstly, I wanted to reach out beyond the psychology community (narrowly conceived) so that the psychological insights generated by my research might infiltrate and influence in some small way other, related disciplines, such as medicine and nursing. Secondly, this journal was already home to an ongoing conversation about the taxonomy on which my research was based (e.g. Pomare, Churruca, Ellis, Long & Braithwaite, 2019; Han & Djulbegovic, 2019), so I felt that this was an appropriate channel through which to communicate to an interested audience some of the initial insights from my research. I was pleased that my article was accepted and published by the journal (Dwan & Willig, 2021), and that the conversations which drove the research described within the pages of this portfolio are beginning to percolate further afield.

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PART A: DOCTORAL THESIS

Existential uncertainty in health care: Developing the concept

0.0 Abstract

Rationale, aims and objectives

According to an influential taxonomy of uncertainty in health care (Han, Klein & Arora, 2011), existential uncertainty is a key aspect of uncertainty for patients alongside more heavily researched aspects such as uncertainty around diagnosis, prognosis, treatment recommendations, etc. 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 research is to construct a theoretically-informed conceptualisation of existential uncertainty within the context of an established taxonomy.

Method

The concept of existential uncertainty was analysed and further developed using a methodology known as the hybrid model of concept development (Schwartz-Barcott & Kim, 2000), which was pioneered by nursing scholars. The analysis involved three phases: an analysis of the concept of existential uncertainty in existing literature; a thematic analysis of semi-structured interviews carried out with six people who reported experiencing uncertainty in relation to their cancer diagnosis; and a synthesis of these two analyses. The synthesis yielded a list of defining attributes of existential uncertainty, a list of features that distinguish it from other concepts within the taxonomy, and a narrative conceptualisation.

Results

Existential uncertainty is conceptualised as a bodily awareness at cognitive or precognitive levels that is focused on the undetermined but finite nature of one's future, as well as on identity and meaning. This awareness is argued to be a consequence of living with the spectre of dying in a context characterised by questions of control and agency. The analysis suggests that existential uncertainty is concerned with: meaning rather than discoverable facts; the person rather than the disease; and the fundamental principles of existence rather than the practicalities of living. The thesis concludes with a discussion of the implications of this conceptualisation for the taxonomy on which the research was based; for psycho-oncology and cancer care more generally; and for counselling psychology as a discipline.

1.0 Introduction

This research project was born out of a long interest in health-related uncertainty and is best understood in the context of this interest. Given the importance of reflexivity in social science research (Finlay & Gough, 2003), I will begin this thesis with an account of my relationship with uncertainty, and its evolution from a personal to an academic interest. I will proceed from there to describe how this relationship shaped my engagement with the research literature on uncertainty, and led ultimately to the formulation of the fundamental question underpinning this research: how might we usefully conceptualise existential uncertainty?

1.1 Personal interest

When I was about nine years old, I began to develop headaches. There was no obvious reason why. As time went on, the headaches became more frequent until they were constant – a dull, uncomfortable feeling in my head. I also began feeling nauseous and would spend perhaps a day a week at home in bed because the nausea made it too difficult to go to school. Nobody knew why I was experiencing these things, including the GP to whom I paid frequent visits over the course of three years. She suggested a range of possible explanations for the nausea, none of which I thought likely: perhaps it was something I ate, perhaps it was because I wasn't eating enough, or perhaps it was something to do with a build-up of phlegm? Notwithstanding my young age, I knew intuitively it was none of these things. In any case, what about the headaches? More attention was paid to the nausea than the headaches since the nausea was incapacitating in a way the headaches weren't, and so I was referred to a gastroenterologist, who couldn't find anything wrong. I briefly saw a child psychologist, who also couldn't find a reason for these symptoms. Eventually, when I began to develop numbness on one side of my body, the GP acceded to my mother's increasingly desperate demands for a brain scan. At the age of 12, I was diagnosed with a brain tumour. I remember quite clearly the huge relief I felt at being given an explanation for my symptoms. I did not experience the worry that my parents did on receipt of the results of the scan because I was not aware of the implications of the diagnosis – I was just delighted that we now *knew* why I had been sick for three years, that the uncertainty had been resolved. The brain tumour was surgically removed a few days later and found to be 'benign'. The headaches and nausea soon receded, and have not returned in the 30 years since.

I start with this story because living for three years with the symptoms of an undiagnosed brain tumour is a formative experience that continues to loom large in my mind – it has undoubtedly shaped my attitude to medical uncertainty. I recently reviewed my medical notes from that time and was interested to read some of the correspondence between doctors. For example, the gastroenterologist was of the view that my symptoms were ‘non-organic in nature’ – he wrote: ‘I have reassured his mother however that there is unlikely to be major organic pathology underlining [sic] this’, before recommending a psychiatric assessment. The following year, the neurosurgeon who ended up removing the tumour reported the results of an MRI scan showing ‘an extremely large midline cerebellar tumour and massive hydrocephalus with periventricular lucency indicative of high intracranial pressure and seepage of spinal fluid into the brain substance’. These two snippets illustrate the uncertainty that arises when there is a gap between what exists (in this case an ‘extremely large’ brain tumour) and our ability to know about it (in this case the attempts of the GP and various specialists to diagnose the cause of the symptoms). For three years, I lived in this gap, and this experience taught me that in spite of the rigorous training and good intentions of doctors, sometimes they simply don’t know, and we are left alone to grapple with our unexplained symptoms. In other words, I developed an appreciation from a young age of the limitations of human knowledge, and the isolation and suffering entailed in this. This made me receptive to the ideas of existential writers when I first encountered them as a teenager, and perhaps goes some way to accounting for the existential orientation of this research.

Although my own illness experience inevitably informed the way in which I approached this research, and arguably sensitised me to aspects of the illness experiences of participants that would not be so salient for someone who never had to reckon with such an unsettling experience, the reflexivity required of qualitative research means “mov[ing] beyond the partiality of our previous understandings and our investment in particular research outcomes” (Finlay, 2003, p.108). At the most basic level, this means acknowledging that my perspective is not the perspective of the participants in this study, and that we might even have conflicting perspectives. For example, I feel a strong ambivalence towards the medical profession – on the one hand, the awesome stores of knowledge and expertise contained therein made possible the complex operation that restored my health, while on the other hand, for three years I saw a range of doctors whose attempts to explain my symptoms felt like poor guesswork to me, even at the time. It was important for me to be aware that my resignation to the limitations of medicine is very much shaped by my own experience and may not have been shared by participants. With this in mind, I tried not just to remain open to views that might have contradicted my own, but to welcome such views as a way of keeping my pre-established ideas in check.

1.2 Academic interest

I can pinpoint precisely the genesis of my academic interest in uncertainty – I awoke on 26th October, 2015 to the news on the radio that the World Health Organization had made the decision to classify red meat consumption as “probably carcinogenic to humans” (World Health Organization, 2015). I was struck by the use of the word *probably* – why the uncertainty? Presumably it either was or it wasn’t. However, I was interested not just in why scientists couldn’t say one way or the other whether red meat consumption was carcinogenic, but also in what we – the population at large – might make of this uncertainty. As a keen consumer of red meat, I was curious to know how my fondness for red meat might influence my interpretation of the uncertainty, and how my interpretation might differ from the interpretation of others. This question became the topic of the research component of a master’s degree in psychology that I was doing at the time. One of the key findings of this study (Dwan & Miles, 2018) was that the ambivalence of a person’s attitude to red meat (e.g. believing that red meat contains important nutrients *and* that its consumption is bad for the environment) might influence their perception of the risk attached to its consumption. The article argues:

> “The attempt to accommodate conflicting perspectives is at the heart of what lay people do every day as they try to negotiate the risks associated with modern life, and the interaction between sources [of evidence] is likely to play a particularly important role in situations where there is a great discrepancy between those sources.” (p.157)

The article concludes that people use a mix of rational strategies (thought, calculation), non-rational strategies (belief, hope, faith), and in-between strategies (trust, intuition, emotion) to achieve this accommodation (Zinn, 2008).

The reason I highlight my previous work on uncertainty is because it informs my approach to this research in important ways. The emphasis on ambivalence in the red meat study reflects the ambivalence I feel not just towards medical science (described above), but towards any question pertaining to humanity. My ambivalent disposition is one of the things that first drew me to counselling psychology and its openness to a pluralistic philosophy that admits of a range of valid answers to any substantial human question, even when those answers conflict with one another (Cooper & McLeod, 2007). How people make sense of the uncertainty they experience when facing serious illness is surely such a question.

1.3 Taxonomy of health-related uncertainty

It was in the course of the research just described that I first encountered a taxonomy of health-related uncertainty developed by Han, Klein and Arora (2011). This taxonomy was developed in response to a perceived lack of systematicity in the existing literature on uncertainty in health care – the authors argued that "the body of knowledge on the uncertainties faced by clinicians and patients is fragmented and incomplete, and important insights have not been translated to clinical practice" (p.829). The intention of the taxonomy was to guide research and improve clinical practice. What appealed to me most about it was that it provided "an organizing conceptual framework" (ibid.) for a complex and interesting topic – health-related uncertainty – and this dovetails with the kind of research I most enjoy: applying an organising principle to a complex topic with the aim of generating clarity.

The taxonomy itself comprises three dimensions. The first dimension specifies three *sources* for any health-related uncertainty: probability, which is described as "the indeterminacy of future outcome" (Han et al., 2011, p.834); ambiguity, which is concerned with the imprecision of evidence, e.g. when there is conflicting evidence; and complexity, which is relevant to situations where there is a multiplicity of factors to be taken into account. The second dimension specifies eight *issues*[1] of uncertainty (see Figure 1), which is to say eight aspects of the illness experience in relation to which a person might experience uncertainty – these range from scientific aspects such as prognosis and treatment recommendations to practical aspects concerned with accessing care to personal aspects, comprising psycho-social uncertainty and existential uncertainty. The third dimension specifies the *locus* of uncertainty, which is to say the person who is experiencing uncertainty (patient, clinician, family member, etc.). According to the taxonomy, it should be possible to classify any instance of uncertainty in health care according to these three dimensions, e.g. the ambiguity of the evidence (first dimension) associated with a certain treatment option (second dimension) might be associated with uncertainty in the patient (third dimension).

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[1] Although Han et al. (2011) refer to these as 'issues' of uncertainty, I have chosen in this thesis to call them 'aspects' of uncertainty as this describes what they are in a way that is clearer and more consistent with my philosophical positioning – see Methodology 2.1.3 for further elaboration of this point.

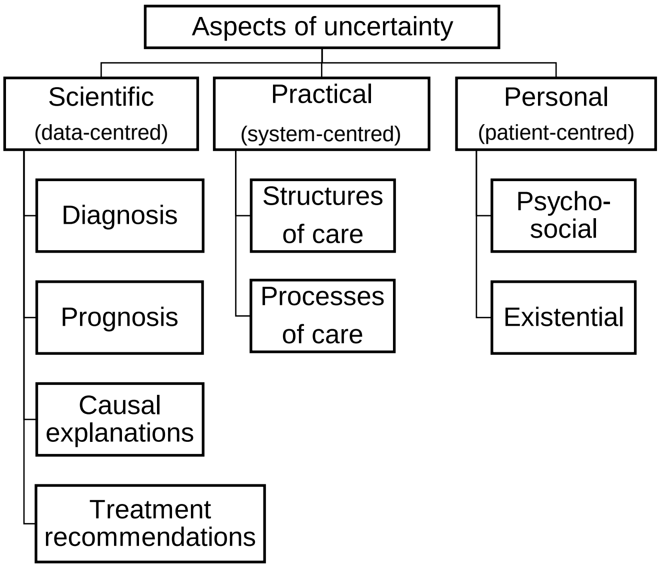

Figure 1: The second dimension of the Han et al. (2011) taxonomy of uncertainty in health care, comprising scientific, practical and personal aspects.

One of the things that stood out for me when I first came across the taxonomy was the inclusion of 'existential uncertainty' in the second dimension. My curiosity was immediately piqued as to what existential uncertainty might mean. Whereas I thought scientific and practical aspects of uncertainty were specific and easy to grasp, personal aspects of uncertainty seemed neither – for instance, it did not make sense to me to say that existential uncertainty is uncertainty about one's existence in the same way that diagnostic uncertainty is uncertainty about one's diagnosis. At the very least, the term 'existential uncertainty' required further explication in a way that other aspects of uncertainty within the taxonomy did not. Han et al. (2011) suggest that existential uncertainty is "related to patients' sense of meaning in life" (p.833) before offering the following elaboration:

> "Personal uncertainty pertains to psychosocial and existential issues including the effects of one's illness or treatment on one's goals or outlook on life, one's personal relationships, the welfare of loved ones, or one's sense of meaning in life." (ibid.)

My assumption was that the first and fourth examples here (effect of illness on goals or outlook on life and sense of meaning in life) were existential whereas the second and third (effects on personal relationships and welfare of loved ones) were psycho-social. However, a list of examples is not the same as a definition, and it surprised me that there wasn't a more explicit distinction made between the two aspects of personal uncertainty.

When it came to choosing a research topic for my doctorate in counselling psychology, I returned to the questions that had been sparked by my original engagement with the taxonomy, and set out on an exploratory mission to track down a definition of existential uncertainty in the literature that would satisfy my liking for clarity, precision and rigour. Before embarking on this mission, however, I jotted down some notes as to what intuitively I felt existential uncertainty might be. I wrote:

> ‘When I think of existential uncertainty, I think of the future and the idea that the future is unknowable (although we can guess at what might happen), and the idea that no amount of thinking, planning, researching, reassurance or comforting is going to change this. There is no parent figure or ‘grown-up’ to tell me that everything is going to be alright because nobody knows for sure. And what would it mean anyway to say that everything is going to be *alright*, given we are all certainly going to die? The implications of this are dizzying and at times nauseating, and sometimes manifest as a little turning of the stomach that occasionally intrudes on my day-to-day experience before quickly dissipating and allowing me to get back to whatever I was occupied with.’

This is to acknowledge that before engaging with the literature in any systematic way, I already had hunches as to what domains the concept of existential uncertainty might cover, notably the future, the limits of our knowledge, the inescapability of our human predicament, and somatic experiencing.

1.4 Existential uncertainty – the literature

When I set out to locate a definition of existential uncertainty in the literature, I fully expected to find one. In other words, I was not aware when I began my exploration of the literature that the quest to define existential uncertainty would become the entire focus of this research. A more formal, comprehensive literature review is reported as part of the concept analysis (see Analysis 3.1.2 and 3.1.3), so my intention in this section is not to provide a thorough analysis of the existing literature, but rather to give a narrative account of what I found when I began my search, and how this led me to the conclusion that there was a need for a study whose aim was to define and develop the concept of existential uncertainty in a systematic way.

I conducted a preliminary search of articles indexed in Academic Search Complete, CINAHL Complete, MEDLINE Complete and APA PsychInfo between 1997 (the earliest date permitted by the EBSCOhost interface) and 2020 that had ‘existential uncertainty’ in the title. My rationale was that the most likely source of a considered definition of existential uncertainty would be an article with that term in the title (implying a focus on that concept in the article).

There are other search strategies I might have adopted. For example, I might have included related concepts, e.g. existential anxiety, in my search. I decided against this strategy because fundamentally I was interested in uncertainty rather than existential experiences *per se*. I might also have searched for published studies grounded in the Han et al. (2011) taxonomy on the basis that these might have shed light on the various aspects of uncertainty and the differences between them. I considered this a less direct route to a formal conceptualisation of existential uncertainty since the search I conducted would presumably have yielded such a conceptualisation, if one had existed. In any case, published articles citing the Han et al. taxonomy were included in the formal concept analysis reported in the Analysis chapter (see 3.1.2.2).

My preliminary search returned 11 results. Three of these were specifically related to health. I will begin by discussing how these three articles conceptualise existential uncertainty before turning my attention to the other articles.

1.4.1 Existential uncertainty in the health literature

The most recent article (Røysland & Friberg, 2016) was entitled: ‘Unexplained chest pain and physical activity – balancing between existential uncertainty and certainty.’ The stated aim of the study was to develop an understanding of the meaning of physical activity for people with unexplained chest pain using a phenomenological hermeneutic approach. I expected that the first time existential uncertainty was mentioned in the article, it would be accompanied by a brief definition to establish a clear understanding of the term. The first time it appears is in the results section, and it does so in the following way:

> “Out of this [analysis], a comprehensive understanding was formulated: being physically active while living with unexplained chest pain means balancing between existential uncertainty and existential certainty.” (p.221)

At no point do the authors offer a clearer sense of what they mean when they refer to existential uncertainty (or certainty). They talked about physical activity as representing a threat to life: “Exposed to existential aspects such as vulnerability during physical activity, the respondents bring themselves in the vicinity of illness and even death.” (ibid.) They also invoked the ideas of the philosopher Paul Ricoeur, emphasising the role of choice and responsibility in living a good life. But I found myself frustrated that while they seemed to point to certain conceptual terrain (the body, threat to life, death, choice, responsibility), there was no attempt to specify precisely what was meant by existential uncertainty.

The second article (Karlsson, Friberg, Wallengren & Öhlen, 2014) was entitled: ‘Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study.’ As with the Røysland and Friberg (2016) article, I hoped to find a definition of existential uncertainty at the first mention of the term. This is how the concept is referenced in the introduction:

> “…when a person becomes ill with cancer, the bodily experience involves becoming aware of one’s own mortality and this awareness means to live in existential uncertainties due to the mortal threat of the body. It follows that the existential uncertainty of individuals in this situation is about the uncertainty of the prospect of the disease trajectory, about being able to survive or not and how life will be before death.” (p.2)

While one might not dispute the validity of this statement, it is unclear whether the authors mean to say that awareness of mortality is the only dimension of existential uncertainty or one of many. Furthermore, I found it interesting to notice that the authors seemed to regard existential uncertainty and uncertainty about disease progression as one and the same thing, whereas Han et al. (2011) make a distinction in their taxonomy between existential uncertainty and uncertainty about prognosis. Reading this article left me with more questions than answers.

The third article (Stockl, 2007) was entitled: ‘Complex syndromes, ambivalent diagnosis, and existential uncertainty – the case of systemic lupus erythematosus (SLE).’ This was a sociological study combining methods of ethnography and grounded theory to explore the relationship between complex syndromes and clinical practice. Stockl argued that ambivalent diagnosis leads to existential uncertainty amongst patients, where existential uncertainty is the patient’s realisation that the “future life of his or her mind, body, and self is in jeopardy” (p.1551). This – the only definition offered – is, in fact, a direct quotation from Adamson’s (1997) idiographic account of an illness trajectory defined by inflammatory bowel disease and avascular necrosis, which distinguished between existential uncertainty and clinical uncertainty. It was a relief to me to locate the Adamson article, because this was the first time I encountered what felt like a clear and considered conceptualisation of existential uncertainty. He wrote:

> “I follow existentialist usage in using the term existential uncertainty to refer to the individual's awareness that his or her future is open and undetermined. In the medical encounter, existential uncertainty is 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.” (p.134)

Adamson distinguished between existential uncertainty (the uncertainty of the individual patient) and clinical uncertainty (the uncertainty of the clinical scientist whose responsibility it is to diagnose and treat the illness). None of the other authors mentioned in this section had distinguished existential uncertainty from any other form of uncertainty, so it was useful to have Adamson lay out not just what to his mind existential uncertainty was, but also what it was *not*. My mind immediately went to the Han et al. (2011) taxonomy and the distinction it makes in the second dimension between scientific aspects of uncertainty and personal aspects of uncertainty (including existential uncertainty), as well as the locus of uncertainty specified in the third dimension (patient or clinician).

1.4.2 Existential uncertainty beyond the health literature

Of the other articles returned by the preliminary search, five were drawn from diverse fields (psychoanalysis, politics, cultural anthropology, geoscience, sociology), while the remaining three were drawn from the psychological literature (two from the literature on terror management theory, which is based on the idea that the inevitability of death generates a terror from which we spend our lives trying to distract ourselves, and one from the literature on personality). Although the literature review reported in the Analysis chapter at 3.1.2 and 3.1.3 will adopt an interdisciplinary approach, for now I will confine myself to observations on the three articles drawn from the psychological literature.

In one of the articles drawn from the terror management theory literature, Landau, Rothschild and Sullivan (2012) define existential uncertainty as “uncertainty about life’s significance” (p.132), arguing that we invest in cultural worldviews as a way of mitigating the terrifying possibility that life is insignificant. This pithy definition is consistent with the suggestion in the Han et al. (2011) paper that existential uncertainty is related to our sense of meaning in life. An emphasis on death is more explicit in the second article drawn from the terror management theory literature, in which Rubin (2018) presents a measure for ‘fear of existential uncertainty’, which he describes as “fear about uncertainty regarding what happens after death” (p.301). The four items in the measure require participants to rate the extent to which they are frightened by the following death-related issues: ‘the uncertainty of what to expect’; ‘the uncertainty of any sort of existence after death’; ‘its mysteriousness’; ‘the unknowns associated with it'. It is interesting to note that this measure of existential uncertainty is focused on what happens *after* death, whereas the health literature described in the section above seemed much more focused on the uncertainty of life *before* death.

The final article in the psychological literature returned by the preliminary search (Lewis & Bates, 2013) was entitled: 'Common genetic influences underpin religiosity, community integration, and existential uncertainty.' These authors present a measure for 'existential uncertainty' that is comprised of two items on which participants rated their level of agreement: 'the world is too complex for me'; 'I cannot make sense of what's going on in the world'. These items represent a marked contrast with the items used by Rubin (2018) in his measure – while Rubin's measure was concerned with what happens after death, this measure was concerned with making sense of the world. It was interesting to observe that while the preliminary search returned two measures of existential uncertainty, these did not seem to me to be measuring the same concept.

1.4.3 My conclusion

This preliminary review of the existential uncertainty literature yielded no published concept analysis of existential uncertainty. This was enough to convince me that there was some potentially valuable work to be done in carrying out a formal analysis to define and delineate the concept. The lack of explicit definition offered by researchers seemed to imply that the meaning of 'existential uncertainty' is self-evident and not in need of definition. However, the fact that the concept was being used by researchers in a variety of ways (without any acknowledgement of this variety) suggested otherwise to me. Although the various uses seemed to share conceptual terrain (something to do with the future, threat, mortality, death, sense making, meaning, etc.), this terrain ranged broadly, with different researchers emphasising different aspects, sometimes in a manner that raised questions, e.g. is existential uncertainty about what happens before death or after death or both? Furthermore, with the exception of Adamson (1997), none of the researchers made an attempt to delineate the concept, i.e. to distinguish it from *non*-existential uncertainties by setting out where existential uncertainty might be said to begin and end.

In arguing for the importance of analysing concepts, Wilson (1963) makes a case for "becom[ing] *self-conscious* about words which hitherto we had used without thinking – not necessarily used wrongly, but used unselfconsciously" (p.14). I concluded from my preliminary review of the literature that health research could benefit from a more self-conscious use of the term 'existential uncertainty', and that the work required to facilitate this change was well suited to my doctoral research project, given my interests.

1.5 Research rationale and aims

The question is *why* it is important to become more self-conscious about our use of terms such as ‘existential uncertainty’. My answer is that our theories are only as good as the components with which they are constructed, and concepts are “the basic building blocks in theory construction” (Walker & Avant, 2019, p.167) – if we are unthinkingly using the same term to mean different things, then the confusion that inevitably follows will limit the capacity of our theories to deepen our understanding of important psychological issues. Nor is this a concern that is particular to a certain approach to research – whether one’s orientation is realist, phenomenological or social constructionist, a failure to take explicit account of the meaning (or possible meanings) of basic concepts will thwart the development of theory within research as well as the translation of research into clinical practice.

Given that research is driven in part by “the need to link theory and empirical observation” (Yardley & Bishop, 2008, p.363), there is a strong rationale for bridging the gap between empirical research on existential uncertainty (e.g. Røysland & Friberg, 2016; Karlsson et al., 2014; Stockl, 2007) and theoretical models of uncertainty (e.g. Han et al., 2011), starting with a clarification of the concepts that underpin both.

1.5.1 Why uncertainty?

Uncertainty is an intrinsic aspect of human existence (Spinelli, 2015). It is salient when we are faced with a serious threat to our health (Han et al., 2011), and its impact on health outcomes can be negative (Wright, Afari & Zautra, 2009). When it comes to ill health, some people struggle to come to terms with the uncertainty that remains once they are in receipt of all available information, and these are the people who are likely to be referred for psychological support (McCormack et al., 2011). It is important that psychologists know how to work with irreducible uncertainty, which necessitates having some framework for conceptualising different aspects of uncertainty as a basis for distinguishing between reducible and irreducible uncertainty.

Uncertainty is a particularly prominent aspect of the cancer experience because of the life-threatening nature of the disease (Nissim et al., 2012). However, UK guidelines for improving supportive and palliative care for adults with cancer (National Institute for Health and Care Excellence, 2004) suggest that health professionals working in cancer care may not feel adequately trained in exploring uncertainty, particularly uncertainty around the future course of the disease. Developing a better understanding of the way uncertainty features in the cancer experience is a necessary first step towards addressing this need within cancer care.

Han et al. (2011) draw attention to the fact that existential uncertainty has not traditionally received a great deal of attention and yet may be a bigger concern for patients than scientific aspects of uncertainty, which are more heavily researched. This is consistent with Penrod's (2007) claim that "despite the breadth of experiences and research contexts explored in the scientific literature related to uncertainty, the conceptual definition [of uncertainty] failed to specify the more existential characteristics of the concept" (p.660). This research is a way of beginning to redress this imbalance.

1.5.2 Relevance to counselling psychology

The modernist scientific paradigm, driven by positivist principles, has tended to focus more on the unknown (which is to say the not-yet-known) than the unknowable – Gordon (2003) characterises the epistemological assumption on which this paradigm is based as follows: "if we keep to the scientific project – ask the right questions, gather enough information, solve the problems – then finally we will run out of problems to solve." (p.101) This quest for certainty is particularly evident in clinical medicine (Gillett, 2004), which is underpinned by an "ideology of uncertainty reduction" (Babrow & Kline, 2000, p.1805). It ignores the possibility that while greater quantities of information can lead to increased knowledge and scientific breakthroughs, they also lead to commensurate increases in uncertainty and doubt because they inevitably raise more questions (Michael, 2000).

The postmodern paradigm that informs counselling psychology has a different philosophical perspective on uncertainty. In her discussion of the relationship between counselling psychology and research, Rafalin (2010) writes of a paradigm shift that fuelled the birth and growth of the profession:

> "Counselling psychology values a search for understanding, rather than demanding universal truths. Through this profession, psychology's historical fetish for insisting on answers has seen an evolution to a valuing of questions." (p.41)

A research study on uncertainty is really a research study on questions. I would argue that counselling psychology, committed as it is to the scientific model while at the same time recognising the intrinsic value of questions (rather than seeing them merely as the precursor to an answer), is in a strong position to develop valuable insights into the nature of uncertainty.

In clinical terms, existential interventions that focus on meaning making rather than uncertainty reduction have been shown to be effective for cancer patients (Bauereiß, Obermaier, Özünal

& Baumeister, 2018), and counselling psychologists are well placed to deliver existentially-informed interventions given counselling psychology and existential psychotherapy share a humanistic ethic (Cooper, 2009). Although the research presented in this thesis is conceptual rather than clinical in nature, it is reasonable to suggest that a deeper theoretical understanding of uncertainty in health care might helpfully inform the development of more effective psychological support for people living with health-related uncertainty.

It is important to acknowledge that existential uncertainty is not a concern unique to the health context (as the preliminary literature review attests). Writing from a psychoanalytic perspective, Brothers (2008) suggests that existential uncertainty makes its presence felt in the consulting room itself:

> “Nowhere do I experience what I shall call *existential uncertainty* more starkly than in my own consulting room. It is there, as waves of this nightmarish dread wash over me and my patients, that I feel most tempted to dig my heels into the dry shore of analytic certitude.” (p.13)

Given the importance of reflexivity within the practice of counselling psychology (Rizq & Target, 2008), it is crucial that counselling psychologists consider how their own relationship with existential uncertainty might shape their encounters with clients. This, of course, requires an understanding of existential uncertainty, which this research aims to provide.

1.5.3 Research questions

On the basis of what I have discussed above, I aim in this research to answer two related questions:

1) How might existential uncertainty be usefully conceptualised?
2) How might the relationship between existential uncertainty and other aspects of uncertainty be understood in the experience of people living with cancer?

1.6 Summary

In this chapter, I have set out how I came to the concept of existential uncertainty and how my own experiences have shaped my engagement with it. Through a preliminary search of the most relevant literature, I established that the term ‘existential uncertainty’ is used by different researchers to mean different things in the health literature and beyond, but that there are common threads running through the various usages. I have argued that a clearer definition and delineation of the concept would contribute to a deeper understanding of health-related uncertainty, and that counselling psychology's postmodern orientation provides an opportunity to approach this task in a way that has perhaps been neglected in the past by researchers who are more committed to a positivist orientation. I concluded by setting out the two questions that this thesis will endeavour to answer.

In the next chapter, I will give a detailed account of the methodological approach I developed in order to answer these questions, addressing some of the epistemological issues I encountered along the way.

2.0 Methodology

This research is conceptual in nature, which is to say it is concerned with the *concept* rather than the *experience* of existential uncertainty. It is my intention in this chapter to establish a clear theoretical position as a means of clarifying what kind of knowledge conceptual research can hope to generate. I will begin by setting out the kinds of knowledge implicated in conceptual research on uncertainty. I will then proceed to describe the methodology used, the procedure followed, and my role in shaping these. Finally, I will introduce the participants I recruited to the study, and explore some of the issues I encountered in seeking to ensure the research was ethically sound as well as epistemologically valid.

2.1 Theoretical position

In order to establish a coherent theoretical position for this research from the outset, I had to decide on the extent to which the analytic approach would be driven by theory, i.e. the extent to which it should be ‘top down’ rather than ‘bottom up’. To counteract the diffuseness and heterogeneity of the existential uncertainty literature (see Introduction 1.4), I decided that the analytic approach should have a strong theoretical underpinning. I chose the taxonomy developed by Han et al. (2011) as the theoretical framework on which to base this research for three main reasons. Firstly, because it integrates principles and insights from earlier approaches in a comprehensive and systematic manner rather than representing a radically different way of conceptualising uncertainty from pre-existing approaches – its purview is therefore broad and inclusive. Secondly, between the date of its publication and 2020, it has generated considerable research and discussion around the nature of health-related uncertainty – according to Scopus, it had been cited 264 times by July 2020 (the time of my search), with 56 citations in 2019, up from 34 in 2018. This corresponds to a field-weighted citation impact of 7.64, which is in the 98th percentile. I felt that by situating this study within a “deliberate, coordinated, integrated program of work” (Han et al., 2019, p.1757) on uncertainty, I was more likely to achieve a meaningful impact with my results than if I had added to “the plethora of disconnected – and either redundant or unnoticed – findings, concepts, and theories” (ibid.) that are a feature of the literature. Finally – and crucially – the taxonomy includes the concept of existential uncertainty (which other models do not), and identifies it as a key but under-researched aspect of uncertainty.

This study aims to generate knowledge about uncertainty, where uncertainty is broadly defined as “the subjective perception of ignorance” (Han et al., 2011, p.830). According to this definition, uncertainty is a metacognition in that it describes a type of *knowing about not* *knowing*. In concrete terms, the aim is to find out how (conceptually) people living with cancer might make sense of the things related to their cancer experience that they do not (yet) know. This means that three different types of knowledge are implicated in the study: (i) a knowledge deficit, i.e. what is unknown; (ii) the knowledge that people have when they become aware of this deficit, i.e. uncertainty; and (iii) the knowledge the study seeks to generate, i.e. what is presented in this thesis. It is important to distinguish these different types of knowledge and their underlying assumptions when clarifying the theoretical position adopted by the research, as I will now briefly discuss.

2.1.1 The knowledge deficit – what is there to (not) know?

This research is underpinned by an existential ontology (Hersch, 2015), which assumes the existence of a world characterised 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).

This is not to say that certainty does not exist at all. On the contrary, this study follows Spinelli (2015) in positing a real, material basis for the world about which much can be known, but arguing that within the constraints imposed by the world's material basis, there will always be much that is unknown – the knowledge deficit referred to above. In the case of cancer, this means acknowledging that what we call cancer has a basis in cell division, for example, but we cannot know for sure how this cellular activity is going to eventuate in any individual case. As Spinelli puts it: "I can never fully determine with complete and final certainty or control not only *what* will present itself as stimulus to my experience, but also *how* I will experience and respond to stimuli." (p.22) This amounts to a critical realist position (Willig, 1999).

Uncertainty is often oriented towards the future, particularly in the case of cancer where people are understandably occupied with the question of disease progression. This study assumes that "the future is not already in existence waiting for scientific methods to reveal that future", but rather that "time moves toward a future that exists only as potential" (Staley, 2017, p.41). In effect, this makes the future a function of aleatory uncertainty, i.e. fundamentally unpredictable, rather than epistemic uncertainty, i.e. knowable in principle if not in practice (Spiegelhalter, 2008). This position is consistent with the emphasis on freedom, 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.

It is important to state that uncertainty is assumed to be a given of *human* existence and does not exist in any absolute sense. This point can be obscured by the way we often talk about uncertainty *surrounding* such and such a thing or the idea that we live in *an uncertain world*, as if uncertainty exists somewhere *out there* for us to discover. On the contrary, uncertainty is taken to be “a state of mind rather than a feature of the objective world” (Han et al., 2011, p.829). This is not to endorse the dualistic subject/object view implied by that statement, but rather to make the point that uncertainty is inextricably tied up with what it is to be human. This study regards uncertainty 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 emerging from our being-in-the-world-with-others (Cohn, 1997), which cannot be determined or controlled ahead of time since it implicates me but also extends beyond me and what is in my gift to control.

Although the study allows that the uncertainty experienced by people living with cancer will be characterised by highly idiosyncratic elements unique to their particular circumstances, there is also an assumption that there exists a relatively stable and enduring meaning *structure* that underlies this uncertainty. In other words, notwithstanding individual differences between people living with cancer, there will be commonalities in the way they seek to make sense of their experience. These commonalities are the focus of this study’s investigation.

2.1.2 Awareness of the knowledge deficit – knowing about not knowing

While the section above was primarily concerned with questions of ontology, what follows focuses on the study’s epistemological position. This section describes the epistemological position being adopted in relation to the human capacity for metacognition, i.e. knowing that we know/don’t know.

It is not the knowledge deficit itself but rather the *awareness* of the knowledge deficit that generates a sense of uncertainty, and it is the meaning structure of this *knowing about not knowing* that is the primary focus of the study. The following four categories of meta-knowledge, drawn from the risk analysis literature (Daase & Kessler, 2007), are assumed: known knowns – things we know we know; known unknowns – things we know we do not know; unknown unknowns – things we do not know we do not know; and unknown knowns – “the knowledge we do not want to know” (p.412) and are motivated to turn away from. The latter three categories are relevant to this research in the following ways: there are many known unknowns in the cancer experience, often manifesting as uncertainty about the future;

and as people are introduced to a new biomedical discourse[2] with talk of white blood cell counts, obscure anatomical structures, treatment side effects, etc., they may begin to feel uncertain about things they never even knew existed before; but 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), they may also become aware of things they previously *preferred* not to know and therefore kept out of awareness, such as the reality of life's finitude. No assumption is made that people will always *want* to reduce the knowledge deficit, if doing so is perceived as a bigger threat than the uncertainty they are experiencing, e.g. in the case of a very poor prognosis (Mishel, 1988).

The approach I have taken in this study is informed by literature that recognises both "cognitive and precognitive ways of knowing" (Penrod, 2007, p.662). It draws on the embodied phenomenology of Merleau-Ponty (1998/1962) in conceptualising knowledge/knowing as encompassing that which is intuitive, experiential and somatic as well as cognitive, rational and conceptual (Peile, 1998; Barbour, 2004). 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 the key epistemological assumptions made in the study is that the uncertainty we experience is socially constructed (Babrow, Kasch & Ford, 1998). A moderate position is adopted such that uncertainty is conceptualised as being an indirect response to something real in the world, i.e. a response that is mediated through language, culture and social interaction (Willig, 1999, 2012). For example, a woman who detects a lump in her breast might initially experience an uncertainty that is mediated by what she already knows from external sources about the possible implications of such a lump; if she visits a GP, this interaction will shape the uncertainty she feels; and if she is diagnosed with breast cancer, she will use her interactions with the specialist medical team, family and friends as well as her own sense of agency and bodily knowledge to make sense of what is happening, and the uncertainty she experiences as a result. In doing so, she is assumed to be drawing on "socially available ways of talking about" (Willig, 2012, p.12) cancer and uncertainty, whether that be the oncologist's

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[2] Throughout this thesis, the word 'discourse' does not imply any commitment to the analytic strategies associated with methodologies such as discursive psychology or Foucauldian discourse analysis. I use it in a looser sense to refer to "anything spoken or written (including stories of all kinds), talk, narrative, narrating, telling, conversation" (Mair, 2000, p.335), encompassing both the vocabularies associated with specific domains of knowledge and the philosophical assumptions that underpin them. For example, a biomedical discourse might conceptualise pain within a positivist scientific framework using the vocabulary of "tissue damage", "sensory neurons", "hyperalgesia", etc., whereas a religious discourse might conceptualise it within a theological framework using the vocabulary of "suffering", "mercy", "redemption", "a cross to bear", etc.

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 emphasise personal responsibility and divine determinism to differing degrees, or some other discourse for constructing uncertainty.

In epistemological terms, this amounts to a social constructivist approach, which Crotty (1998) describes as “primarily an individualistic understanding of the constructionist position” (p.58). This is logically consistent with a critical realist position (Willig, 1999, 2016; Elder-Vass, 2012). It also fits well with an existential ontology in that it balances the role of the particular social and material context within which meaning making takes place (Braun & Clarke, 2006) – what in existential terms is labelled facticity (Spinelli, 2015) – with the fact that “each person perceives the world differently and actively creates their own meanings from events” (Burr, 2015, p.21). In both cases, the notion of essential meaning is rejected in favour of an emphasis on the role of individual agency and choice in the meaning-making process.

2.1.3 Knowledge about awareness of the knowledge deficit

In seeking to generate a better understanding of the meaning structure of uncertainty for people in the context of health care, this study will draw on insights from extant literature as well as newly gathered empirical data from people living with cancer. The methodology chosen as most appropriate to the aims of the research is concept development, which has its origins in Wilson’s (1963) concept analysis and subsequent work by researchers in nursing (Rodgers & Knafl, 2000; Fitzpatrick & McCarthy, 2016; Walker & Avant, 2019). It encompasses a range of approaches, methods and techniques that aim “to distinguish between concepts, and thus to clarify the relationships and the distinguishing characteristics between concepts” (Fitzpatrick & McCarthy, p.3). If one accepts that concepts are “the basic building blocks of a theory” (Schwartz-Barcott & Kim, 2000, p.130), then concept development offers the potential for the generation of valuable new theoretical knowledge within the discipline of psychology, where concept development is not widely used or even known.

In the next section, I will describe the concept development methodology in greater detail, addressing its epistemological implications, and the ways in which I adapted it for the specific purposes of this study. Before embarking on a full account of this methodology, however, I would first like to address a fundamental question, an answer to which is necessary in order to establish what kind of knowledge this research can hope to generate: what is a concept? In explicating the taxonomy that provides the theoretical framework for this research, Han et al. (2011) state that the taxonomy’s “categories and concepts, like those of existing taxonomies, are theoretical and have no definite grounding at an ontological level” (p.834). The authors do not explain exactly what they mean by this, but my interpretation of it is that we should think of concepts in this context not as entities or essences, i.e. ontological, but rather as ways of looking at or understanding phenomena, i.e. epistemological. Wilson (1963) makes the point clearly when he writes: “We tend to think as if abstract nouns – particularly those which are connected with strong feelings on our part, like ‘justice’, ‘love’, ‘truth’, etc. – are the names of abstract or ideal objects: as if there were somewhere, in heaven if not on earth, *things* called ‘justice’, ‘love’, and ‘truth’.” (p.40) Put simply, existential uncertainty is not a *thing*.

Philosophical perspectives on concepts have changed through history from the classical view associated with Aristotle, Descartes, Kant and Locke, which is based on an entity theory of concepts (i.e. they have an essence that is independent of their context), to the more pragmatic view of recent thinkers like Wittgenstein (in his later works) and Ryle, who emphasise the *use* of concepts – as Rodgers (2000) summarises:

> “[…] a concept for Ryle is an abstracted feature of the world and is directly related to the ability to perform certain tasks. One of these tasks, and a critical one, is the effective use of language. In his view, concepts are neither objects nor the names of objects; they are not inherently true or false, nor are they the components of creating truths or falsehoods. Instead, they constitute the ability to move effectively through the world. As a result, concept development, the clarification and elaboration of concepts, can be viewed as the creation of improved abilities and new ways to function effectively.” (p.25)

The implication here is that the knowledge generated by this research should not be evaluated against some notional standard of truth or accuracy, but rather against the criterion of usefulness – in other words, is the conceptualisation of existential uncertainty that this research will produce useful in understanding the uncertainty experienced by people in the health care context? To the extent that it is possible, I have avoided the use of language that *objectifies* the concepts included in the Han et al. (2011) taxonomy. Therefore I have preferred to talk about prognostic uncertainty, diagnostic uncertainty, psycho-social uncertainty, existential uncertainty, etc. not as ‘types’ of uncertainty or ‘issues’ of uncertainty (the term favoured by Han et al.), since this implies that they are discrete, categorical and thing-like, but rather as ‘aspects’ of uncertainty, since this implies that they are ways of looking at the phenomenon of uncertainty that can be more or less useful.

Finally, the approach to concepts taken in this research follows Toulmin (1972) in assuming that “the particular sets of concepts we pick up reflect forms of life and thought, understanding and expression *current in our society*” (p.38, emphasis added). The idea that concepts are a reflection of our social world makes them contextually bound and therefore ever evolving (Rodgers, 2000) – a stance that is very much in keeping with an existential ontology (Spinelli, 2015). An evolutionary approach to concept development "indicates a direction for further research and does not provide a definite conclusion" (Tofthagen & Fagerstrøm, 2010, p.22) – this means that the conceptualisation of existential uncertainty generated by this research should be seen as part of an ongoing conversation rather than as a fixed destination.

2.2 Methodology

For this study, I adapted the hybrid model of concept development (Schwartz-Barcott & Kim, 2000) to fit the specific questions under investigation and the concerns of psychology as a discipline. 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, which manifest in this study as follows:

Phase 1 – concept analysis (existing literature)
Phase 2 – analysis of new empirical data (interviews with people living with cancer)
Phase 3 – synthesis of first two phases

I will now proceed to outline each of these phases in greater detail.

2.2.1 Phase 1 – concept analysis

The first phase aimed to produce a rigorous, systematic definition of the concept of existential uncertainty using the technique of concept analysis (Walker & Avant, 2019). This technique involved eight steps:

Step 1: Select a concept.
Step 2: Determine purpose of the analysis.
Step 3: Identify all uses of the concept that can be found.[3]
Step 4: Determine defining attributes.
Step 5: Identify antecedents and consequences.

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[3] Steps 3 and 4 used the immersion/crystallisation technique set out by Borkan (1999), which was also used in the Phase 2 analysis and is described below at 2.2.2.3.

Step 6: Define empirical referents.
Step 7: Identify model case.
Step 8: Identify other cases (borderline, related, contrary).

Phase 1 concluded by offering a tentative yet systematic definition of existential uncertainty, which drew on published academic literature from psychology, nursing, medicine, sociology and philosophy, but also on autobiography (for Step 7 and Step 8).

Although Schwartz-Barcott and Kim (2000) recommend that Phase 1 be limited to “drafting an initial, very loose definition” (p.132), a systematic definition was justified in this case on two counts. Firstly, existential uncertainty is a highly specific concept in that it is assumed to be a constituent aspect of the superordinate category of what I will call ‘global’ uncertainty (i.e. all aspects of uncertainty), and therefore must be differentiated from other aspects of uncertainty. The problem with developing a loose definition is that in its looseness it may not be sufficiently differentiated from other aspects of uncertainty to serve the required purpose. Secondly, because a systematic definition of existential uncertainty is missing from the literature, it seemed reasonable that Phase 1 should offer one, even if it ended up being challenged by the empirical data gathered in Phase 2. Schwartz-Barcott and Kim argue quite reasonably that there is a danger of becoming attached to the Phase 1 definition if it is too fully developed, and Phase 2 then becomes more about validating this definition than “probing and questioning” (p.132) the nature of the concept. I therefore made a deliberate effort to analyse the empirical data gathered in Phase 2 with an open mind (see Epistemological reflexivity below at 2.5).

As the presentation of the results of Steps 1 and 2 of the concept analysis technique requires some discussion of methodological issues, I will for the sake of clarity postpone further discussion of specific methodological considerations relating to the Phase 1 analysis until I present the results of this analysis – see Analysis 3.1.1 and 3.1.2.

2.2.2 Phase 2 – analysis of interviews

In the second phase, people living with cancer were invited to explore their experience of uncertainty in an interview lasting up to 90 minutes. The aim of this stage of the research was to gather rich accounts of cancer-related uncertainty that might yield 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 interview had two integrated components (see Appendix 1 for interview schedule):

i. *Object elicitation exercise*

The interviews began with an object elicitation exercise (Willig, 2017): when I was screening participants, I invited them to prepare for the interview by identifying two objects that were linked in their mind with the uncertainty associated with their cancer experience and that they would be happy to talk about in the interview. The only guidance I gave them was as follows: ‘These objects can be anything at all and there are no right or wrong answers – so they can be anything from everyday objects like clothing and household items to documents, photographs and artwork. The most important thing is that you somehow associate the object with your uncertainty and are able to say something about that.’

This technique offers three advantages. Firstly, it gave participants time ahead of the interview to focus their mind on the meaning of uncertainty in their lives, about which it might have been difficult to formulate thoughts spontaneously. Secondly, introducing objects with personal meaning into the interview facilitates the concretising of an abstract concept, which may have made it easier for participants to talk about it (particularly in the early part of the interview). Finally, and arguably most importantly, engaging in an object elicitation exercise at the beginning of the interview allowed participants to frame the meaning that uncertainty has for them in their own terms before responding to my questions, which inevitably reflected *my* frame of reference.

ii. *Semi-structured interview*

Once we had explored the meaning associated with the objects (which lasted up to 30 minutes), I began to ask participants a number of open questions that were designed to help them describe different aspects of their uncertainty experience. I tried to move as seamlessly as possible between the first and second components of the interview schedule, taking account of what we had just been discussing rather than sticking rigidly to the questions set out in the schedule. Throughout the interviews, I avoided specific terms from the Han et al. (2011) taxonomy such as ‘scientific uncertainty’ or ‘existential uncertainty’, as although these may be helpful ways of conceptualising the meaning structure of uncertainty, they were unlikely to correspond to how participants thought of their own experience of uncertainty and therefore risked imposing a structure on their accounts at the data collection stage.

There were three interlocking strands to the analysis of these interviews, which I will describe in the following order: (i) transcription of the interviews; (ii) coding and chunking of the data; (iii) immersion/crystallisation.

2.2.2.1 Transcription of interviews

After I completed the interviews in July 2020, I transcribed them verbatim, spending a considerable amount of time listening and re-listening to them as a way of familiarising myself as intimately as possible with the data and allowing participants' testimony to percolate in my mind. This strand overlaps with immersion/crystallisation (below).

2.2.2.2 Coding and chunking of the data

The theoretical position detailed above at 2.1 pointed firmly in the direction of a top-down approach to coding, and the development of "a preliminary code manual […] based on an initial conceptual model" (Crabtree & Miller, 1999, p.168) that would underpin the coding procedure. I decided to use the eight aspects of uncertainty specified by the Han et al. (2011) taxonomy's second dimension as the basis for the manual since this is the dimension in which existential uncertainty is included, which is to say existential uncertainty is classified as an 'aspect' of uncertainty rather than a 'source' of uncertainty (first dimension) or a 'locus' of uncertainty (third dimension). In other words, I decided to use the eight topics that people might be uncertain *about* as a way of organising the interview data before defining and delineating the concept of existential uncertainty.

I expanded the eight aspects of uncertainty specified by the Han et al. (2011) taxonomy into the coding manual set out in Appendix 2 as a way of making explicit my approach to coding, and as a tool for determining practically what aspect of uncertainty might lie behind any given section of interview text. The aim of this was to ensure clarity and consistency across interviews. The third column in the table ('operative question') is a heuristic – if one accepts that uncertainty is always associated with a question, then it is useful to ask at any given point in the text: what is the implied question underlying the participant's testimony at this point in the interview? The operative questions were helpful because the way they are expressed is closer to the lay terms in which participants are likely to describe their experience than the technical terms of the taxonomy. In other words, people are more likely to say 'I didn't know how much confidence I could have in my medical team' than 'I was experiencing uncertainty in relation to structures of care'. My intention here was to make it easier to identify the aspect of uncertainty implicated at different points in the interview.

Once I had finalised the coding manual, I went through each of the six interviews and coded participants' testimony according to the eight aspects of uncertainty contained therein – in other words, asking myself: at this point in the interview, is the participant talking about diagnostic uncertainty, prognostic uncertainty, psycho-social uncertainty, existential uncertainty, etc.? In accordance with the procedure described by Crabtree and Miller (1999), once each of the interviews had been coded, all the text that had been coded for each of the individual aspects was chunked and gathered together in one place in preparation for the immersion/crystallisation stage of the analysis.

2.2.2.3 Immersion/crystallisation

Once the related segments of text had been chunked and gathered together, I used the immersion/crystallisation technique set out by Borkan (1999) to construct themes that reflected my interpretation of the segments as a whole. This approach involves "cycles whereby the analyst immerses him- or herself into and experiences the text, emerging after concerned reflection with intuitive crystallizations, until reportable interpretations are reached" (p.180). I also drew on the guiding principles of thematic analysis set out by Braun and Clarke (2006), which allow for a balancing of material 'reality' with the broader social context within which meaning making occurs. On a practical level, the approach suggested by Braun and Clarke is consistent with Borkan's approach in describing a recursive (rather than linear) process, involving movement back and forth between phases. The themes generated by this analytic procedure were then used as the basis for defining attributes of the concepts in the taxonomy.

2.2.3 Phase 3 – synthesis of concept analysis and analysis of interviews

The third phase was the final analytic phase in which findings from the first two phases were synthesised to offer: (i) a more fully developed and refined set of defining attributes of existential uncertainty than the one proposed in Phase 1; (ii) a revised and expanded conceptualisation of existential uncertainty as compared with the one offered at the end of Phase 1; and (iii) an account of how existential uncertainty might be delineated from those aspects of uncertainty in the taxonomy with which it shares some conceptual terrain within the overall context of 'global' uncertainty.

2.3 Participants

2.3.1 Sampling

When it comes to the gathering of empirical data in the hybrid model of concept development, Schwartz-Barcott and Kim (2000) assert that a large number of cases is undesirable, and suggest doing an in-depth study of three to six individuals. I therefore chose to recruit six participants to Phase 2 of this research.

A relatively small number of participants is justified on the basis that this research is conceptual rather than phenomenological. The assumption underlying the research is that the meaning *structure* of uncertainty, of which the concept of existential uncertainty is a constituent aspect, is relatively stable, enduring and consistent across people (unlike the *experience* of existential uncertainty, which one would expect to vary considerably across people). According to Heidegger (1996/1927), human being-in-the-world is “distinguished by the fact that in its being this being is concerned about its very being” (p.10). On a conceptual level, the uncertainty implicated in this uniquely human being-in-the-world is assumed to transcend demographics or the specifics of any given situation. One would expect the experience, by contrast, to be very much tied to such specifics. Guest, Bunce and Johnson (2006) argue that “the more widely distributed a particular experience or domain of knowledge, the fewer the number of participants required to provide an understanding of the phenomenon of interest” (p.75). The domain of knowledge to which the concept of existential uncertainty belongs, i.e. the domain of knowledge concerned with what it means to exist as a human being, is assumed by definition to be distributed across all of humanity, so the testimony of six participants is likely to yield sufficient data to tell us something meaningful about the concept of existential uncertainty. Furthermore, there is evidence that six interviews are sufficient to generate meaningful themes in qualitative analysis (Morse, 1994).

To be eligible for inclusion in the study, potential participants had to: (i) be in receipt of a cancer diagnosis within the last five years; (ii) be experiencing uncertainty; and (iii) be willing to explore that uncertainty in the context of a semi-structured interview. The capacity to reflect on the uncertainty of one’s own existence is an intrinsic human capacity, but this uncertainty is assumed to be particularly salient for (and therefore accessible to) people living with a life-threatening illness like cancer. This is why the study targeted people living with cancer. The requirement for the diagnosis to be within the last five years was to ensure the experience of diagnosis, treatment, etc. would be relatively fresh in participants’ minds and therefore more easily accessible. There were no inclusion/exclusion criteria relating to type or stage of cancer because, as outlined above, the *concept* of existential uncertainty was assumed to be stable across such specifics. Anyone who fulfilled the criteria above was assumed to be aware of the fundamental uncertainty of human existence, and this ensured sample homogeneity.

2.3.2 Recruitment

Recruitment took place online via Twitter. I adopted a two-pronged strategy: firstly, I tweeted the recruitment poster (see Appendix 3) publicly from my personal account, and relied on my followers to share it; secondly, I sent a private message to a small number of people who tweet about cancer or who are involved in support initiatives for people living with cancer, and asked them to share the poster with their followers. I used this as an opportunity to reach out to LGBT groups, which are underrepresented in psychological research (Pérez-Stable, 2016; Institute of Medicine, 2011). I believe it is important to incorporate the views of underrepresented groups into psychological research across the board, not just research that pertains specifically to an issue with which that group is closely associated. Therefore, even though this research is not explicitly concerned with sexuality or gender, I wanted it to be informed by LGBT voices (above and beyond my own), as well as the voices of the heterosexual majority. This is consistent with counselling psychology's mission to give voice to underrepresented groups and to challenge normative assumptions (Woolfe, 2016).

I had originally investigated the possibility of recruiting participants through the NHS. At the time of initial planning, I was working in a specialist cancer hospital and began to explore this with the relevant people at the trust. I decided ultimately not to pursue this route because the research sponsor at the trust wanted to make changes to the design of the study that would have altered the project in fundamental ways. I therefore decided to recruit participants independently. This worked out well for two reasons: firstly, the Covid-19 pandemic would have scuppered the plans to recruit through the NHS if I had continued down that route; and secondly, I believe the interviews I conducted would have been different if they had been carried out in a health service setting – participants may have focused more on the medical aspects of their uncertainty experience and may not have felt able to express themselves as freely if they perceived a connection between me and their medical team (Marks & Yardley, 2004).

I recruited participants and carried out the interviews in July 2020. I secured three participants through the first prong of the recruitment strategy and three through the second. Once prospective participants got in touch (either via Twitter or via e-mail), I arranged a time for a screening phone call. During the screening call, I gave prospective participants more detail on what would be involved if they chose to take part, and asked a series of questions designed to minimise the risk that participation would harm them in any way (see Appendix 4 for screening call protocol, and 2.4 Ethical considerations below). At the end of the screening call, I arranged a time for us to carry out the interview (since all participants fulfilled the criteria and were deemed unlikely to be harmed by participation). I then e-mailed them the participant information sheet (see Appendix 5) and the consent form (see Appendix 6), which I asked them to complete and return to me before the interview.

All interviews were carried out via Zoom. This enabled me to reach people across a greater spread of geographical locations than would have been possible if I had carried out the interviews in person. All participants were based in the UK (north of England, south-east of England and Wales) – see Table 1 for further details.

Table 1: Details of participants in the study (with pseudonyms used to ensure anonymity)

Name	**Age**	**Gender**	**Diagnosis**	**Time since diagnosis**
‘Liz’	62	Female	Bilateral breast cancer	2 years
‘Jane’	59	Female	Bladder cancer	7 weeks
‘Eddie’	64	Male	Lung cancer	3 years
‘Sam’	32	Non-binary	Chronic myeloid leukaemia	3.5 years
‘Brian’	61	Male	Prostate cancer	2 years
‘Jim’	67	Male	Prostate cancer	4 years

Following the interview, I sent participants a debrief sheet (see Appendix 7) inviting them to get in touch with me or my supervisor if they had any questions, and signposting them to Macmillan Cancer Support or Maggie’s, if they felt at any point that they might need psychological support. In accordance with confidentiality requirements and data protection legislation, all participant data was anonymised and stored securely (electronically) on a City University OneDrive.

2.4 Ethical considerations

The life-threatening nature of cancer and the uncertainty with which it is associated make the disease a suitable context for a study exploring the concept of existential uncertainty. However there are also important ethical questions raised by such a study. One of the assumptions underpinning this research is that uncertainty is socially constructed (see 2.1.2 above), so there was a possibility that the interview would itself generate an awareness of uncertainty in participants that did not exist previously (if unknown knowns and/or unknown unknowns were to become known unknowns). This could lead to harm if participants were left feeling uneasy or distressed after the interview. In accordance with the ethical guidelines set out by the British Psychological Society (2014), the wellbeing of participants took priority over all other considerations. What follows is a brief account of the measures I took to ensure the wellbeing of participants.

Although it would not have been right to exclude any groups as a rule (e.g. people with a mental health diagnosis), thereby depriving those groups of the opportunity to contribute to psychological science and to have their stories heard, it was important to minimise the risk that the interview would lead to harm for any of the participants. The main purpose of the screening call was to make sure that potential participants were not already experiencing acute psychological distress, which might have put them at greater risk of harm from the interview itself. In such a case, I would have signposted them to appropriate support services, but in the event, none of the participants reported experiencing acute distress, and all six people who responded to the recruitment drive were deemed eligible to take part.

If participants who had been deemed eligible on ethical grounds to take part in the research project were to become distressed during the interview and struggle to regain composure, I would have offered them the following options: (i) to stop the interview temporarily; (ii) to end the interview for that day but potentially rearrange for another day; or (iii) to withdraw from the study altogether. In all cases, I tried to ensure that participants were feeling stable before the meeting ended. I did this by inviting them to reflect a little on how the experience of the interview was for them, and helping them to reorient themselves to the world outside and the day ahead. Although some participants became emotional at times during the interview, nobody reported feeling distressed at the end – in fact, they all said it had been an interesting and positive experience.

From an ethical point of view, it was necessary for me to be clear at all times that the purpose of the interview was to collect data for a research project rather than to provide therapeutic support. It was particularly important to clarify this given the similarities in format between the two, i.e. a one-to-one meeting in which someone is invited to reflect on their experiences. As I began recruitment, I was coming to the end of a clinical placement in a specialist cancer hospital, so there was the potential for a blurring of boundaries on my part as much as on the part of participants. In one way, my work at the hospital was a great benefit to the research, as I had just spent nine months having in-depth conversations with people about their cancer experiences, so was already comfortable with that situation and the emotions to which it can give rise. Nevertheless, I needed to find a way to distinguish clearly between my role as researcher and my role as therapist (Rowling, 1999). The fact that the interviews took place in a different location (my home) and in a different medium (videoconferencing) from my clinical work helped me to make this distinction. I also did a short mindfulness exercise before each interview as a way of signalling to myself that I was stepping into my researcher role. I also took some time after each interview to bring to awareness the emotional impact the interview had on me as a way of managing this impact and not carrying it with me unawares for the rest of the day. I found many of the interviews moving, and they did stay with me in the following days and weeks, but I felt they did so in a productive way in the sense that they began to spark thoughts and connections that I brought to the analysis.

Ethical approval was granted by the Psychology Research Ethics Committee at City, University of London – reference ETH1920-1358.

2.5 Epistemological reflexivity

Before giving an account of the results of the three phases of the analysis in the next chapter, I would like to conclude this chapter by reflecting on my engagement with some of the epistemological issues thrown up by Phase 2 of the research. Phase 2 was the most complex and demanding phase of this research since it involved the recruitment of participants, deep engagement with them during the interviews, transcription of the interviews and finally analysis. This required a lot from me, not just practically and intellectually, but also in terms of the emotional processing that went with having people share what are extremely personal and challenging experiences. I will now offer some thoughts on the issues and questions that arose during this phase, and how they might have shaped the outcome of the research.

It is clearly the case that people living with cancer experience uncertainty irrespective of any researcher's attempts to engage with it. However, it is also true that if uncertainty is socially constructed, as this research assumes it is, my interviews with participants (including the questions I asked and the rapport I established) will have shaped this uncertainty to some degree and, by extension, both the collection and analysis of the data. While this is not a problem *per se* insofar as a social constructivist approach rejects the notion of an objective truth, it is important to acknowledge the inevitability that my feelings and preconceived ideas will have foreclosed certain avenues of exploration at the data collection stage (i.e. through the questions I did *not* ask in the interviews), and will have made me less sensitive at the analysis stage to potential insights that would have been supported by the data I *did* end up gathering. For example, as described in the Introduction (see 1.4.1), when I first engaged with the existential uncertainty literature, I was frustrated that there was no proper definition of the term, but instead a wide range of sometimes inconsistent uses. My aim in this research was to impose a structure on the concept of existential uncertainty. Although this is surely a legitimate aim, there is a risk that my analytic strategy in Phase 2 could have amounted to a Procrustean attempt to fit participants' testimony to a pre-determined structure (i.e. my own ideas, including the Phase 1 conceptualisation), thereby disregarding important aspects of their accounts of uncertainty that would have relevance to the concept of existential uncertainty. This is a greater risk in a top-down conceptual study than in a phenomenological study where the primacy of participants' experiences is baked into the methodological approach.

This risk was amplified by the fact that the analysis operated at the level of latent meaning, allowing for the examination of "the *underlying* ideas, assumptions, and conceptualizations – and ideologies – that are theorized as shaping or informing the semantic content of the data" (Braun & Clarke, 2006, p.84). It was therefore interpretative in nature. Moreover it was a form of "suspicious interpretation" (Willig, 2013, p.42), grounded in existential theory and the literature around uncertainty in health care. This is appropriate to a critical realist approach, wherein "it is not necessary (in fact, we would not usually expect) that research participants be aware of the underlying mechanisms or conditions that inform their overt behaviours and experiences" (Willig, 2012, p.13). For example, there was no expectation that participants would use the term 'existential uncertainty' to describe any aspect of their experience, so it was up to me to decide what (if anything) in their accounts constituted 'existential uncertainty'. There is an ethical question here given my position of power relative to participants – it was I who asked the questions and I who am now writing the thesis, so it was my responsibility to ensure that participants' testimony was not obscured by my desire to produce a neat account of the meaning structure of uncertainty.

It was to reduce the risk of participants' testimony becoming a mere tool to validate the Han et al. (2011) taxonomy and/or the Phase 1 conceptualisation that I began the interviews with the object elicitation exercise, as described above. When it came to coding the interviews, I made an effort to maintain an awareness that the coding manual informed by the taxonomy was but one way of organising the data, and an inductive approach starting from the data rather than the taxonomy would constitute a different, equally valid approach to coding. Furthermore, when I became aware during the analysis of being more drawn to the accounts of some participants than others (because these accounts chimed with my pre-conceived ideas), I deliberately reoriented myself towards the accounts I was less drawn to on the basis that these arguably had greater potential to illuminate my blind spots than the testimony that chimed more obviously with me. During the immersion/crystallisation process, for example, I looked for elements within the data that did not seem to fit so neatly with the codes and/or my own theoretically-informed ideas, and tried to remain open to what they might indicate about the relevant concepts. This meant that although the coding was predominantly deductive, there was allowance made for the possibility of fresh insights derived from an inductive approach to the data.

The primarily top-down analytic strategy outlined above is justified on the basis that the research is concerned with the *concept* of uncertainty rather than the *experience* of uncertainty, and is seeking to bridge the gap in the existing literature between theoretical and empirical accounts of uncertainty. This is not to say that I was uninterested in the way participants described their experience of uncertainty – on the contrary, I explicitly asked them to describe and elaborate on this. The point is that in conceptual research such as this, the experience is valuable insofar as it tells us something about the concept, and it was equally important to elicit participants' attitudes to, thoughts about and theories on uncertainty, informed (as they will inevitably be) by their experiences. An analysis strategy embedded within a concept development framework is more appropriate to these aims than a phenomenological methodology that would illuminate aspects of experience but not concept, or grounded theory, which has the potential to yield a valuable fresh theoretical perspective, but would not bridge the gap between existing theories and empirical accounts in the literature.

When it came to analysing the Phase 2 interviews, my assumption was that everything participants said in their interviews was relevant to uncertainty, even if this was not always explicit. This is, on the face of it, a reasonable assumption: participants volunteered to take part in a study investigating uncertainty in the cancer experience; they confirmed in a screening call that they had personal experience of cancer-related uncertainty and were prepared to talk about it; and in the interview itself they talked about two objects that they associated with their experience of uncertainty before answering my questions, the aim of which was to draw out their thoughts and feelings on uncertainty. On this basis, I felt it was legitimate to assume that everything they said in the interviews was somehow related to uncertainty.

However, this relationship was not always immediately evident. The reason for this is that it is extremely difficult to talk *directly* about uncertainty for an extended period of time. This is because uncertainty is a meta-cognition that specifies a knowing-about-not-knowing. It is surely easier to talk about knowing something than *not* knowing something, and talking about *not* knowing something is inevitably going to involve talking around the thing that is not known. My assumption was that the stories participants chose to tell about their cancer experience *in the context of an interview about uncertainty* said something about the meanings they made out of their uncertainty experience, and therefore said something about uncertainty itself – it is easier to talk about how we cope with our not knowing, how we respond to our not knowing, how others respond to our not knowing, etc. than it is to talk about the not knowing itself, which, as well as being highly conceptual, is elusive and fuzzy – like trying to describe the negative of a photograph.

Of course it is possible that participants might have talked so far around the thing that is not known that they were no longer really talking about the not knowing, and the challenge in this analytic strategy was to decide where the boundary lay. There were two ways to err: to include sections of text in the analysis that are not actually about uncertainty; or to exclude sections of text from the analysis that *are* about uncertainty. In seeking to tread the line between these errors, I adopted an inclusive approach in the coding phase, i.e. assuming that everything said in the interview context was relevant to uncertainty, while also allowing for the later exclusion of some sections of text during the immersion/crystallisation phase if, once the segments across all the interviews relating to a particular aspect of uncertainty had been gathered together, the connection with uncertainty was deemed to be non-existent rather than just implicit.

It is important to be clear about what the interviews could reasonably be expected to capture. The aim of the interviews was not to obtain for analysis an ‘accurate’ description or ‘objective’ account of the uncertainty the participants experienced at different points in their cancer experience. This would be impossible given the ephemeral nature of uncertainty, which – as with all human experiences – is not a fixed entity but rather part of the ever-changing flow of human existence (Spinelli, 2015). Instead, the interviews were a co-construction of the sense participants made of their uncertainty in respect of their cancer experience (past, present and future) at the time of the interview. There are two important points to make here: firstly, the co-construction is inevitably tied to the time at which the interview took place, and a different co-construction would have emerged if we had conducted the interview at a different time; secondly, the interviews are a co-construction between the participant and me, and a different co-construction would have emerged if someone other than me had conducted the interview. This is very much in keeping with the emphasis on contextual factors within evolutionary approaches to concept development (Rodgers, 2000).

2.6 Summary

In this Methodology chapter, I began by setting out the theoretical position adopted in my research. In so doing, I justified my use of the Han et al. (2011) taxonomy as a framework for conceptualising existential uncertainty before identifying the three different types of knowledge implicated in the research: a knowledge deficit, an awareness of this knowledge deficit, and my conceptual construction of this awareness. I then proceeded to describe the three phases of the hybrid model of concept development (Schwartz-Barcott & Kim, 2000), and the ways in which I adapted them to the specific requirements of this research project. I concluded by exploring some of the ethical and epistemological issues thrown up by this study, and how I tried to address and mitigate them.

In the next chapter, I will set out the results of each of the three phases of the analysis in turn.

3.0 Analysis

In this chapter, I will give a detailed account of the outcome of the three phases of the research described in outline in the last chapter. I will begin with the concept analysis of existential uncertainty, proceeding through each of the eight steps until I am in a position to propose a preliminary conceptualisation of existential uncertainty derived from the existing literature. I will then move on to the second phase of the research and my analysis of the interviews I carried out with six people living with cancer. I will consider what these interviews might tell us about the concept of existential uncertainty, and its relationship with other aspects of uncertainty in the cancer experience. In the third and final phase of the analysis, I will discuss how the insights of the first two phases might be integrated to offer a more nuanced and better delineated conceptualisation of existential uncertainty than the one proposed at the end of the first phase, informed by the empirical data gathered in the interviews as well as by the existing literature.

3.1 Phase 1 – concept analysis

3.1.1 Step 1: Concept selection

The concept selected for analysis was existential uncertainty. On the basis of the preliminary literature search reported in the Introduction (see 1.4), I deemed existential uncertainty to be an immature concept (Penrod, 2001) in that it had never been systemically defined, delineated, or reliably operationalised; its use was not consistent across contexts; and it was not integrated with related concepts within any theoretical framework. If a concept is “still nebulous and has not been well explicated” (Morse, 1995, p.36), as with existential uncertainty, then methods of concept development are appropriate for the clarification of its attributes, its boundaries and its manifestations.

3.1.2 Step 2: Purpose of the analysis

My aim in the concept analysis was to establish a tentative but theoretically-informed conceptualisation of existential uncertainty within the context of the Han et al. (2011) taxonomy of varieties of health-related uncertainty. That is to say I wanted to develop an understanding of how existential uncertainty might be defined as distinct from other aspects of uncertainty specified in the taxonomy, not how it might be defined as distinct from other existential experiences (for instance existential certainty, existential distress, existential anxiety, etc.), or from any other reference point one might reasonably choose. I deliberately made the decision to use this taxonomy as a framework within which to conduct the analysis, notwithstanding the limitations a predetermined framework might impose on the development of a relatively immature concept. The decision was justified on the following grounds:

i. In calling for a “more deliberate, coordinated, integrated program of work” on uncertainty, Han et al. (2019) argue that the organic, piecemeal manner in which the research on uncertainty has evolved up to this point has generated “[a] plethora of disconnected – and either redundant or unnoticed – findings, concepts, and theories” (p.1757). The existing literature in which the concept of existential uncertainty is invoked supports this description, as evidenced in the preliminary literature search. I therefore felt that developing this concept in the context of an established and systematic research programme would constitute a greater contribution to this area of research than developing it outside of such a programme.

ii. Rodgers (2000) argues that there is no absolute or universal truth when it comes to concepts – their value lies in their pragmatic utility within a given context. This is undoubtedly true in an applied discipline like counselling psychology, where concepts must have some clinical utility. In order for a concept to have clinical utility, it must be understood as part of a theoretical framework. The Han et al. (2011) taxonomy was chosen because it offers a clear and comprehensive account of health-related uncertainty, and because crucially it acknowledges the importance of existential uncertainty in the patient experience (where others do not). I felt that developing the concept of existential uncertainty in this context would be most likely to yield insights that can be applied in practice.

iii. There are precedents for concept analysis that focuses on a specified framework. For example, Firth et al. (2015) conducted a concept analysis of healing within a care-delivery framework known as ‘optimal healing environments’.

3.1.2.1 Scope of source material

Where there is a large body of literature on a given concept that contains detailed but confused or overlapping accounts, the primary purpose of an analysis might be to clarify or delineate the concept (Morse, 1995). In such cases, it may suffice to identify all uses of the concept as they exist within that body of literature, and to synthesise the common elements in a way that serves to clarify the concept or differentiate it from related concepts. For example, in their concept analysis of healing, Firth et al. (2015) state that healing is “a commonly used term”, but “understanding of the concept remains confusing and inexact” (p.44). They identify five published concept analyses of healing, and only include in their analysis research that relates to healing in humans – "healing in relation to political relationships, conflict, the environment, and so forth were reviewed but not included in the analysis" (p.45). In other words, when there is much data on the concept of interest, it is legitimate and often necessary to limit the literature search to a specific context.

However when the literature on a given concept is limited or impoverished in some way, it is necessary to go beyond simply identifying all *existing* uses of the concept and to seek *possible* uses of the concept too, supplementing empirical accounts of the concept with insights from theoretical research that, while not focused explicitly on the concept of interest, is relevant to the field of research to which the concept belongs. The justification for this is that a body of literature that is impoverished will necessarily yield an impoverished concept analysis. This is relevant to the case of existential uncertainty. Existential uncertainty is not a commonly used term in the way that healing or many other concepts subjected to analysis are. The preliminary literature search did not yield any published concept analysis, and the literature in which the term does feature is diffuse and inconsistent. This means that in order to *develop* the concept of existential uncertainty, it was necessary not simply to synthesise existing accounts as with more mature concepts in need of clarification or delineation, but to cast the net wider in terms of search strategy.

As the preliminary literature search showed, surprisingly little attention has been paid in the existing research to what exactly we mean when we say uncertainty is existential. This is true of the uncertainty literature, but it is true too of the broader literature on existential concepts. For example, in a recent concept analysis of the existential experience of adults with advanced cancer, Tarbi and Meghani (2019) write: "To avoid perpetuating linguistic ambiguity, in this analysis 'existential experience' will encompass all of the existential needs, issues, concerns, and aspects of patient experience, including existential suffering and existential health." (p.541) Ironically, while acknowledging the linguistic ambiguity that exists, they do not go on to specify exactly what makes an experience existential – curiously, the meaning of the word 'existential' seems to be taken for granted. Given linguistic clarity is one of the determinants of concept maturity (Penrod, 2001), I felt it was important that this concept analysis address the persistent ambiguity around the word, and to propose some theoretical framework for its use. Thus, although the concept analysis was situated within the superordinate category of 'global' uncertainty, I thought it necessary to extend the search strategy beyond the confines of the uncertainty literature to a body of literature that might help explicate the force of 'existential' in the concept of interest – see Strand 3 of the search strategy below.

3.1.2.2 Search strategy

There were three strands to the strategy that was used to identify the relevant literature.

- *Strand 1: existential uncertainty*

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 the earliest possible date (1997) to the time of the search (July 2020). Search term (i) was chosen because existential uncertainty is the subject of the concept analysis; (ii) because existential uncertainty is classified in the Han et al. (2011) taxonomy under the subordinate category of 'personal uncertainty', so it was important to investigate whether there was relevant research on the concept of personal uncertainty that included an existential aspect; and (iii) because doubt and uncertainty are closely related in meaning (Concise Oxford Thesaurus, 1997), so it made sense to take into account the possibility of relevant literature about existential doubt.

The chosen databases were selected to capture research from as broad a range of disciplines as possible, including: the social sciences, specifically psychology, sociology, anthropology and politics; medicine, nursing and allied health professions; and the humanities. Walker and Avant (2019) advocate this broad, interdisciplinary approach to concept analysis to guard against any bias that might emerge from a narrow focus on disciplines that may seem more immediately relevant to the concept (such as health-related disciplines in the current analysis).

Following the removal of duplicates and results that were deemed not directly relevant to the concept analysis, there were 42 articles and book chapters. Results were removed according to the following criteria: (i) they were not available in English; (ii) they were from highly technical disciplines (e.g. geoscience, data mining, etc.) that were not relevant to human relations; and (iii) the focus of the article or book chapter was not uncertainty and contained only a passing mention of existential uncertainty without any attempt at definition – this was established by searching the document for the term 'uncertainty' to see how many times it was mentioned.

The 42 articles and book chapters were read in their entirety and any research cited therein that had potential relevance was sourced and reviewed. A further 7 articles were identified in this manner. These 49 articles were then re-read carefully in order to extract key themes and definitions. See Appendix 8 for a selection of key quotes from the search results.

- *Strand 2: uncertainty theory*

Since the aim of this analysis was to explicate the concept of existential uncertainty in the context of ‘global’ uncertainty as a superordinate category, it was necessary to ensure that key insights from the theoretical literature on uncertainty more broadly were included in the analysis. Given that uncertainty pervades every aspect of human existence, the research literature on uncertainty is vast and spans multiple disciplines ranging from physics and engineering to medicine and psychology. The aim here was not to do a systematic review of all theories of uncertainty that may have relevance to the concept of existential uncertainty, but rather to take account of the theoretical underpinning of the Han et al. (2011) taxonomy and the research this taxonomy has spawned. This was justified for two reasons:

i. The Han et al. (2011) taxonomy does not represent a radically different way of conceptualising uncertainty from pre-existing approaches, but rather seeks to integrate principles and insights from earlier approaches in a more comprehensive and systematic manner. Therefore the Han et al. paper, including the earlier models it references, is broad and inclusive in its conceptualisation of ‘global’ uncertainty as a category, and these qualities make it an appropriate springboard from which to begin a concept analysis.

ii. The Han et al. (2011) taxonomy continues to generate considerable research and discussion around the nature of health-related uncertainty (see 2.1 Theoretical position). To ensure this concept analysis was informed by the ongoing research and discussion generated by the taxonomy, the titles and/or abstracts of articles and book chapters citing the taxonomy were reviewed to identify the literature most relevant to the current study. The review sought to identify health-related research that was theoretically oriented, specifically reviews and proposed models of uncertainty that are broadly applicable to the uncertainty experienced by people living with illness. Items were excluded if they were not related to health care, or if they focused on a specific aspect of, or situation in, health care that was not immediately relevant to the current study, e.g. the evolution of uncertainty in second opinions, the ethics of uncertainty in genomic medicine, etc.

- *Strand 3: existential theory*

Given the failure to locate any rigorous, theoretically-derived definition of the term ‘existential’ in the initial literature search, I deemed it necessary to venture further afield in order to develop a deeper understanding of the meaning that might be carried by ‘existential’ in the concept of interest. This raised the question of where to turn in the search for such a meaning. I decided to turn to the field of existential therapy for possible insights into the meaning of the word and the relevance of its theoretical underpinnings to uncertainty in the health context. This was justified on the basis that a field of academic enquiry defined by a given word is likely to have a more fully developed sense of the meaning of that word than one that uses the word in a more incidental manner. There are two related fields to which the word existential belongs intrinsically: existential philosophy and existential therapy. Although existential philosophy emerged before existential therapy (Cooper, 2003), the latter is more aligned with the purposes of this concept analysis given that existential therapy is an applied discipline that shares many of the concerns and interests of counselling psychology (Spinelli, 2014). Given this is a counselling psychology research study, I decided to turn to the existential therapy literature.

The chief difficulty in trying to glean insights from a field of inquiry as rich, varied and vast as existential therapy is deciding how to do so in a way that is practically manageable and theoretically coherent. The task is made more difficult by the fact that existential therapy itself seems to resist definition – as Cooper (2003) writes, “it is best understood as a rich tapestry of intersecting therapeutic practices, all of which orientate themselves around a shared concern: human lived existence” (p.1). I therefore decided to focus on one approach within the rich tapestry – the existential-phenomenological approach. This decision was taken on the following grounds:

i. The existential-phenomenological approach is argued to be the “most philosophical of all existential approaches” (van Deurzen, 2019, p.130), and aligns itself closely with the movement of existential philosophy developed in Europe in the nineteenth and twentieth centuries. By contrast, the existential-humanistic approach in the USA, for example, was heavily influenced by the philosophies of humanism and pragmatism, and incorporated the principles of existential philosophy in a diluted form (Cooper, 2003; Cohn, 1997; van Deurzen-Smith, 1984). In this sense, the existential-phenomenological approach strikes a balance between the principles of existentialism in their purely philosophical form and the application of these in a therapeutic context.

ii. One of the hallmarks of the existential-phenomenological approach is, according to van Deurzen (2019), that it adopts “the philosophers’ habit of questioning definitions of concepts and of the assumptions that people carry with them” (p.128). Likewise, Cooper (2003) points to the approach’s rejection of diagnostic categories and normative judgments of ‘healthy’ and ‘pathological’ functioning. This questioning and critical perspective is appropriate to a concept analysis, and is important in the context of uncertainty research, for instance in resisting the tendency to see uncertainty as pathological.

I hoped that drawing on insights from a single approach to existential therapy would yield a consistency and coherence to the existentially oriented insights brought to bear on the concept analysis. It is important to state, however, that existential-phenomenological therapy is not narrow in its theoretical outlook, but rather encapsulates a diverse range of views (Cooper, 2003). For this reason, it was deemed to have the potential to introduce valuable new ideas and insights into the analysis. The analysis drew primarily on the theoretical overviews of the approach as formulated by Cooper (2003) and Hayes and Adams (2019), as well as the particular theories expounded by three of the approach’s most influential theorist-practitioners (as identified in these overviews): Emmy van Deurzen, Hans Cohn and Ernesto Spinelli. As a detailed survey of the entire written output of these three existential therapists was beyond the scope of this analysis, emphasis was placed on the theories and ideas contained in what might be regarded as their manifesto works: Cohn (1997); van Deurzen (2012); and Spinelli (2015).

3.1.3 Step 3: Uses of the concept

I will begin this section by reviewing the existing conceptualisations of existential uncertainty in the literature captured by Strand 1 of the search strategy, and using Borkan’s (1999) immersion/crystallisation technique (see 2.2.2.3) to draw out the commonalities between conceptualisations. I will then proceed to consider how these conceptualisations, which are often informed by accounts of people’s lived experiences, relate to the more theoretically oriented literature captured by Strands 2 and 3.

3.1.3.1 Existing uses of the concept

Although the term ‘existential uncertainty’ is not often defined explicitly in the literature, some researchers do offer a definition, or – perhaps more accurately – some terms of reference. What follows is a distillation of the commonalities I discerned between these terms of reference across the literature.

- *Existential uncertainty is an awareness.*

Adamson (1997) and Brothers (2012a) describe existential uncertainty as an awareness, and the word also features in the conceptualisations of Karlsson et al. (2014), Parry (2003), Penrod (2007) and Warran, Fancourt and Perkins (2019). The word was even used by one of the participants in the Karlsson et al. study to describe her own experience of living in a palliative phase of cancer: “I have a completely different awareness now.” (p.6) When it comes to identifying specifically what constitutes this awareness, there are a range of possibilities. When Hoffman (2009) refers to “the existential uncertainty that accompanies the realization that there are multiple good ways to be” (p.1043), his use of the word ‘realisation’ implies he is talking about an awareness that is conscious, cognitive and elaborated. Likewise, when Cohen (1993) writes that “thinking about the future seems to invite the threat of loss” and refers to “a normless world of ambiguous boundaries, unclear rules, probabilistic predictions, and sinister possibilities” (p.83), she too seems to be talking about a form of uncertainty that is available to conscious deliberation.

This is not the case elsewhere in the literature. While acknowledging the importance of cognitive processing, Penrod (2007) points to the role of “precognitive sensations (e.g. a feeling in your gut that this is right)” (p.663) in the experience of existential uncertainty. She writes:

> “Uncertainty is possible only when evidence (cognitive and/or precognitive forms) permeates being to a level of awareness that prompts a tallying and conclusion of doubt or of not knowing that challenges the sense of confidence and/or control. This is why distraction and other forms of blocking of authentic being in the world (i.e. a state in which the precognitive and cognitive evidence are embraced into awareness rather than held away from being) are effective barriers to sensing uncertainty.” (p.661)

Elsewhere she describes uncertainty as “not simply a set of probabilities, but a state of being” (Penrod, 2001, p.241), and argues that “states of uncertainty are uniquely determined by an individual’s perception of being in the world – while opportunities for uncertainty may abound, the state is highly individualized” (Penrod, 2002, p.60). This ties in to the idea of saliency – what is salient for one person will not necessarily be salient for another (Cohen, 1993; Kasper, Geiger, Freiberger & Schmidt, 2008). The idea that existential uncertainty cannot be reduced to a cognitive state, and may be more to do with an individual’s unique sense of being in the world, is reflected in the inclusion of ‘feeling’, ‘sensing’ and ‘emotion’ in many of the conceptualisations in the literature, e.g. Soroka (2007), Yair (2007), Karlsson et al. (2014), Sperry (2016). Van den Bos (2009) 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” (p.198). He refers to both cognitive and affective reactions, as well as physiological arousal, including raised blood pressure.

The point here is that existential uncertainty seems to be conceptualised as an awareness that manifests at different levels, sometimes simultaneously. In their study exploring the experience of men living with cancer who were in a singing group, Warran, Fancourt and Perkins (2019) write that "participants described the choir as providing a distraction from thinking about death, in addition to an awareness of death in the rehearsal room which heightened the connection between choristers" (p.4). This suggests that members of the choir had an *awareness* of death while not *thinking* about death.

I was conscious while carrying out this part of the analysis that the idea of existential uncertainty as an awareness chimed closely with my own preconceived sense of it as 'a little turning of the stomach that occasionally intrudes on my day-to-day experience' (see Introduction 1.3), i.e. an intrusion into awareness. While my preconception almost certainly made 'awareness' salient for me as I engaged with the literature, I also felt that it was a sufficiently prominent feature of the literature to warrant being highlighted as a key commonality between accounts.

- *Existential uncertainty is associated with a threat to survival.*

Explicit references to death and mortality are common in the literature reviewed, e.g. Cohen (1993), Gullick et al. (2017), Karlsson et al. (2014), Landau et al. (2010), Landau et al. (2012), Parry (2003), Pascal & Endacott (2010), Røysland & Friberg (2016), Røysland et al. (2016), van den Bos (2009), Warran, Fancourt & Perkins (2019), Wegleitner, Schuchter & Prieth (2018). However there is some variation in the extent to which different researchers conceive of death as being central to the concept of existential uncertainty. For some, such as Landau et al. (2010), the inevitability of death and the possibility of annihilation are the driving force behind all of life's existential anxieties, threatening the idea that life is meaningful and significant. In a similar vein, Rubin (2018) conceptualises existential uncertainty narrowly as uncertainty about what happens after death.

For other researchers, the emphasis of existential uncertainty is on *living* in the shadow of death – a nuance that is captured in the word 'survival', with its suggestion of threat (Abulof, 2009; Brothers, 2009; Pascal & Endacott, 2010). This balancing of life and death is common to many conceptualisations, e.g. "unbearable doubt about one's going-on-being" (Brothers, 2012b, p.392), "the uncertainty of […] how life will be before death" (Karlsson et al., 2014, p.2), "how do I lead my life after diagnosis?" (Pascal & Endacott, 2010, p.279). Seppola-Edvardsen, Andersen and Risør (2016) associate existential uncertainty with not knowing "how to take part in, enjoy, and fulfil a role in everyday social life" (p.368). For participants in the Belpame et al. (2019) study who had completed cancer treatment, existential uncertainty was less about the risk of death from relapse and more about "having to repeat the entire cancer experience again: the intensive treatment, the pain and discomfort" (p.e33).

- *Existential uncertainty is concerned with temporality.*

Cohen (1993) writes of the families of sick children: "Suddenly, family relationships take on a temporal quality and thinking about the future seems to invite the threat of loss. Present time becomes discontinuous with past and future time." (p. 83) This is mirrored by Gullick et al. (2017) when they say that "acute coronary syndrome disrupts lived temporality" (p.393), and by Penrod (2007) when she writes about "the shifting temporality of uncertainty. Uncertainty is a present-oriented state that is influenced by perceptions of the past and future." (p.663)

Outside of the health literature, Abulof (2009, p.229) is concerned with existential uncertainty at the level of the state, and contrasts Israeli Jews, who are uncertain about the future survival of their state, with French Canadians, who are uncertain about their ethnic identity: "The former asks: 'do we have a future?' – the latter: 'do we have a past?'" The idea that existential uncertainty is tied up with past (Abulof, 2009), present (Penrod, 2007) and future time (Adamson, 1997) suggests a possible connection with identity and relationality. This connection is made explicitly by Seppola-Edvardsen et al. (2016), who report that participants in their study who had completed treatment for cancer "talked about striving to stay in their present, everyday life situations. Central to this was being able to maintain their roles in important relationships to family, friends and colleagues." (p.380)

- *Existential uncertainty is experienced privately by the individual while also being intrinsically relational.*

The notion that the concept of existential uncertainty is relevant beyond the level of the individual emphasised by Adamson (1997) is supported by the conceptualisation offered in the psychoanalytic literature, which describes the relational aspect of the concept – in particular Hoffman's (2009) invocation of the influence of culture, socio-political mind-set and personal values in the context of the analytic relationship, and Brothers' (2012b) belief that "feeling that one is a welcome and familiar member of the human family goes a long way toward mitigating the anguish of what I have called 'existential uncertainty'" (p.391). Even as Adamson writes of existential uncertainty as being "experienced privately by the individual patient" (p.134), he acknowledges that this experience takes place within the context of a "medical encounter" (ibid.), so even here there is a relational aspect. The relationality of existential uncertainty is also emphasised by Seppola-Edvardsen et al. (2016) – they suggest that "managing this form of existential uncertainty is inherently a social process and [people's] considerations of whether or not to share worries are part of the everyday management of social relationships" (p.367). This is echoed by Pascal and Endacott (2010), who refer to the "questioning of self, family and place in the social world" (p.279) that follows an existential crisis.

In politics, economics and sociology, existential uncertainty is often conceptualised in collective terms. For example, in the context of political conflict, Hammack (2010) writes that young people "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" (p.173). In economics, Kyriacou and Trivin (2020) argue that "individuals turn towards identifiable in-groups to reduce uncertainty in social interaction" (p.26), which they equate with existential uncertainty. A similar conceptualisation is found in Kinnvall (2004), who writes that "one main response to [ontological] insecurity is to seek reaffirmation of one's self identity by drawing closer to any collective that is perceived as being able to reduce insecurity and existential anxiety" (p.741). A sense of belonging is seen as a bulwark against the threat of exile or social exclusion, which some researchers (Soroka, 2007; Brothers, 2008, 2009; Tersbøl, 2006) have associated with existential uncertainty.

- *Existential uncertainty is about meaning, significance and sense-making, and is distinct from scientific, clinical or informational uncertainty.*

The issue of identity discussed above is intimately tied up with the issue of meaning which, for Han et al. (2011), is central to the concept of existential uncertainty: Landau et al. (2012) argue that people minimise their existential uncertainty by investing in a cultural worldview as a source of meaning in the face of mortality, while van den Bos (2009) argues that "persons or events that bolster one's cultural worldviews provide the existential meaning one is looking for under conditions of personal uncertainty; an effect one could label as the existential uncertainty effect" (p.203).

Miké (2000) asserts that "the question of meaning, the greatest mystery, is beyond the scope of science" (p.357), echoing the distinction made by Adamson (1997) between existential uncertainty and clinical uncertainty, which seems to parallel the distinction made by van den Bos (2009) between personal uncertainty and informational uncertainty. Adamson writes that within a scientific paradigm, the assumption is that "the source of the clinical uncertainty can, in principle, be solved" (p.135) in a way that existential uncertainty cannot. This is consistent with ideas expressed elsewhere in the literature: Furtak (2019) points to instances of existential uncertainty where "the kind of knowledge that we *can* gain does not remove the fundamental uncertainty of our predicament" (p.383), while Persson et al. (2012) suggest that information is of limited use (and can actually be unhelpful) in cases of existential uncertainty because people cannot take it in. Cohen (1993) refers to the "countless unanswerable questions and fears" (p.84) experienced by the parents of a child diagnosed with cancer.

What this research may be pointing to is the inadequacy of an exclusively medico-scientific discourse when it comes to existential uncertainty. Friberg and Öhlen (2007) 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" (p.225). Similarly, Seppola-Edvardsen et al. (2016) emphasise "the symbolic and existential dimension of [uncertainty] – something that a risk discourse departing from clinical risk does not fully encompass" (p.368). There is a consensus that existential uncertainty is not a question of information *per se*.

A number of alternatives to a scientific discourse are proposed in the literature. Friberg and Öhlen (2007) report that the subject of their case study who was receiving palliative care "reflectively explored the situations he went through and turned to literature in order to get an answer" (p.222). Miké (2000) suggests that "to come to terms with the uncertainty of meaning, the ethics of evidence counsels a look at all the evidence, and this includes the insights of religion" (p.358). The potential relevance of a religious discourse to existential uncertainty is also highlighted by Ahmed, Terrill and Sherry (2019), Mrdjenovich (2019) and Lewis and Bates (2013), who suggest that religiosity is "a source of existential certainty, generating a sense of agency and control" (p.399). Nature too is identified as a source of existential certainty – Karlsson et al. (2014) write of the participants in their study who were receiving palliative treatment following a cancer diagnosis that they "described different kinds of experiences with nature and related that in close proximity to nature they could find existential certainty in their existential uncertainty" (p.5).

- *Existential uncertainty is bound up with limitations and choice.*

Pascal and Endacott (2010) refer to existential angst as "a confrontation with the limitations of one's own mortality" (p.279), which mirrors Furtak's (2019) concern with the limitations of human existence. Furtak is more concerned with our persistent desire to be freed from "the cognitive limits that are a structural feature of the human condition" (p.383) than he is with the physical limits imposed by death. However the combination of physical limits and cognitive limits means both that choosing is necessary (which is to say we cannot physically choose every option that presents itself to our experience), and that we can't know for sure when choosing that we are making the right choice. In discussing the meanings of existential uncertainty for people living with cancer, Karlsson et al. (2014) report that "existential uncertainty had raised the question of what was important in [participants'] individual lives and promoted the insight that there is no point in wasting time on boring things – it was more important to *choose* things that were interesting and fun" (p.5, emphasis added). Penrod (2007) writes of "consciously choosing a path to meet a desired outcome" (p.663), and Hoffman (2009) refers to the choices one makes from the range of possible "ways to be" (p.1043). Ultimately, however, the necessity of choosing a way to be leads to uncertainty as to the *right* way to be.

3.1.3.2 Theoretical insights

Having established some of the commonalities between the various conceptualisations of existential uncertainty in the existing literature, I will now draw on insights from the more theoretically oriented literature to establish the extent of the concordance between these conceptualisations and established theory. I will begin by surveying some of the relevant principles underpinning the existential-phenomenological approach to therapy, before turning to the theoretical literature on uncertainty.

What does it mean to say that something is 'existential'? In spite of the frequency with which the word appears in the literature on existential uncertainty, scant attention is paid to its particular lexical properties. Even in the literature on existential therapy, Cohn (1997) bemoans "a rather imprecise and almost colloquial use of words like 'existential'" (p.vi). I found this lack of precision both curious and frustrating – how can its meaning be so much taken for granted when it is so far from clear? For this reason, I decided to begin this analysis by considering the properties of the word itself.

The basic definition of 'existential', according to the Oxford English Dictionary (2020), is: 'of or relating to existence; involving or relating to the existence of a thing.' The dictionary distinguishes between a general use, which is covered by this basic definition, and a more technical use, which is qualified in important ways: 'of, relating to, or concerned with individual human existence, esp. as seen from the point of view of existentialism; of, relating to, or characteristic of existentialism; having, or prompted by, a keen awareness of individual freedom and responsibility.' It would seem important to differentiate between the general use such as one sees in the phrase 'existential threat', referring straightforwardly to a threat to the existence of something, and the more technical and abstract use that is seen in a phrase like 'existential crisis', referring to a crisis that is concerned with individual existence *and* that is prompted by the givens of human existence, including freedom and responsibility.

For the purposes of this analysis, 'existential uncertainty' falls quite clearly into the technical category, concerned as it is with uncertainty relating to *human* existence. The implications of this are important. It means that the concept being analysed here encapsulates not just uncertainty *about* one's existence, but also uncertainty *prompted by* the particular nature of one's existence: Heidegger's being-in-the-world (Cohn, 1997; Cooper, 2003). In this sense, human existence is both the source and the object of existential uncertainty. In existential terms, there is no actual distinction between the two because they cannot be disentangled, and are perhaps more helpfully seen as two sides of the same coin – I am uncertain *about* my being-in-the-world *due to* the self-conscious nature of my being-in-the-world.

It is possible to draw parallels between this conceptualisation of existential uncertainty and ways of thinking about human concerns presented in the literature on existential therapy. Cohn (1997), drawing on Heidegger, distinguishes between ontic issues, which relate to "the specific individual ways in which each of us is in the world" (p.3), and ontological issues, which are concerned with "those intrinsic aspects of Being which are 'given' and unescapable" (ibid.). The interrelationship between existence as the source of our uncertainty and existence as the object of our uncertainty is reflected in the interrelationship between the ontological and the ontic, bound up as they are with one another. In a similar vein, in trying to tease out what distinguishes existential therapy from other forms of therapy, Spinelli (2015) draws attention to the thematic emphasis of many existential thinkers in the field, which implies that existential therapy is therapy *about* certain thematic existence concerns such as death, meaning, choice, etc. Spinelli is critical of this approach as it fails to distinguish existential therapy in any meaningful way from other modalities that would claim equally to concern themselves with such fundamentally human concerns. He suggests that "it is necessary to step beyond – or beneath – thematic existence concerns themselves and instead highlight the existential 'grounding' or *foundational Principles* from which they are being addressed" (p.10). In other words, just as ontic concerns must be addressed with ontological issues in mind, Spinelli argues that existential therapy needs to address existence concerns in a way that is intrinsically informed by the fundamental existential principles that set it apart from other therapeutic modalities.

Spinelli (2015) posits three foundational principles of existential therapy, which follow one from the other. These are: existential relatedness, uncertainty and existential anxiety. In challenging the Western view of the individual self as separate and boundaried, he argues that "it is only via its prior grounding in relatedness that the self's distinctive and unique sense of being becomes possible" (p.17). The fundamental nature of this relatedness gives rise to the principle of uncertainty, because it follows that:

> "…our reflections upon existence, be they in general or having to do with 'my own' existence, can no longer be held *solely* by me or exist in some way exclusively 'within' me. Instead, relatedness exposes the many uncertainties that impinge upon every attempt at reflection. The Principle of uncertainty asserts that I can never fully determine with complete and final certainty or control not only *what* will present itself as stimulus to my experience, but also *how* I will experience and respond to stimuli." (p.22)

Existential anxiety follows from the first two principles in the form of a "generally felt experience of incompleteness and perpetual potentiality which is expressive of an inherent openness to the unknown possibilities of life experience" (p.29). These three foundational principles are reflected in some of the recurring themes in the literature on existential uncertainty reviewed above, in particular the emphasis on relationality and on the openness of the future.

Another prominent feature of Spinelli's (2015) theoretical framework that has parallels in the literature on existential uncertainty is the concept of the worldview. In existential-phenomenological terms, Hayes and Adams (2019) describe worldview as "a synonym for both selfhood and meaning-creation. The worldview is the set of fundamental beliefs about self, others, and the world on which the individual seeks to base her life choices and actions." (p.162) The worldview acts as a way of structuring "the flow of experience and the activity of the human being in living in her relational world" (ibid.), which is termed worlding. Worlding is a process, characterised by instability, ambiguity and chaos, whereas the worldview is a more substantial entity, characterised by stability, identity and order. Spinelli writes (p.61): "If worlding offers us the certainty of uncertainty and the worldview provides us with uncertain certainties, then, together, worlding and worldview elicit *uncertain uncertainty*."

These ideas are relevant to this concept analysis for two main reasons. Firstly, they chime with the literature that focuses on the relationship between worldview, identity and existential uncertainty, most notably the work of terror management theorists such as Landau et al. (2012, p.131), who write: "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." Although there are differences in the way terror management theorists and existential therapists conceptualise 'worldview', their conceptualisations share an understanding of the worldview as a way of containing and making sense of our being-in-the-world, which inevitably presents us with challenges and threats.

Secondly, Spinelli's (2015) reference to "uncertain uncertainty" (p.61) points to the complexity of uncertainty as a phenomenon. He highlights the paradox that because uncertainty is so deeply embedded in the human experience, one cannot even be certain that something is uncertain – "there can only be uncertain certainties and uncertain uncertainties" (p.25). Spinelli's rejection of the dualism that pervades Western thought is expressed in his call for mutually exclusive polarities – certainty vs uncertainty – to be replaced with "mutually influencing continuum polarities" (p.14) – certainty and uncertainty co-existing in unified if paradoxical interrelation. This is consistent with certain conceptualisations in the literature identified in Strand 1, such as Parry's (2003) suggestion that "uncertainty and certainty might not be oppositional forces; instead, they might be dialectic, reflexive, and inextricably linked" (p.239). She argues that certainties can emerge from uncertainties, something that is supported by the Karlsson et al. (2014) study in which participants "related that in close proximity to nature they could find existential certainty in their existential uncertainty" (p.5). Nor should it be assumed that uncertainty is uniformly negative – as Hayes and Adams (2019) argue: "The unresolvable paradox of our situation is not a conclusion of defeatist passivity, but rather an acknowledgment that our impossible desire for certainty and solidity is the source of human activity and production, personal identity, and relationship." (p.157)

Perhaps the idea that we can experience certainty and uncertainty at the same time makes more sense when we take into account van Deurzen's (2012) existential framework, which sets out the four domains of the 'personal worldview' – the physical, the social, the personal and the spiritual/philosophical. Drawing on this framework, Gulbrandsen et al. (2016) propose that in the health context, attention needs to be paid to uncertainty around bodily needs, sense of belonging, views about self, and meaning. In medicine, bodily needs are (understandably) prioritised and an "ideology of uncertainty reduction" prevails (Babrow & Kline, 2000, p.1805). The fundamental problem with this approach is "the assumption that the successful management of uncertainty – and the most valid indicator of this outcome – consists of knowledge or care processes related to the provision or acquisition of information alone" (Han et al., 2011, p.10). As discussed above, the literature on existential uncertainty suggests that this aspect of uncertainty is not informational. In other words, traditional conceptualisations of uncertainty as being either epistemic, i.e. due to deficient knowledge, or aleatory, i.e. due to the irreducible randomness of events, may not take into account the particular nature of existential uncertainty, concerned as it seems to be with meaning. While it may work to use a medico-scientific discourse to address bodily needs, this may not be sufficient to address the concerns captured by the other three domains in the van Deurzen framework, which are more focused on identity and meaning. This supports the literature that calls for the inclusion of alternative discourses in addressing existential uncertainty, e.g. Friberg & Öhlen (2007), Seppola-Edvardsen et al. (2016).

If existential uncertainty is not amenable to a medico-scientific discourse that is defined by the twin principles of knowledge generation and uncertainty reduction (Gordon, 2003), then the question is how one might better engage with the uncertainty relating to social, personal and spiritual domains. Before this question can begin to be answered, it is sensible to ask how uncertainties in the different domains are experienced. Earlier models of uncertainty such as Mishel's (1988, 1990) uncertainty in illness theory regard uncertainty as a cognitive state that results from an inability to define or categorise an event or to predict an outcome accurately. This may not be problematic in the physical domain where events are easier to identify and isolate, e.g. a scan or test may generate uncertainty around diagnosis, prognosis or treatment options, but it is less clear that uncertainty in the social, personal and spiritual domains is always event related. This is particularly relevant to the case of existential uncertainty, if it is true – as argued above – that the source of existential uncertainty is human existence rather than a specific event. Hilton's (1994) conceptualisation of uncertainty as "a cognitive perceptual state that ranges from a feeling of just less than surety to vagueness" (p.18) is broader than Mishel's, and importantly opens up the possibility that uncertainty can manifest as a feeling and not just as a cognitive state.

While there is no generally accepted, unifying theory that explains the relationship between uncertainty and affect, existing research has tended to focus on uncertainties that manifest within people's conscious awareness. In a recent review of this research, Anderson, Carleton, Diefenbach and Han (2019) acknowledge that there are different levels of awareness, and that "awareness of ignorance may occur at a preconscious or unconscious level" (p.2). They cite psychophysiological evidence, for example, suggesting that people have somatic responses in situations such as gambling that are intrinsically uncertain, and while more research is needed, the principle that uncertainty can exist at different levels of awareness provides some theoretical basis for the empirical studies discussed above, most notably Penrod's (2007) emphasis on precognitive sensations as well as cognitive evidence.

Summary

Step 3 of the analysis has shown that for the most part there is consistency in the literature in terms of the use of existential uncertainty as a concept – that is to say, there are not multiple conflicting uses of the concept. However, existing conceptualisations are vague and diffuse, with different researchers focusing on different dimensions of the concept, and no consensus on where it begins and ends, or on where it might sensibly be situated in terms of adjacent and related concepts. This lack of specificity undermines its utility.

3.1.4 Step 4: Defining attributes

Step 3 above gave an account of the immersion part of the immersion/crystallisation process (Borkan, 1999), i.e. reading and re-reading the texts and drawing out the commonalities, while in Step 4 below I will report my interpretations, which are derived from the intuitive crystallisations to which Step 3 gave rise. Although Step 3 took a broad view of the possible uses and meanings of existential uncertainty as a concept, encompassing interdisciplinary insights from fields such as politics, economics and anthropology that are not directly related to health, Step 4 will focus on how these insights can help us to understand the concept as it relates to health, and more specifically the Han et al. (2011) taxonomy. The sources supporting the defining attributes are listed separately for each attribute in Appendix 9.

According to the Phase 1 analysis, existential uncertainty is defined by the four attributes below, the first two of which are concerned with its focus, and the second two with its qualitative properties. Existential uncertainty involves:

i. The undetermined but finite nature of one’s own being-in-the-world
ii. Identity, meaning and choice
iii. An awareness that is fundamental, ineradicable and always available
iv. Manifestation at different levels of awareness

i. The undetermined but finite nature of one’s own being-in-the-world

Existential uncertainty encompasses an awareness of unknown unknowns and of unknown knowns (Daase & Kessler, 2007). The former involves an awareness that our future is open and unknowable (Spinelli, 2015). The latter involves an awareness that certain death awaits us, even if we prefer not always to embrace this awareness in our day-to-day living (Landau et al., 2010).

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 in the physical, 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 therefore a much broader concept than uncertainty about physical death – existential uncertainty is really sparked by the question: how do I live when my survival is constantly under threat?

ii. 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 (Brothers, 2009; Spinelli, 2015). This means that existential uncertainty is about psychological as well as physical survival. Although the vast majority of the health literature that concerns itself with existential uncertainty is focused on conditions closely associated with physical death (most notably cancer and chest pain), it is plausible to suggest that existential uncertainty features in other conditions such as dementia that may be more closely associated with psychological death in the form of death of the self (Blandin, 2016). The question is: what does it mean to live *as me* in the world?

The question of how we fit into social systems (ranging from family to community to wider culture and society) is evident in discussions of identity in the literature on existential uncertainty. Our sense of individual or collective identity, and the worldview associated with it, help to give life meaning – when our identity or worldview 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” (Landau et al., 2010, p.198). 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.

iii. An awareness that is fundamental, ineradicable and always available

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. Penrod (2007) illustrates this by means of a distinction between situational uncertainty, which is specific to a particular event (e.g. a diagnostic test), and existential uncertainty, which is concerned with human existence *per se*. While existential uncertainty can be made salient by events, it is not created by them. A shock diagnosis or dire prognosis may lead to existential uncertainty, but such uncertainty is not conjured *ex nihilo* by the diagnosis or the prognosis – they merely bring to awareness something that was hitherto kept out of direct awareness: that our existence is undetermined and finite.

Our worldview is constantly being challenged by our direct experience, but if the worldview is sufficiently flexible and “receptive to the challenges of life experiences” (Spinelli, 2015, p.75), then it is able to maintain a balance between its own certainties and the uncertainties of everyday living. There are times, however, when our direct experience is so challenging to our worldview that it threatens to overwhelm it, and this is when existential uncertainty is experienced as “an abrupt discontinuity with the past and the anticipated future” (Cohen, 1993, p.80).

Sometimes we cannot regain our prior equilibrium, and we must grapple with the implications of our new awareness: what does it mean to live with unanswerable questions?

iv. Manifestation at different levels of awareness

Whereas most aspects of uncertainty are conceptualised as conscious, cognitive phenomena (Anderson et al., 2019), existential uncertainty can manifest at different levels of awareness, ranging from bodily sensations (Penrod, 2007; van den Bos, 2009) to cognitive elaboration (Cohen, 1993; Hoffman, 2009).

Other forms of uncertainty in the Han et al. (2011) taxonomy are centred on the disease (diagnosis, prognosis, causal explanations, treatment recommendations) or on health care systems (structures of care, processes of care) and therefore amenable to a medico-scientific discourse, but 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. This is reflected in the empirical literature where people living with cancer talk about having “a completely different awareness” (Karlsson et al., 2014, p.6), or being “interested in the other things, not the disease itself” (Friberg & Öhlen, 2007, p.220). This suggests that existential uncertainty is not about what people know as much as how they know it. As one person 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.” (Karlsson et al., p.5)

3.1.5 Step 5: Antecedents and consequences

3.1.5.1 Antecedents

The antecedents of existential uncertainty are those conditions that are necessary in order for a person to experience existential uncertainty. 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 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. This could take the form of unusual somatic sensations (Meranius & Engstrom, 2015; Røysland & Friberg, 2016) or the receipt of a diagnosis, test result or prognosis that carry a reminder of the vulnerability of human existence (Gulbrandsen et al., 2016). It is plausible to suggest that this would be particularly relevant to diagnoses such as cancer (Karlsson et al., 2014) or to experiences such as unexplained chest pain (Røysland & Friberg, 2016) that may carry with them the perceived threat of physical death.

- The perception, conscious or subliminal, of a threat to one's worldview (Landau et al., 2010; Landau et al., 2012), including sense of identity (Karlsson et al., 2014). This may be relevant to diagnoses such as dementia that carry with them the threat of psychological death (Blandin, 2016), or diagnoses such as HIV that carry with them the threat of rejection and social alienation and therefore a threat to one's identity (Brashers, Neidig & Goldsmith, 2004). These suggestions are inevitably speculative until we have a firmer understanding of existential uncertainty.

3.1.5.2 Consequences

The main consequence of existential uncertainty is anxiety, as argued by Spinelli (2015) and by Landau et al. (2012), who propose that "existential uncertainty – uncertainty about how, and whether it is possible to, achieve a significant life – is particularly threatening because certain belief in life's significance serves as a shield against anxiety-arousing thoughts of death" (p132).

Other consequences of existential uncertainty are:

- A sense of vulnerability – Gulbrandsen et al. (2016) write that "the existential journey of becoming ill may typically start with a perception of uncertainty, and proceed with recognition of being vulnerable" (p1506), which is echoed by Sperry (2016), Røysland et al. (2016) and Belpame et al. (2019).

- An attempt to incorporate the threatening event or experience into a recalibrated worldview (Spinelli, 2015). If successful, this attempt may lead to a new awareness or a fresh sense of meaning (Karlsson et al., 2014; Parry, 2003; Pascal & Endacott, 2010). If it is not successful, it may lead to disorganisation and despair (Cohen, 1993; Mishel, 1990; Grech & Marks, 2017).

When considering the antecedents and consequences of existential uncertainty, it is necessary to offer two caveats. Firstly, because this is the first known concept analysis of existential uncertainty, the proposed antecedents and consequences are most tentative and provisional. Secondly, it is perhaps harder with existential uncertainty to pinpoint discrete antecedents and consequences than it is with concepts that have a more physical or behavioural (and therefore observable) dimension. For example, it is arguably clearer to see in the case of ‘healing’ that “brokenness” precedes it and “the realization of wholeness” follows it (Firth et al., 2015, p.47) than it is in the case of existential uncertainty to identify what goes before and what comes after. This is because existential uncertainty does not ‘take place’ – it is, as argued above, ineradicable and always available to our awareness. It is important therefore not to see the antecedents and consequences proposed above as a causal chain, but more as a description of circumstances in which existential uncertainty is likely to manifest as “an interweaving of thought, feeling and action” (Spinelli, 2015, p.66).

3.1.6 Step 6: Empirical referents

Walker and Avant (2019) describe empirical referents as “classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself” (p.179). Although empirical referents can in some cases be the same as the defining attributes, when the concept and its defining attributes are abstract (as in the case of existential uncertainty), it is necessary to specify empirical referents that relate to the defining attributes so that the concept can be recognised. The purpose of identifying empirical referents is to detect the presence of the defining attributes, not to measure the concept.

There are two possible ways of detecting the defining attributes of existential uncertainty. One is by asking a person who is thought to be experiencing uncertainty relevant questions using probes corresponding to the four defining attributes, e.g.

- ‘How confident are you that you know what’s ahead of you?’
- ‘How do you see yourself in the future?’
- ‘What questions would you most like to know the answer to?’
- ‘How do you know when you are experiencing uncertainty?’

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. Due to the highly subjective nature of the defining attributes, concerned as they are with the unknown and meaning in life, these questions would be better suited to an interview setting than a questionnaire.

A second way of detecting the presence of existential uncertainty in someone is by observing them in conversation with others, most obviously with their medical team (if they are under the care of a team). If they present in a way that tallies with the defining attributes, e.g. if they ask persistent questions about their treatment plan and prognosis, if they are dissatisfied with the answers they receive, and if they seem agitated, 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.

These two approaches to specifying empirical referents are informed by Meize-Grochowski's (1984) concept analysis of trust, and by Firth et al.'s (2015) concept analysis of healing.

3.1.7 Step 7: Model case

Cases in concept analysis are not case studies of individuals (as often in the psychological literature), but concrete examples of concepts that help to clarify what the concept of interest is (as in 'model case') and is not (as in 'borderline case', 'related case', 'contrary case'). The cases outlined in the following sections are taken from one woman's autobiographical account (in book form) of her cancer experience (Carr, 2004). Kate Carr was diagnosed with breast cancer in 1997 and died in 2004, two days before the publication of the book (Lott, 2004). The justification for choosing this book as the source for the cases in this analysis is that it provides an in-depth and nuanced account of the uncertainty associated with one person's cancer experience, and the complex dynamics of that experience. The centrality of uncertainty to Kate's experience is captured by the opening line of the book: "By the time you read this book, I may be dead. Or dying. On the other hand, I may be just fine. The thing is, you see, I don't know for sure." (p.1)

Cases have no claim to representativeness, so there is no problem with the use of a single individual's account of her unique experience. It is, in fact, plausible to suggest that case material sourced from outside of the scientific literature has the advantage of being less susceptible to demand characteristics than participant quotes used by researchers in the literature (which could equally provide cases for a concept analysis). The existence of Carr's

(2004) book was brought to my attention by a citation in a concept analysis of cancer survivorship (Doyle, 2008).

The model case is “a pure case of the concept, a paradigmatic example” (Walker & Avant, 2019, p.174). The following passage from Carr (2004) describes an exchange she 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.” (p.106)

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” (asked and then repeated twice) 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” (p.94) – suggesting a loss of meaning. Her desire to hear the doctor tell her something she knew he never could, because “the facts got in the way”, constitutes a painful acknowledgment of the ineradicable presence of existential uncertainty in her being-in-the-world. This also conveys 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”.

The fact that Kate looked away from the doctor as she asked if she would be okay also suggests that the question was something other than a request for information – averting her gaze may indicate a felt sense within her that his answer was not going to dispel the uncertainty she was feeling. The fact that the uncertainty is captured here in the form of an exchange between Kate and her oncologist is consistent with the conceptualisation of existential uncertainty as an intrinsically relational concept focused on Kate’s own being-in-the-world.

3.1.8 Step 8: Other cases

3.1.8.1 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 idea is that the inconsistency in the borderline case helps to clarify why the model case is not inconsistent.

> “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.” (p.58-9)

As I see it, this is a borderline case between existential uncertainty and psycho-social uncertainty, which is an adjacent concept in the Han et al. (2011) taxonomy. 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, as she writes of one question *lurking* behind another. It is relational in the sense that it is concerned with the relationships in her life. 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”. In this sense, they may veer more towards the practical uncertainty that characterises uncertainty around structures of care and processes of care within the Han et al. taxonomy. Furthermore the uncertainties are more focused on others than on her own being-in-the-world, which arguably makes them psycho-social rather than existential. However, 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 concepts within the taxonomy, an issue that will be addressed more fully in Phases 2 and 3 of the analysis.

3.1.8.2 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. I chose prognostic uncertainty here because it shares with existential uncertainty a concern with future possibilities – Christakis (1999) refers to prognostication as a “well calibrated best guess about the patient’s future”. In the following exchange between Kate and one of her doctors, she asks about the ability of ‘cancer diets’ such as the Gerson regimen 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.*” (p.75)

The final line in this excerpt encapsulates the difference between prognostic uncertainty and existential uncertainty – prognostic uncertainty is a form of scientific uncertainty concerned with the outcome of a disease and predicated on a conceptualisation of disease as “generic and generally independent of its expression in an individual” (Christakis, 1999, p.4), whereas existential uncertainty is a form of personal uncertainty concerned with the survival of a person. In time, the accuracy of a prognosis can be determined – Kate’s death in 2004 made it possible to judge the accuracy of whatever her prognosis was, eliminating the uncertainty. As Christakis puts it: “After the fact, a particular outcome may be observed, and we may speak of a ‘realized prognosis’ – as when physicians say, ‘His prognosis was good, but he died anyway; the prognosis turned out to be bad’.” (p.20) As existential uncertainty is concerned with meaning, it does not make sense to consider its accuracy, and whatever existential uncertainty Kate experienced before death was not resolved as such on her death – she just ceased (presumably) to experience it.

3.1.8.3 Contrary case

A contrary case is a case that is relevant to the concept in question, but clearly not an example of that concept. Identifying a contrary case helps to delineate the boundaries of the concept of interest by highlighting what it is not.

> “After the scan, I was told to make an appointment with Mr Sinnett to get the results. I said I wanted them. Now. They said that wasn’t how it worked. I said I wasn’t leaving until I got them. The head of the unit came in and said the protocol was that Mr Sinnett would tell me the results. I said I knew he had looked at the scan, knew what was on it and I wanted the results.” (p.149-50)

This is a straightforward case of epistemic uncertainty, corresponding most closely to diagnostic uncertainty in the Han et al. (2011) taxonomy – the fact that the results of the scan were knowable but unknown to Kate generated an uncertainty that could be eliminated by providing her with the results of the scan. Other aspects of uncertainty (including existential) may emerge following disclosure of the results of the scan, but at this point in time, the uncertainty seems to be purely informational.

3.1.9 Conceptualisation

Drawing on the eight steps of the concept analysis presented above, I developed the following (tentative but theoretically-informed) initial conceptualisation of existential uncertainty:

> 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?

While I was satisfied that this conceptualisation captured the defining attributes identified in the preceding analysis, I was also conscious of the possibility that my desire to impose order and structure on the concept might have led me to produce a definition that was *too* neat and didn’t take enough account of the complexity and multi-faceted nature of existential uncertainty. I had two responses to this. One was to remind myself that concepts are reductive by nature inasmuch as they are a way for us to simplify the dizzying complexity of experience in order to get a handle on it, whether in a concrete or a figurative sense. The second was to remind myself that this conceptualisation was a way of looking at existential uncertainty and was not making a claim to any ‘absolute truth’ (see Methodology 2.1.3). It was therefore open to challenge and revision, and I welcomed the opportunity that would be afforded by Phase 2 of the research to do both of those things – to use participants’ accounts of their cancer-related uncertainty to challenge and revise this conceptualisation.

3.2 Phase 2 – analysis of interviews

Having established an initial conceptualisation of existential uncertainty in Phase 1 of the analysis, I will present in Phase 2 the results of the thematic analysis of six semi-structured interviews in which individuals living with cancer talked about the uncertainty related to their experience. I will focus first on my interpretation of what the interviews tell us about existential uncertainty itself, before turning my attention to the relationship between existential uncertainty and the other aspects of uncertainty in the Han et al. (2011) taxonomy. I will confine myself in this phase of the analysis to the interview data. Phase 3 of the analysis will address in greater depth how the interview data might be synthesised with the Phase 1 conceptualisation and the literature on which it was based.

Before setting out the results of the thematic analysis, I would like to begin by offering some reflections on the process of coding and chunking the interviews (Crabtree & Miller, 1999), and on the immersion/crystallisation process (Borkan, 1999) that happened concurrently – see Methodology section above for an explication of these processes. For clarity, I will use data drawn from one interview (the interview with Sam) to illustrate the points I am making, which are pertinent to the interviews in general.

3.2.1 Reflections on the analytic process

The codes specified in the coding manual seemed to do an adequate job of covering the different aspects of uncertainty that the participants highlighted in their interviews. Each of the eight codes was used in the coding, although participants talked more about issues of personal uncertainty (existential, psycho-social) and practical uncertainty (processes of care, structures of care) than issues of scientific uncertainty. This is not unexpected given the suggestion that "[p]ractical and existential uncertainties […] may be more important to patients than uncertainties surrounding scientific information" (Han et al., 2011, p.833). Within the context of scientific uncertainty, participants seemed more concerned about uncertainty around treatment, diagnosis and prognosis than uncertainty around causal explanations. These impressions are supported by the table in Appendix 10, which lists the number of words corresponding to each of the eight codes once the chunking process was complete.

It is interesting (if unsurprising) to note that aspects of uncertainty that are adjacent in the taxonomy were often adjacent in the coded interviews. For example, the section of coded interview reproduced in Appendix 11 shows Sam cycling between existential uncertainty and psycho-social uncertainty as they talked about cancer making them re-evaluate themselves (existential), then feeling like nobody is going to want to put up with the cancer in the dating context (psycho-social), then trying to figure out how the cancer intersects with their non-binary identity and their body (existential), then having to deal with other people's perceptions of what a cancer patient should look like (psycho-social), before returning to the question of how the different aspects of their being fit together (existential). Coding a section like this is not straightforward, as although the taxonomy – categorical by nature – must draw clear lines between concepts, people's experience of uncertainty is a much more fluid affair. This means that the coding manual is inevitably seeking to impose a neat structure on a phenomenon that is anything but neat. There are strong pragmatic reasons for developing such a structure (see Methodology section), but as this example shows, the boundaries between the concepts that make up this structure are not clear cut.

The degree to which the concepts within the taxonomy are interwoven with one another is evident in the section of coded interview reproduced in Appendix 12, in which Sam moves swiftly between existential uncertainty, uncertainty around treatment, diagnostic uncertainty, uncertainty around causal explanations, uncertainty around structures of care and uncertainty around processes of care before returning to existential uncertainty. In spite of the fact that Sam is cycling rapidly through different aspects of uncertainty, there is a fluidity to this passage that acts as a reminder that although the taxonomy on which the coding manual is based conceptualises ‘global’ uncertainty as encapsulating different aspects of uncertainty, this is not to suggest that uncertainty is fractured along these lines in people’s actual experience. In other words, there is no suggestion that people are in experiential terms actually *switching* between different aspects of uncertainty.

It is important to emphasise that this coding strategy is not attempting to capture the *experience* of uncertainty (as one would expect if the research were phenomenological rather than conceptual), but rather the *meaning structure* of uncertainty. In other words, the aim of the coding strategy is not to explore how the participants experience uncertainty, but more how they *makes sense* of their uncertainty experience, and ultimately what this means for them. What the coding captures is the different aspects of uncertainty that they draw on in their attempts to make meaning of their cancer-related uncertainty. The conceptual rather than phenomenological nature of the research accounts for the inclusion in the analysis of transcript data that is not concerned with the direct experience of uncertainty. For example, at one point Sam says:

> ‘I think in order to generate hope, you have to have a certain level of stability and comfort to daydream these positive things, and when you don't have that, your brain works very differently, like, you know, when you're in survival mode, that's all you can think about.’

Sam is not describing the experience of uncertainty here, but rather saying something about their understanding of existential uncertainty (presumably *derived from* their experience), which is concerned with the undetermined (‘generate hope’) but finite (‘survival mode’) nature of their being-in-the-world and the necessity of making meaning from this (‘daydream these positive things’).

Nevertheless, the decision to include such passages (where uncertainty is not explicitly mentioned) in the coding and chunking phase required some deliberation. I adopted an inclusive strategy in the analytic process, in particular at the coding and chunking stage, with the following justifications in mind:

- Given the assumption underpinning this research is that uncertainty pervades human existence at the most fundamental level (Spinelli, 2015), it is reasonable to argue that uncertainty can be discerned in almost every utterance participants made in their interviews, the topic of which was the uncertainty they experienced in relation to their cancer.

- While there are many passages in the interviews where participants were not speaking explicitly about uncertainty and where one could wonder whether they weren't really just describing their *experience of* or *thoughts about* diagnosis, prognosis, treatment, etc. rather than their *uncertainty* in respect of these things, I believe that uncertainty was evident at a latent level. For example, Sam offered the following reflections on their approach to appointments:

  > '…in the beginning as well you're just a sponge, you just absorb all of these, eh, ideas and names of drugs and treatments and all this information around you from all these multiple doctors because you're seeing a lot of doctors at once and it's all very new, so you have to kind of just soak it all up and kind of process it later.'

  I coded this as processes of care, where the operative question is: what role do I play in my care? Although Sam was not explicitly saying 'I felt uncertain about what role I needed to play in my care', I would suggest that 'it's all very new' points to a level of uncertainty – novelty and uncertainty go hand in hand, as when something is new, we must spend some time *getting to know* that thing, during which time we inevitably experience uncertainty; and secondly, 'in the beginning' implies a contrast with a later time, which suggests change, and change is invariably linked with uncertainty (Spinelli, 2015).

- Instances where participants talked about certainty were still coded as uncertainty (usually with a minus symbol to denote a contrast) because statements of certainty are never absolute – they are always made in relation to *un*certainty. As Spinelli (2015) writes: "there can only be uncertain certainties and uncertain uncertainties." (p.25) For example, Sam talked about their early experience of cancer and 'all these kind of morsels of that certainty idea' – they referred to 'a certainty that things would be okay in the end', 'that kind of dangling carrot of like this is where we're going to get to, almost everybody gets there, we're not worried about you, you're young, we caught it early', etc. Although most of this passage is concerned with certainty, it is interwoven with expressions of uncertainty – 'like in the back of my mind there was like well maybe not, you know, it's cancer', 'for it not to go down that suggested path has been tricky'.

For these reasons, the vast majority of the interview transcripts were coded as some aspect of uncertainty. An advantage of such an inclusive approach is that it does not foreclose aspects of the participants' meaning structure that might not be immediately obvious to me at the coding stage. To excise sections of text prematurely would risk skewing the analysis in favour of my theoretical understanding of uncertainty at the expense of participants' perspectives. Although remaining open to the potential value of sections of text that did not address uncertainty directly prolonged my own sense of uncertainty, I felt it was necessary from an ethical standpoint to remain open to meanings and connections that might emerge once the interviews had been chunked and coded sections had been gathered together.

A disadvantage of a coding strategy that discerns uncertainty in almost every statement participants made is that uncertainty risks ending up as an undifferentiated and amorphous universal – if everything is an expression of uncertainty, then how meaningful or useful is it as a concept? The challenge for this research was to decide when the uncertainty that could be said to underpin a statement is *useful* for helping us to understand the meaning structure of uncertainty. The analytic strategy had two safeguards built into it to prevent uncertainty becoming an inconsequential universal: firstly, the taxonomy itself is predicated on the assumption that there are different aspects of uncertainty, and this ensures differentiation (as it's not enough simply to identify 'uncertainty' – I had to decide which *aspect* of uncertainty is being invoked); secondly, although the coding stage of the analysis was characterised by a broad, inclusive approach, some sections of text were excluded at a later stage – once coded sections had been chunked and gathered together in one place – if the relevance to the particular aspect of uncertainty of which they were originally deemed a potential instance remained obscure to me when viewed in the context of other, clearer instances of that aspect. For example, I initially coded the following section of my interview with Sam as 'processes of care':

> '…normally what they'll do is they'll do the blood tests and e-mail them to me so I get to see them before my next appointment because the system is very weird, I have to go in and get them done because they can only be done there, but they take a week to ten days to process, so I go in for an appointment, talk about whatever, but it's not really that useful because we don't have my bloods to look at, very strange, so luckily they always e-mail them to me.'

However, when I read this in the context of other sections of text coded 'processes of care', it was clear to me that although Sam was describing the process of having their blood checked, they were offering a factual account of the process itself and not revealing anything useful about the uncertainty associated with it. I therefore excluded it from the final stage of the analysis.

While the coding stage of the immersion/crystallisation process was concerned with identifying broadly *what* the participants were talking about, i.e. which of the different aspects of uncertainty they were talking about, the later stage was concerned with *how* they were talking about it, i.e. the different discourses (vocabularies and their associated conceptual frameworks) on which they drew when constructing and engaging with each aspect. It was important to consider the *how* as well as the *what* since the crystallisations would form the basis for the defining attributes of the different aspects of uncertainty, and these defining attributes needed to include how the different aspects were constructed and positioned by participants. In other words, it is of central relevance to the concept of existential uncertainty if participants talked about it in terms of 'scientific ignorance' or in terms of 'a fundamental mystery' or in terms of something else again. This type of analysis required a more interpretative approach, as I drew out what I saw as the commonalities and distinctions between the six participants' accounts in a bid to develop a meaning structure that would be consistent with those accounts. The biggest challenge of this part of the analysis for me was balancing the "risks of either prematurely drawing conclusions or, conversely, being unable to reach closure, frozen in indecision as to what the data mean" (Borkan, 1999, p.191). As I read and re-read the chunked texts, I made notes in the margins of key words that seemed significant to me (see sample in Appendix 13), which I then gathered together and rationalised into themes. These themes became the attributes of the different aspects of uncertainty that I report below.

The overall process was theory driven – deliberately and unavoidably so – in that it was structured by the aspects of uncertainty specified in the Han et al. (2011) taxonomy and influenced by the defining attributes proposed in Phase 1. However, I made a conscious effort not to use the interview data simply as a means to confirm the Phase 1 conceptualisation, but rather to look for and welcome data that might offer fresh and unexpected insights. As themes began to crystallise in my mind, I tried to remain open to dimensions of the data that did not fit so neatly with the existing literature and/or the Phase 1 conceptualisation.

Having offered these reflections on the analytic process itself, I will now discuss the results of the analysis. I will begin by setting out the attributes of existential uncertainty yielded by the analysis, with quotes to substantiate them. I will then proceed to compare these attributes to the attributes of other aspects of uncertainty as a means of clarifying the concept of existential uncertainty.

3.2.2 Existential uncertainty – attributes

According to the Phase 2 analysis, existential uncertainty involves the following six attributes:

i. An undetermined future
ii. Questions of control and agency
iii. Identity and meaning
iv. Living with the spectre of dying
v. An intrusion into awareness
vi. Embodiment

What follows is a discussion of each of these attributes in turn, supported by quotes from participants' interviews.

i. An undetermined future

The cancer seemed to bring home to participants that the future was unknown. Liz said of the uncertainty around her cancer:

> 'I suppose it makes you appreciate that 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…'

Jane, for whom music was an important part of family life, had a specific concern about the future:

> 'I've got a nine-month-old grandson, and, who loves to make music... noise... and my thoughts were wouldn't it be lovely to see if he developed and had those same sort of interests, so I think the uncertainty is I might not be here to see it, you know.'

This uncertainty seemed to challenge certain assumptions that she had previously held about her future:

> 'I think the difficulty accepting it is, is because of [my genetics and my family], I had assumed we would go into our seven… sixties, seventies, pretty healthy. That's not to say I won't be, you know, I feel fine, you know.'

The idea that cancer interferes with assumptions previously held is articulated by Sam too, who said of people who are *not* living with cancer:

> ‘…there's this kind of field of, eh, invincibility around you mentally cos you don't think you're going to get sick, no one thinks they're going to get sick, you know, nobody takes preventive medicine seriously, no one...’

Of their own situation, however, Sam said:

> ‘…my questions are based in the idea of a timeline that you obviously can't access, like, where are we going to go? And, and I think maybe before all of the experiences I've had with my disease and treatment, I probably would have thought those kind of questions could be entertained.’

Here Sam seems to be pointing to an appreciation of the unknowability of the future that has come with the cancer. Jim put it in stark terms when he said:

> ‘…life is uncertain, everything in life is uncertain, you never know, even with, eh, things, oh, that's a certainty, nothing is, nothing is one hundred per cent certain, apart from death, so there's everything that you do in life has got some form of uncertainty…’

ii. Questions of control and agency

Many of the participants were preoccupied by questions of control and agency, both in terms of their cancer experience but also more generally in life. For example, Liz said of her cancer experience:

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

Jane too talked about her irritation at having been diagnosed with cancer in spite of the efforts she made to live a healthy life:

> ‘…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, and I think that's, that's the being annoyed thing, angry is probably too strong, irritated is more the..., how dare it, you know, when I've done all of this…’

Eddie seemed to take a more fatalistic stance when he said:

> '…it's just destiny almost, innit. It's what's, what, what, what is, you know, down to happen to you, em, you've just got to live with it cos you can't change it.'

In a similar vein, Brian talked about the 'bottomless dread' he feels when he goes to receive the results of the regular blood test that measures the level of prostate-specific antigen (PSA) in his blood:

> '…cos there's nothing, nothing, there's nothing I can do about it, I can't, there's nothing I can change in my life that would make it more likely that, that I'll have a good result or less likely I'll have a good result, it's completely out of my hands.'

The question of agency was also picked up by Jim when talking about his decision to have hormone treatment for his prostate cancer:

> 'I think because I went into it voluntarily, it was my decision to do it, it didn't mentally affect me say as bad as like the chemical castration of Alan Turing did, where his was forced upon him mentally, I suspect it really screwed his head because it wasn't his choice, with me it was my choice, I'd made a considered decision to do that, and it made it easier for me to deal with…'

iii. Identity and meaning

Brian was grappling with the question of identity, specifically his identity as a man now that he no longer gets erections naturally following the treatment for prostate cancer:

> '…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…'

For Jane, the cancer experience had implications for her sense of herself as a mother:

> '…why can't I manage this? I think because I've got my boys worrying about me now, whereas it's my job to worry about them, you never stop being a mum…'

While Sam felt that ‘in some ways cancer makes you sort of re-evaluate who you are’, and that they had become a ‘very different person’ following their diagnosis, it was important for them to find meaning in their experience. They reported:

> ‘…just thinking like, okay, well let's use the time and energy I have, let's use the privilege I have to open doors for other people, 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, and not in some sense of grand design, but just, it would be, I think it would be a waste if I was to go through all of this bad stuff and just sit at home and feel bad for myself…’

Meanwhile for Jim, who had been living with his wife even though the marriage was over and he had come out as gay, the cancer experience helped to clarify what was important to him in life. He ended up moving out and embarking on a new relationship with a man:

> ‘…the whole experience has really sort of helped me, em, organise my life, you know, a lot better. It's not that I don't get anxious about things still, but, em, you know, I do, I hope I deal with things, em, a lot better, you know, than eh, I used to.’

For some participants, this aspect of existential uncertainty seemed to extend beyond individual identity and meaning. Liz brought to the interview a photograph of herself at a march in protest at the Brexit referendum result as an object that was associated with her cancer-related uncertainty. She became 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.’

I understood the association Liz made between the day at the march and her cancer experience as one of contrast – that while the previous year had been characterised by existential uncertainty, she one day found herself on the march *not* experiencing this existential uncertainty. I interpreted the sense of belonging and common purpose evoked by the image of Liz ensconced in a crowd of like-minded people all heading in the same direction to indicate that questions of identity and meaning were part of the existential uncertainty she had experienced over the previous year.

Liz's mention of music and singing echoed the importance of music in Eddie's account of his cancer experience too. One of the objects he brought to the interview was a music CD. For him, 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.'

It is perhaps significant that, although he is a rock music lover, two of the examples he namechecks are Vera Lynn and Land of Hope and Glory which, for many, capture something of the quintessence of the British spirit in the twentieth century, and therefore reflect an aspect of the British national identity. These examples may point to an association between existential uncertainty and the feeling of connection with (or disconnection from) something transcendent, whether that be a political movement or a shared cultural heritage, and the meaning with which these are imbued.

iv. Living with the spectre of dying

Dying was an issue that most participants raised, and the impact this had on their day-to-day living. Eddie said that 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, em, but I suppose before the diagnosis, it would have been a flippant remark, well everybody's got to die sometime, whereas now since the diagnosis, thinking about it, yeah, and it could happen

> sooner rather than later, em, and that does, that is there's certainly an element of uncertainty that you get which influences the life-changing decisions that you make or even your life decisions.’

Brian was clear that his concern was about quality of life and the fear of prostate cancer returning and leaving him in ‘a more diminished state’, not about death *per se*:

> ‘I'm not particularly bothered about being dead, if that makes sense, a bit difficult to describe to people who say yeah but you're alive, but if I was dead I wouldn't care about it, em, so, em, cos I'm an atheist, I don't, if you're dead, you're dead, that's it, I have no, no fear of it at all, em, but I wouldn't like an unpleasant, the act of dying I wouldn't like to be unpleasant, yeah?’

Sam talked about the effect of knowing ‘what is probably going to be 90 per cent chance will be the thing’ that kills them, and being reminded of this every day when they take their medication. For Sam:

> ‘…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…’

For Jim, the fact that we will all die someday seemed to offer a kind of solace, not just in terms of his own death, but the deaths of others too:

> ‘…you know, life, you never get, you know, something you don't get out of alive, you know, you, everybody is going to die, and it, it helps me also deal with deaths in the family, when my parents died, when my son committed suicide, em, you know, death, death is all around us, you know, and, you know, you know you're going to die, why worry about it?’

v. An intrusion into awareness

Participants talked about the intrusion of cancer into their awareness, both at the time of the diagnosis and in an ongoing way. Liz went to her GP after she found a lump in one of her breasts. She said:

> ‘…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, and I've always been a really healthy person, but now I suppose it makes me think, ah, it can happen again, it's happened once, it maybe can happen again…’

The fact that she is not invincible ‘hit’ Jane when she was diagnosed, but the cancer continues to come to her awareness even now that she has been treated:

> ‘And I think it's kind of hit me with this, em, you know, 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, you know what I mean…’

Brian talked about the fact that when he sees someone attractive in the street now, he immediately has the thought that they are off limits to him because of the erectile dysfunction he has experienced since the treatment. He said:

> ‘…the emotions hit me, and that, that just stays there, that, ‘til it, ‘til it sort of wears off […] it's emotion of loss, em, yeah? And em, eh, being, being less than, less than I was, yeah? Yeah. So it's quite odd.’

Eddie talked about the feeling that emerges when he’s listening to music as coming ‘out of the blue […] it just sort of hits, hits a nerve’. Later in the interview, he said:

> ‘I don't think about cancer very often, so I almost forget I've got it and it's only when I realise that other people [in the support group] have had a bit of bad news on their visits and then it's had the change or even worse, you know, it's got worse and they can't offer anything anymore, it comes home as a, if you like, a warning sign to say, well look, just remember, you have got this.’

vi. Embodiment

Liz described breast cancer as ‘quite a disfiguring thing, all about your body image anyway’. She seemed surprised by her response to the loss of her hair and the doubts she had around whether it would grow back to how it was before the treatment. She said:

> ‘…I always thought that I would cope okay with being bald, but honestly for me that was the worst bit of it, that was the worst bit of the whole experience really, em, I kept a turban on 24 hours a day, seven days a week, I could not stand looking at my bald head…’

She also described feeling a physical pain in the week between having biopsies done on her breasts and lymph nodes, and receiving the results:

> '…so that's when the uncertainty started, and I did get my results, it was just under a week, and that week I got such physical pain, em, like I've never had. I got pain under my ribs, like in my liver, I got pain in my head, very, very physical pain…'

Once she received the results of the biopsies and was assured that her cancer was treatable, she said 'it was like this huge weight went from me', and she never experienced the pain again. She wonders now whether the pain was a manifestation of her stress and anxiety.

For Sam too, weight is a defining quality of the bodily experience associated with 'larger scope questions of, you know, am I going to be alright'. They said:

> '…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.'

When asked whether they could locate feelings of uncertainty in their body, participants often referenced the stomach. Liz talked about 'that sinking feeling in your tummy', Sam said 'you kind of feel like the pit of your stomach kind of go', while Brian also referred to that 'pit-in-the-stomach feeling' he would get when he was weighing up the effects that the different treatment options would have on his life – he described it as 'hollow, empty and leaden'.

The fact that Brian's 'pit-in-the-stomach feeling' was associated with the choice he had to make among treatment options raises a key question for this research: what distinguishes existential uncertainty from other aspects of uncertainty, such as uncertainty about treatment? I will address this question in the next section by exploring some of the themes that I drew from passages coded as other aspects of uncertainty and suggesting how these might help to delineate existential uncertainty as a concept.

3.2.3 Existential uncertainty – relationship with other aspects of uncertainty

As space precludes a full exploration of all the different aspects of uncertainty in the taxonomy and their associated themes (see Appendix 14), I will focus in this section on what in Phase 1 I called borderline cases – in other words, cases in which some of the attributes of existential uncertainty are present but which are also somehow different from existential uncertainty. My reason for this is that borderline cases are more likely to yield insights into the borders between existential uncertainty and other aspects of uncertainty than *unambiguous* cases of other aspects of uncertainty.

I will focus specifically on prognostic uncertainty and psycho-social uncertainty since these are arguably the two aspects of uncertainty that overlap most with existential uncertainty (see Step 8 of Phase 1), explicitly concerned as they are with the future course of the disease and with relationships respectively. However, I will begin by offering some reflections on treatment uncertainty, as I think this suggests an important distinction between existential uncertainty and other aspects of uncertainty in the taxonomy.

3.2.3.1 Existential uncertainty vs treatment uncertainty

I coded the passage in which Brian talked about the ‘pit-in-the-stomach feeling’ as both treatment uncertainty and existential uncertainty. I coded it as treatment uncertainty because the feeling was associated with the decision he had to make as to whether to have surgery or radiotherapy to treat the prostate cancer. However, it was not a straightforward matter of scientific uncertainty, as the following account of his interactions with his care team illustrates:

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

It seemed likely to me that the ‘pit-in-the-stomach feeling’ was associated with Brian’s need to reflect on what was *important* for him, i.e. the meaning of life, rather than uncertainty around the treatment itself. The radiologist and surgeon could reduce any uncertainty Brian had about side effects of treatment, for instance, by providing him with facts and data, but they couldn’t tell him what it would *mean* for him if he were to experience these side effects.

Side-effects and quality of life were aspects of the treatment that many participants spoke about. I would argue that these issues border on existential uncertainty insofar as they touch on the question of what makes life worth living. For example, Eddie described his thinking around tablets he was taking for his lung cancer:

> ‘…one of the side effects for these tablets was chronic, em, diarrhoea and it knocked me confidence cos I couldn't go out for fear of having an accident while I was out sort of thing and it took away me taste buds and me sense of smell, and I'm thinking to myself at the time, probably be, into me mind-set at that time, well is life really worth living anyway if it's going to be like this all the time?’

Jim also found himself questioning what was important in life when he had to choose between radiotherapy and hormone therapy for his prostate cancer:

> ‘…when I first said well I'll do the radiotherapy, I'd read what the side effects were, em, and the long-term sort of effects, and I'd read what the side effects were of the hormone treatment, what the long-term effects were for that, em, my heart, em, was saying well you want a sex life, em, and that, just go for the radiotherapy, the side effects are less effective, you know, not going to be as, em, bad for your sex life as the hormone treatments are, but then when the head kicks in, em, then it was a case of yes, but there's more to life than sex…’

As these quotes show, there is a close connection between treatment uncertainty (especially around side effects) and existential uncertainty – what do the (potential) side effects mean for the kind of life one wants to lead? As ever, it does not make sense to draw too sharp a distinction between the two aspects of uncertainty, but I would argue that treatment uncertainty might involve uncertainty about side-effects and the likelihood of their occurrence (and is therefore amenable to an informational intervention), whereas existential uncertainty involves questions about what these side-effects would *mean* for the kind of life the person wants to lead (which is a deeply personal matter and therefore not a question that medical professionals can answer, as Brian experienced above).

I would suggest that one way of distinguishing between existential uncertainty and the aspects of uncertainty classified as scientific is that the former is concerned with meaning while the latter are concerned with information. The informational quality of scientific uncertainty was evident not just in treatment uncertainty, but in uncertainty around diagnosis, prognosis and causal explanations too. For example, Jane told me how she wanted to speak to her consultant because she was not clear about an aspect of her diagnosis:

> ‘I have some more questions cos mine was a mixed tumour, so it was low grade with a focal point of high, and they told me that's fine we're just casting it as low grade and the more I've thought about it, the more I've got questions which the nurse couldn't answer. Being a pharmacist myself, I can read the papers and understand them, and I know it's subjective, so I just have some questions, em, not necessarily a second opinion, just have some questions, so all of that I feel is uncertain.’

It is reasonable to imagine that Jane’s consultant could give her information as to why the cancer was cast as low grade, which would have reduced that aspect of her uncertainty. This was not a question of meaning for Jane.

3.2.3.2 Existential uncertainty vs prognostic uncertainty

Prognostic uncertainty is related to treatment uncertainty inasmuch as prognosis describes the course of a disease, which treatment is intended to influence. I drew three themes from interview passages coded as prognostic uncertainty.

(i) Time and death

For many participants, prognosis was tied up with notions of time and death. When Liz thought she had secondary breast cancer, the question on her mind was how long it would take her to die. Jane talked about ‘seeing it was a lump and thinking the worst, and I was going to be dead in five years’. Sam expressed doubt that they would still be alive in ten years:

> ‘I don't really think I'm going to make it into my forties, I'd like to, I'm 32 now, but, you know, I've gone through treatment after treatment after treatment, we're running out of treatments, the longer that it is detectable in your blood, the more likely there's a mutation which is treatment resistant…’

Brian referred to his regular PSA tests as ‘that sort of sword of Damocles’ that makes him wonder how many years he has left, while Jim remembered asking his doctor ‘a very simple question – how long will I live if I don't have treatment?’ It was a comment that Eddie made, however, that seemed to me to point towards a potential distinction between prognostic uncertainty and existential uncertainty:

> ‘The biggest question I would ask is the one I was afraid of asking, was how long have I got. Really. Because it's, it's like everything, innit, if you're at work and you need to develop a project, and the first question you ask is, how long have I got to develop it, and then it'll come along, well what's the investment, what resources can I have, em, you

> know, and everything else. If I'm looking towards dealing with an illness, it's the same thing – how long have I got? Cos that'll help me decide whether I take early pension and get the caravan or, you know, we sell up the house and downsize, em, or whatever we do with our lives. And from a practical side of things, that's what I should have known, but from an emotional side of things, I didn't really want to know or ask that question.'

I think the distinction Eddie makes here between the 'practical' and the 'emotional' side of things reflects the distinction between prognostic uncertainty and existential uncertainty: prognosis conveys information about the likely course of a disease, but as with treatment uncertainty above, the information is not emotional *per se* – it is the meaning of the information for the individual that gives it an emotional (and therefore embodied) quality. A prognosis will mean something different to the doctor delivering it and to the patient receiving it, and it is more likely to be associated with existential uncertainty for the patient than the doctor.

(ii) Variability and unpredictability

Another aspect of prognostic uncertainty for participants was its variability and unpredictability. Sam spoke about the variance associated with their regular blood tests, which meant that the results are 'just so all over the place'. Meanwhile Jane talked about wanting more clarity:

> 'And I'm putting the worst prognosis on it all, and you know, [my husband] says stop reading papers about it, because all I find is it's very subjective, so there is no right answer…'

For Brian there was a question mark over what prognosis really means, in particular the notion of a cure:

> '…medically they think if you survive five years, you're cured of cancer, yeah? Cos that's the, the, the time horizon they, they, they work on. Cos they think, if you've gone for five years, you could die of something else in five years, so, eh, but, em, which is fine from a medical point of view, but from a, from a real point of view, seeing that, that, that, yeah, things, there seems to be a reoccurrence even in people who've had a radical prostatectomy at around the 10-year mark, some have had 15, still, still completely free, em, some haven't got to 10, you know, they've got about six or seven and it's come back with a vengeance…'

It is interesting to consider what Brian might mean when he distinguishes between the 'medical point of view' and the 'real point of view'. He may be making the point that prognosis and cure are part of a medical discourse predicated on probabilities and typical cases, which do not necessarily reflect the reality of individual human experience – which, I would argue, is better described in terms of existential uncertainty.

(iii) Direction and recurrence

Participants were concerned about the direction of the disease trajectory or, if they had finished treatment, the possibility of its recurrence. Eddie said:

> ‘I'm certain I've got it, and I'm certain that it's incurable. I'm not certain when it comes back, but I know whatever treatment I'm on, it will do…’

Both Brian and Jim talked about the anxiety they experience when they go to receive the results of their regular PSA tests, and the fear that the numbers will start rising. Brian said:

> ‘…it's stayed around the nought point six, nought point five, nought point six every six months now, but it's been stable, but as I get close to the date when I have my PSA test done, as I have it regularly done, and then have it done and waiting for the results, that's, that's not a great place to be because there's always a worry that if that number goes up, it's come back…’

When I asked Sam to talk about the difference between the uncertainty around their blood tests and the uncertainty around the ‘larger scope questions’, they offered these reflections:

> ‘…it's this idea of like the difference between my quantifiable evidence of your health and this metaphysical concept of your health. So this idea of, okay when I look at a blood test I understand what's going on, this is fine, and it's, you know, you can see the evidence of where it's going. This big overarching question, especially because I'm not a person of faith, is just, it's very hard to feel okay about that, and, and to have a positive faith for it because when all of the previous evidence has been nothing but complicated…’

The distinction they make between health as something quantifiable and health as something metaphysical seems to mirror quite closely the distinction between prognosis as an issue of scientific uncertainty and a person’s life as an issue of existential uncertainty, echoing Brian’s distinction between the ‘medical’ perspective and the ‘real’ perspective discussed above.

So what might the examples above tell us about the distinction between prognostic uncertainty and existential uncertainty? It seems to me that while both of them are concerned with the future, the former is focused on the future course of the disease and amenable to a quantitative, medico-scientific discourse whereas the latter is focused on the future of the person and more amenable to an alternative discourse – perhaps one that is consistent with Sam’s invoking of ‘faith’.

3.2.3.3 Existential uncertainty vs psycho-social uncertainty

If existential uncertainty can be distinguished from treatment uncertainty by its emphasis on meaning rather than information, and from prognostic uncertainty by its emphasis on the person rather than the disease, perhaps the most difficult distinction to make is between existential uncertainty and psycho-social uncertainty, given both are about meaning and both are squarely focused on the person. In a bid to suggest ways in which the two might nevertheless be distinguishable from one another, I will first outline the three themes I derived from the interview passages coded psycho-social uncertainty before reflecting on some of the nuances that set it apart from existential uncertainty.

(i) Practical/material concerns

The practical uncertainties that arose in the context of the cancer were a common concern for participants. Eddie felt it necessary to make provisions for his wife if he were to die:

> ‘…we've used a chunk of my, em, pension up, we've both gone short time work, we've spent all this money updating stuff, so we haven't got an awful lot of money left in the kitty, and what we're earning now is not allowing us to top it up very much, so we've had the house valued, we've got to make a decision as to whether we downsize, if we downsize we'll move nearer where our children are, em, obviously, then if anything happens to me, [my wife]'s got people local to her, family local to her.’

Meanwhile Sam described how they became unemployed and homeless following their cancer diagnosis, and reflected on the challenges presented by this:

> ‘Like, especially on benefits, like yes, I now have the disability one on top, but I can't afford to pay the London rent, I would have to leave London and I don't have a good relationship with my family, so that would leave me with no support, which is what the council were originally suggesting…’

Liz and Brian both made major practical decisions that were informed by their cancer experience: Liz decided to move back to the city from the countryside where she had been living in order to be closer to her friends; and Brian decided to leave his job because it didn’t feel relevant to him anymore.

(ii) Socio-political/socio-cultural factors

Although participants tended to focus on the impact of cancer on the immediate context of their lives, Liz and Sam in particular drew attention to the wider social factors that affected their cancer experience. For Liz, this was Brexit:

> ‘I've never been terribly political, I do have views, but Brexit I was a very staunch Remainer, and I was so upset when, you know, we were going to... Leave won, em, and I think that was then exacerbated because if we were leaving with no deal, which it looked like at that time, em, and it would have been the end of March 2019, the uncertainty for me there was there was all this stuff about drugs are going to run out, we're going to have to stockpile drugs, but we can't stockpile radiotherapy drugs because they have a very short shelf life, and I knew, and this is part of the uncertainty of the cancer experience, isn't it, if I couldn't do all my chemotherapies on time, if I got an infection or something stopped me having some of those chemotherapies, my radiotherapy would be put back…’

For Sam, this was how their queer identity intersected with the cancer. They talked about how presenting in the way they feel most comfortable presenting, such as wearing earrings or painting their nails, changes the way they are perceived by others and carries the risk of losing certain cis-passing privileges. For this reason, they found themselves doing a ‘cost-benefit analysis’ to mitigate any disadvantage they might incur. Their experience of cancer care was that ‘people want to treat you like a cancer patient but they don't know how to treat you as an LGBT person’.

(iii) Managing relationships

One of the concerns that participants shared was around how and when to tell people about their cancer diagnosis. For example, Liz said:

> ‘…you don't know how long this is, this is, this is going to go on, and at what point do I tell people? Em, you know, because it was only my husband knew, and my niece cos I couldn't go and look after the baby while I was having all of this done, so it was only my husband and my niece knew, there was definitely a point where I was going to have to tell [my daughter], and I had no idea how I was going to do that, but I didn't have any inkling then of when I should tell her, em, because I didn't know what the real news was

> going to be, you know. So the, the uncertainty around the timing of a lot of stuff for me in this process was huge.'

Jane and Eddie both expressed concern about the impact of their cancer diagnosis on those around them. For Eddie, the cancer:

> '…wasn't only affecting my state of mind, it was affecting my wife's, my children's, my friends', and everything, and by me being as I am, em, it's making everybody miserable and anxious and stuff.'

Sam and Brian talked about the challenges of managing other people's reactions to the cancer. This is exemplified in the different ways in which Sam's friends engaged with the issue:

> '…with friends it's tricky because some friends don't want to talk about it, some friends are, em, sickeningly positive, which is fine, it helps them but it doesn't help me because they're not the ones dealing with it every day and going to these appointments and having all this bad news, they kind of take that blind faith thing of like, oh, it'll be fine, it'll be fine, this one will work, and it's like, okay, you know, that's, that's where you're at, em, and I have other friends that are just, I have one friend that's Swedish and just is way too Nordic about it, and just you know, she's always tells me that I'm dying so, it's, it's very weird the way that it impacts sort of friend personal things, and I almost feel like I can't talk to them about it…'

3.2.3.3.1 Issues in distinguishing between existential and psycho-social uncertainty

I would suggest that one way of distinguishing psycho-social uncertainty from existential uncertainty in participants' accounts of their cancer experience is that psycho-social uncertainty has a practical, concrete dimension to it. In many cases, it was possible to identify how the psycho-social uncertainty could be reduced, if not solved – stable, appropriate housing in the case of Sam, more money in the case of Eddie, relocating to the city in the case of Liz. Even in the realm of human relations entailed by the second and third themes, there were practical measures that could reduce the uncertainty – a Brexit deal that would safeguard the delivery of the medication necessary for cancer treatment, measures to reduce the exclusion of marginalised groups in society, support for people who are struggling with the impact of cancer on their relationships. By contrast, it is less than clear that the attributes of existential uncertainty identified above have solutions at all, attainable or otherwise – the future is undetermined no matter how hard we might try to forecast it, most things are outside of our control however much we might try to control them, we are unavoidably embodied and on a journey towards death, etc. These are not problems to be solved, but rather what it means to live as a human being.

This is not, however, to over-simplify things by suggesting an absolute distinction between psycho-social and existential uncertainty. Quite clearly, the practical challenges associated with psycho-social uncertainty are entwined with some of the deeper questions about what it means to live as a human being. Take Liz’s Brexit-related uncertainty:

> ‘[The Brexit referendum is] the one thing, I think, in my life before this pandemic that has made me feel, oh my God, I really don't know what's going to happen, and uncertainty for myself, but uncertainty for young people as well. I think more for young people that what's going to happen to their futures…’

This quote shows that although a Brexit deal to safeguard the medicines supply would have eliminated the aspect of Liz’s uncertainty that involved her own treatment, quite clearly there was another aspect of her uncertainty that was more existential in that the outcome of the referendum challenged her worldview and made her worried for the future – something that a Brexit deal would be unlikely to resolve.

A similar case can be made for uncertainty on the micro level of managing individual relationships. Around the time Jane was having her treatment, her son had found a lump which he was having investigated, but he didn’t tell her about it until a scan revealed it was nothing to be concerned about. So Jane didn’t want to worry her son, and her son didn’t want to worry his mother, so they were careful about what they shared with each other. Although one could say this instance of psycho-social uncertainty was resolved when they had an open conversation about what had been happening for both of them, the fact that he didn’t tell her about it while it was happening triggered an existential uncertainty for Jane:

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

In other words, in the process of managing her relationship with her son (psycho-social uncertainty), Jane was confronted with deeper questions around her identity (existential uncertainty), which intruded on her taken-for-granted sense of herself as a mother.

I would suggest that it is more difficult to draw a clear line between existential uncertainty and psycho-social uncertainty than between existential uncertainty and any other aspect of uncertainty in the taxonomy. This is not surprising given existential uncertainty and psycho-social uncertainty are both classified as aspects of personal uncertainty. In Phase 3 of the analysis, I will return to the theoretical literature to see if it might yield a convincing rationale for such a distinction.

3.2.4 Ways of talking about existential uncertainty

The emphasis of this phase of the analysis has been mostly on *what* participants talked about when they talked about various aspects of their cancer-related uncertainty, but I want to conclude by considering *how* they talked about existential uncertainty. One of the reasons that the interviews began with an object elicitation exercise was to give participants the opportunity to frame their uncertainty experience themselves rather than to have them respond to my framing, as would have been the case if I had begun by asking them direct questions about their uncertainty experience. It is interesting to reflect on the range of objects that participants brought. In some cases, the connection with cancer-related uncertainty was direct and unambiguous: some brought a letter from their doctor, one participant brought a bottle of pills, one brought a booklet entitled ‘prostate cancer and your sex life’, one brought his PSA test record card and a penis pump. In each of these cases, I would suggest that the object was associated with an aspect of scientific uncertainty – diagnosis, prognosis, treatment – and could be talked about in direct terms.

There were other cases where the link between the object and the cancer-related uncertainty was less direct, but still clear. For example, Sam brought a set of keys and explained that they were living in a hostel because the cancer treatment made it impossible for them to continue in their job and keep up with the rent on their flat – the set of keys they brought pointedly lacked a front door key, and they spoke of the psycho-social uncertainty connected with their unstable housing situation. Although they stepped out of the medico-scientific discourse of diagnosis, prognosis and treatment while they talked about the lack of security they felt in their life, the psycho-social uncertainty they experienced could still be articulated in a straightforward manner: they talked about the frustrations they encountered in securing the benefits that were due to them, and in dealing with the council about the housing situation.

There were other cases still, however, where the link with cancer was opaque. One of these was the cathedral choir that Jane identified as an object associated with her cancer-related uncertainty. She explained that both of her sons had gone to a cathedral school and one of them had been a chorister – she spoke of that time as a happy one for her family, and she was keen to see if her grandson would be musical like her two sons turned out to be, but was uncertain as to whether she would be around to find out. There was a parallel between Jane’s harking back to an earlier time of life and Eddie's account of how songs 'bring out the memories' for him. There is a risk of overstating the music connection, but the reason I think it is significant is because the cathedral choir and the music CD were not throwaway comments made in response to a question of mine, but rather the result of reflection on their part prior to the interview, and we must therefore assume that the choices are meaningful. Liz too referred to musical instruments and singing when she talked about the anti-Brexit march captured in the photo she brought as one of her objects.

So what are we to make of the fact that when Jane, Eddie and Liz were asked to identify an object that was somehow associated with their cancer-related uncertainty, they chose a cathedral choir, a music CD and a photo of an anti-Brexit march they had joined? In each case, I think they 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 this felt uncomfortable – perhaps it is significant that the one time in the interview when Liz became visibly upset was when she described the march. For Jane and Eddie there was a strangeness around their objects: Jane regarded her choice of cathedral choir as 'a bit odd', while Eddie found his changed response to music 'weird'. This sense of 'weirdness' recurred with some regularity in passages coded as existential uncertainty, such as when Sam described their weighted blanket metaphor as 'a really weird parallel', or when Brian said it was 'a sort of weird thing' to find that so much of his sense of self was attached to his penis. Eddie described as 'weird' his experience of recurring lucid dreaming, which involved people challenging him and questioning his ability. This weirdness was not evident in passages coded as scientific uncertainty.

In the next and final phase of the analysis, I will endeavour to synthesise the observations and interpretations made in this phase (Phase 2) with the conceptualisation of existential uncertainty proposed at the end of Phase 1 and the literature from which it was derived.

3.3 Phase 3 – synthesis of concept analysis and analysis of interviews

The final phase of the analysis process involves a synthesis of the first two phases, exploring how the insights yielded by the analysis of participant interviews fit with the conceptualisation of existential uncertainty yielded by the concept analysis. This synthesis will take the following form:

i. A discussion of the attributes of existential uncertainty
ii. A discussion of the distinction between existential uncertainty and other aspects of uncertainty
iii. A discussion of the manner in which existential uncertainty can be expressed
iv. A revision of the Phase 1 conceptualisation of existential uncertainty on the basis of i-iii above.

3.3.1 Attributes of existential uncertainty

There was broad support in the Phase 2 analysis for the defining attributes of existential uncertainty proposed in Phase 1. Table 2 brings together the lists of attributes identified in both phases in a way that shows where the points of convergence and divergence are. I will discuss what these points might tell us about existential uncertainty as a concept before proposing a revised set of attributes that attempts to harmonise the two lists.

Table 2: the attributes of existential uncertainty identified in each phase of the analysis grouped by meta-theoretical category

Meta-theoretical category	**Phase 1 attribute**	**Phase 2 attribute**
Quality of existential uncertainty	An awareness that is fundamental, ineradicable and always available	An intrusion into awareness
	Manifestation at different levels of awareness	Embodiment
Focus of existential uncertainty	The undetermined but finite nature of one's own being-in-the-world	An undetermined future
	Identity, meaning and choice	Identity and meaning
Source of existential uncertainty	---	Living with the spectre of dying
	---	Questions of control and agency

When it comes to the focus of existential uncertainty, i.e. what existential uncertainty is *about*, there was agreement between phases that it is concerned with the future, which is both undetermined and finite. There was also clear agreement that it is concerned with questions of identity and meaning, but choice was less salient in Phase 2 than it was in Phase 1. I offer two possible explanations for this: one is that in Phase 2, choice was referenced more explicitly in passages coded as treatment uncertainty, particularly in the cases of Brian and Jim, who were offered a choice as to how they wanted their prostate cancer treated; another is that in Phase 2, choice was an implicit aspect of agency. For example, Sam said:

> '…it's a very strange thing to also know your body's working against you and know that the one certain thing in all of this, the one certain thing is if I did nothing and ignored it, I would die, you know like, that's, that's the one certain thing to take away. The uncertain things are if I'm going to survive, how's it going to work, how is the rest of my life going to be, am I ever going to be able to work again, all those things, but the one thing I know is that if I, if I give up, then within a few years, that would be it. And that's kind of exhausting cos sometimes you want to stop for a bit, you just want to be like, I want to get off, I just want to whatever…'

I think the exhaustion Sam is referring to here is associated with agency – they fantasise about 'doing nothing', 'giving up' and 'getting off', but what is exhausting is that 'doing nothing' involves making a choice to do nothing. It is not so much the existence of the choice *per se* that is integral to existential uncertainty, but rather the need to *make* the choice, i.e. agency. This interpretation is consistent with Brian's frustration when he had to decide between the treatment options presented to him – it would have been easier if the radiologist and the surgeon had made the choice for him.

The connection between agency and control is made by Lewis and Bates (2013) in their discussion of religiosity as a source of existential certainty, and the prominence of control as a theme in the Phase 2 interviews points to what is perhaps the most significant absence in the Phase 1 conceptualisation. I returned to the literature on which the conceptualisation was based to see whether control was largely absent from existing accounts of existential uncertainty or whether I had not been sensitive enough to its presence. I found that while a number of researchers do mention it, it was not as prominent as the other attributes identified: Adamson (1997) argues that "the patient's project involves learning to live with the chaos of lost control" (p.154), while Penrod (2007) emphasises the importance of confidence and control in uncertainty – she suggests in her concept analysis of 'living with uncertainty' that "during existential modes of uncertainty, when different ways of knowing are highly influential in forming perceptions of confidence and/or control, information was not helpful" (p.663). Given that control does in fact feature in the literature and was prominent in the interviews, I thought it was important that it be incorporated into the conceptualisation of existential uncertainty.

Taking these points into account, I suggest that existential uncertainty has five defining attributes, as set out in Table 3.

Table 3: a synthesis of the attributes of existential uncertainty identified in Phase 1 and Phase 2 of the analysis, grouped by meta-theoretical category

Meta-theoretical category	**Attribute**
Quality: Existential uncertainty is *experienced as…*	A bodily awareness at cognitive or precognitive levels
Focus: Existential uncertainty is *concerned with…*	The undetermined but finite nature of one's future
	Identity and meaning
Source: Existential uncertainty is *a consequence of…*	Living with the spectre of dying
	Questions of control and agency

For the reasons discussed above, I propose that a more parsimonious conceptualisation is provided by removing choice as a focus of existential uncertainty and regarding it instead as more fundamentally a source of existential uncertainty, implied in questions of agency. Furthermore, it seems to me that the two qualities of existential uncertainty identified in both phases can be more succinctly expressed as a single quality: bodily awareness. Finally I thought it important to retain the two themes from Phase 2 that I classified as sources of existential uncertainty, which can be seen as mirroring the two focuses of existential uncertainty: because I live with the spectre of dying, I am concerned with the undetermined but finite nature of my future; and because it is not always clear what I can and can't control, I rely on my own agency to construct an identity and meaning in life.

3.3.2 Delineating existential uncertainty

Something the Phase 2 analysis yielded was an empirical basis for distinguishing between existential uncertainty and other aspects of uncertainty in the Han et al. (2011) taxonomy. I will briefly discuss the three distinctions I identified in Phase 2 with reference to the Phase 1 analysis and the theoretical literature.

i. Existential uncertainty is concerned with meaning rather than discoverable facts

This is perhaps the most straightforward distinction that can be made, and is supported by the contrary case cited in Phase 1 in which Kate demanded to know the results of her scan, which she knew were available and therefore discoverable. It is also a distinction supported by the literature, with researchers contrasting existential uncertainty and clinical uncertainty (Adamson, 1997), existential uncertainty and situational uncertainty (Penrod, 2007), personal uncertainty and informational uncertainty (Van den Bos, 2009), irreducible uncertainty and reducible uncertainty (McCormack et al., 2011), and of course personal uncertainty and scientific uncertainty (Han et al., 2011). In each case, the latter term implies a discoverability while the former is about meaning rather than a lack of information. Willig's (2011) statement that "diagnosis initiates the struggle for meaning" (p.901) supports this in that it implies diagnosis and meaning are not one and the same thing. It bears repeating that the distinction is not absolute – when Kate discovered the results of her scan, she would no longer have experienced uncertainty about the results of the scan, but she may have found herself experiencing existential uncertainty, depending on what she made of those results. Likewise, once Jane learned from her consultant why her mixed tumour was classified as low grade, she may have found it difficult to know what this might mean for her life. While it may be useful to think of these as different aspects of uncertainty, it is equally important to remember that they are deeply entwined.

ii. Existential uncertainty is concerned with the person rather than the disease

Christakis (1999) refers to the contemporary medical belief that "conditions have identities independent of their existence in given patients" (p.6). It is possible to understand how this belief has led to the emergence of two foci of uncertainty in the Western health care system – one related to the disease itself (scientific uncertainty), and one related to the person (personal uncertainty). Although one might find fault with this distinction, it is a reflection of the way in which the health care system operates, with an emphasis on the reduction of scientific uncertainty (Babrow & Kline, 2000), and the way in which research into health-related uncertainty has evolved with a bias towards issues of scientific uncertainty (Han et al. 2011).

The distinction between person and disease is less clearly true of the distinction between existential uncertainty and practical uncertainty, i.e. uncertainty around structures and processes of care, since these forms of uncertainty are concerned with the person's relationship with the health care system. Even here though, given the system itself is disease-centred, the focus can be on the disease rather than the person, as Sam found when they tried to share something personal with their consultant:

> '…the medication before this which they put me on, they were like oh well FYI, it can give you like persistent diarrhoea, and I kind of was trying to hint to them as well, I was just like, with my life and lifestyle and just, you know, trying to like hint, I was like, sexual impacts, vuh-vuh-vuh, and, and they just weren't, they weren't getting it, they weren't getting it, and it was that thing of like you know constantly having to come out et cetera, but you just kind of realise like, I don't want to fight this battle with you guys, like, if I'm leaving you breadcrumbs and you're just ignoring it because you just want to give me the medication…'

The sense that Sam had of their consultant just wanting to give them the medication suggests an approach in which Sam is seen more as the host of a disease-in-need-of-treatment than a person with values and an identity that might be more important to them than the disease. There is an echo here of the participant quoted in the Phase 1 analysis who was receiving palliative care for cancer and who said he was "interested in the other things, not the disease itself" (Friberg & Öhlen, 2007, p.220).

The distinction between person and disease is not true at all of the distinction between existential uncertainty and psycho-social uncertainty, however, since these are both issues of *personal* uncertainty. Nevertheless, the final distinction provides a rationale for conceiving of these two aspects of uncertainty as conceptually separable:

iii. Existential uncertainty is concerned with the fundamental principles of existence rather than the practicalities of living

In Phase 2 I acknowledged the difficulty of drawing a clear distinction between existential and psycho-social uncertainty, given both are about our being-in-the-world-with-others (Cohn, 1997). However, I suggested that while psycho-social uncertainty has a practical, concrete dimension to it, existential uncertainty is more concerned with what it means to be human irrespective of the specific conditions in which that humanity manifests itself. The existential therapy literature offers two sources of support for such a distinction:

Firstly, while existential uncertainty and psycho-social uncertainty are both about being with others, Spinelli's (2015) distinction between surface and deeper levels of relatedness is instructive: on the surface level, "every thought, feeling and action experienced or undertaken by me is said to arise not only from the interaction of systems and components *within* me as a boundaried organism, but also from the interaction *between* boundaried organisms" (p.16); while on the deeper level, the sense itself of being a boundaried organism is only possible by virtue of a "prior grounding in relatedness" (p.17) – in other words, the self is not its own originator, but emerges from a foundational precondition of relatedness that is not established in particular instantiations, but is always there as the *sine qua non* of those instantiations. Spinelli argues that a failure to appreciate this deeper level of relatedness reduces relatedness to relationship between boundaried beings. Applying Spinelli's argument to the question at hand, I propose that while psycho-social uncertainty is concerned with boundaried beings and the relationships between them, existential uncertainty is a consequence of the deeper level of relatedness, and therefore concerned with the *grounding* on which these relationships depend for their continued existence.

This distinction is supported by the contrast between the ontic and the ontological as described by Cohn (1997) and discussed in the Phase 1 analysis. My intention is not to suggest that the distinction between ontic and ontological is neat, much less absolute. The ontic and the ontological are always deeply intertwined – it is not possible to talk of the ontological without drawing on the ontic, most obviously one's socio-cultural, socio-linguistic and socio-temporal context. However, they are different in terms of their qualities. In his exploration of meaning and existential givens in psycho-oncology, Vos (2015) writes that "meaning is experienced in concrete examples, though it is simultaneously experienced as transcending the level of concreteness" (p.886). The same can be said for existential uncertainty, and it is this transcendence that sets it apart from other aspects of uncertainty, including psycho-social, that remain in the realm of the concrete. This distinction is exemplified by the borderline case cited in Phase 1 of the analysis, where Kate moves from thinking about how her family will cope during a prolonged stay in hospital (a concrete concern that she addresses with 'lists and plans') to reflecting on the time away from her family as 'a practice run' for her 'permanent absence' (which cannot be addressed with 'lists and plans' in the same way) – thus the existential aspect of her uncertainty comes to the fore.

I observed both the close association between these two aspects of uncertainty and the distinction between them when I found myself sometimes coding passages of the interviews in an alternating manner between the two, such as the extract from the interview with Sam discussed in the Phase 2 analysis (reproduced in Appendix 11). It struck me as I coded such passages how difficult it is to pin down in words the distinction between the two, and I wonder if this can be accounted for, in part, by the same linguistic limitations that Spinelli (2015) identifies when he asserts that the relatedness from which existential uncertainty is derived can only be *indirectly* expressed through analogies due to the dualism and separatism underlying the linguistic structures on which we rely when expressing ourselves. I will now take up again the theme on which the Phase 2 analysis concluded: ways of talking about existential uncertainty.

3.3.3 Discourses

In Phase 1 of the analysis, I drew on the literature to argue that while it is possible to engage with aspects of uncertainty centred on disease and health care systems using a medico-scientific discourse, such a discourse fails to capture the complexity and idiosyncrasy of uncertainty around meaning. I cited evidence of people turning to literature (Friberg & Öhlen, 2007), religion (Miké, 2000; Ahmed, Terrill & Sherry, 2019; Mrdjenovich, 2019; Lewis & Bates, 2013) and nature (Karlsson et al., 2014) as a way of engaging with their existential uncertainty. I would argue that these alternative discourses provide a means by which people can engage with an aspect of their uncertainty that cannot be accessed directly, in the same way that Spinelli (2015) asserts that the deeper level of relatedness cannot be expressed directly.

The interviews from Phase 2 of the analysis provide some support for this argument. The sense I had in passages coded as existential uncertainty is that participants were frequently reaching for something elusive that could not be captured by what Willig (2011) refers to as the “new and unsettling discursive universe” (p.897) into which people are thrown following a cancer diagnosis – a universe characterised by the scientific and practical issues of uncertainty in the Han et al. (2011) taxonomy. They compensated for the limitations of a conventional scientific discourse by invoking metaphor (e.g. uncertainty as weighted blanket), analogy (e.g. uncertainty of having a husband who was a NATO pilot) and other modes of expression such as humour (e.g. Jim naming his tumour Donald) and music (e.g. a cathedral choir, Vera Lynn). Interestingly religious discourses did not feature in participants’ accounts, although Sam referred to ‘faith’ on six occasions (one of which was to say that they were not a ‘person of faith’). Participants’ attempts to describe the existential aspects of their uncertainty were sometimes faltering and tentative, but tended also to be more imaginative in the way they were expressed than other aspects of their uncertainty. Perhaps the ‘weirdness’ they described when talking about existential uncertainty was related to stepping outside of the conventional language of a medico-scientific discourse and forging instead a new and idiosyncratic way of expressing their experience of uncertainty.

When I asked Sam what questions they most wanted answers to, if they 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?'

Sam gamely tried to answer my question 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 it exactly or entirely. It was in analysing passages like this that I was reminded of Gergen's (2018) argument that the limits of language are the limits of psychological explanation, in which he referred to "territories beyond elementary articulation" (p.709). I believe existential uncertainty is such a territory. Gergen calls for a dialogue between psychology and the arts as a way of bridging the gap between the structural limitations of language and the complex meanings that we as humans might wish to convey. This echoes Mair's (2012) argument that "[o]ur lives require the nourishment of poetry and art as well as the precision of science and mathematics" (p.208) – he points to the importance of metaphor, imagination and different modes of storytelling in conveying deeper meanings.

Such arguments chime with my belief in the power of different discourses to articulate different things, in particular the power of the arts to articulate things that cannot be captured in conventional scientific terms. It is a belief that predates the current research project – my first two university degrees were in classical languages and literature, so my psychological inquiries are informed by a sensitivity to the importance of storytelling and the niceties of language in shaping meaning. For this reason, I think passages in the Phase 2 interviews that were not so obviously or explicitly about uncertainty (including Liz's attendance at the march, Jane's invoking of a cathedral choir, Eddie's emotional responses to music) are worthy of close attention, offering an insight into the richness of participants' meaning structures. In the Phase 2 analysis, these passages reflected the difficulty of giving an account of existential uncertainty which, as I argue, is more ontological than ontic in nature. Spinelli's (2015) foundational principles support the suggestion that 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. Bohart (1999) writes of tacit, intuitive knowledge as being “by no means primarily verbal and conceptual”, but rather so rich, detailed and complex that “it could never be entirely spelled out in words” (p.293). Perhaps the same can be said for existential uncertainty, which is a tacit, intuitive form of *not* knowing.

3.3.4 Existential uncertainty vs. ontological insecurity

If it is legitimate to cast existential uncertainty as an ontological uncertainty, then it is worth considering how existential uncertainty might differ from the concept of ontological insecurity, which occupies similar conceptual terrain. Laing (1960) describes ontological insecurity in the following way:

> “The individual in the ordinary circumstances of living may feel more unreal than real: in a literal sense, more dead than alive; precariously differentiated from the rest of the world, so that his identity and autonomy are always in question. He may lack the experience of his own temporal continuity. He may not possess an over-riding sense of personal consistency or cohesiveness.” (p.42).

It is worth noting firstly that Laing uses the term ontological in a non-philosophical sense – for him, it is simply the adjectival derivative of ‘being’ and not therefore to be read as a contrast with *ontic*. Furthermore Laing’s ontological insecurity is narrowly associated with the experience of schizophrenia and the childhood adversity from which it is presumed to emerge – he does not write of it as something that is a feature of everyone’s existence, regardless of their childhood experiences.

The narrow emphasis on schizophrenia is criticised by van Deurzen (1998), who argues that what we call schizophrenia is really “an extreme form of the core human experience of being insecure: deeply and totally essentially insecure” (p.11). She writes that “none of us is really secure: social position, or material ease, or personal relationships may protect us momentarily, but a time might come when we get deprived of such advantages and find ourselves exposed and stripped to the bone” (p.14). This broader conceptualisation of ontological insecurity as something universal that may manifest itself at any time seems to have more in common with my conceptualisation of existential uncertainty, but are they one and the same concept? I would say no for two reasons. Firstly, ontological insecurity seems to me to be closer to the concept of existential anxiety than existential uncertainty – in fact, van Deurzen suggests that “what Laing was describing was pure existential anxiety” (p.8), stating elsewhere that in her view openness in living entails “a deep-seated sense of vulnerability: ontological insecurity, experienced as existential anxiety” (p.12).

Secondly, on a semantic level, uncertainty and insecurity are not synonyms – to say one feels uncertain is not the same as saying one feels insecure. Just as Spinelli (2015) conceptualises existential anxiety as a consequence of the foundational principle of uncertainty, I would suggest that one might very well feel insecure about something as a *consequence* of one's uncertainty about it – further supporting the idea that ontological insecurity is closer to existential anxiety than it is to existential uncertainty. So while there is an aspect of uncertainty in Laing's (1960) conceptualisation (the fact that the person's identity is *in question*), the concept seems to be focused more on the consequences of the uncertainty and therefore does not belong in a taxonomy of different aspects of uncertainty.

3.3.5 Revised conceptualisation

Synthesising the evidence from Phase 1 and Phase 2 of the analysis presented above, I propose the revised conceptualisation of existential uncertainty below. The revision includes: a greater emphasis on control and agency; and a clearer articulation of how existential uncertainty differs from other aspects of uncertainty.

> 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 that is beyond my control. I can use my sense of agency to mitigate the impact of this threat by developing an individual identity, aligning myself with a collective identity, and investing 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 becomes salient at times of change or upheaval, and can be overwhelming when my identity and worldview are threatened by challenging experiences. At times such as these I am reminded that whatever choices I make between now and my death are ultimately mine to make, and that life may be meaningless irrespective of my best efforts.
>
> Existential uncertainty is distinguished from other aspects of uncertainty by the fact that it is ontological in nature, tapping at a fundamental level what it means to be human. While other aspects of uncertainty can be captured in the scientific language of accuracy and rationality, wherein a specific question has a specific answer, even if that answer is not known at the time, existential uncertainty defies a conventional medico-scientific discourse for its articulation, requiring instead a language of metaphor, analogy and imagination to convey its meaning. It is a bodily awareness that I can experience as anything from precognitive bodily sensations to full cognitive elaboration as I engage with the question: how am I to live my life?

3.4 Summary

In this chapter, I presented the results of three phases of analysis, proposing in the final phase a list of five defining attributes of existential uncertainty as well as a rationale for distinguishing between existential uncertainty and other aspects of uncertainty in the health context. I pointed to the role of different discourses in constructing and expressing the various aspects of uncertainty implicated in the experience of ill health, arguing that existential uncertainty is not amenable to a medico-scientific discourse, relying instead on metaphor, analogy and imagination to capture its meaning. I concluded with a narrative conceptualisation of existential uncertainty that captures all of the above. In the next chapter, I will turn to a discussion of the practical and theoretical implications of this conceptualisation for health care, including for the discipline of counselling psychology.

4.0 Discussion

Having proposed a conceptualisation of existential uncertainty that encapsulates its defining attributes as well as the features that distinguish it from other aspects of uncertainty, I will turn now to a consideration of the implications of this conceptualisation for theory and practice. I will argue that an awareness of the concept of existential uncertainty is important for the provision of patient-centred health care, and that a failure to acknowledge that uncertainty is an intrinsic part of life risks pathologising life itself, generating further distress for people who are already in a vulnerable position.

I will conclude by offering some reflections on what it was like to carry out this research during the time of Covid-19, which has posed so many questions about the way we can or should live our lives and therefore speaks directly to the concept of existential uncertainty. I will use this experience to suggest future directions for research in this area, while also acknowledging the limitations of conceptual work of this kind.

4.1 Implications for health care

4.1.1 The Han et al. (2011) taxonomy

The conceptualisation of existential uncertainty yielded by this analysis raises two important issues for the Han et al. (2011) taxonomy. Firstly, the emphasis on existential uncertainty as an intrinsic part of human existence rather than an aspect of uncertainty that is restricted to a health 'event' distinguishes it from other aspects of uncertainty in the taxonomy, such as diagnosis, treatment options and processes of care. In other words, although it is conceivable that a person might encounter health issues without any significant prior experience of health-related uncertainty (as captured by the taxonomy's scientific and practical issues) – for instance the first time they are faced with a non-trivial health problem – it is hard to imagine any adult encountering health issues without some experience, however minor, of personal (i.e. psycho-social or existential) uncertainty – a doubt about relationships, identity or meaning in life. If clinicians fail to take account of those aspects of uncertainty that are 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 concept of uncertainty tolerance (Hillen, Gutheil, Strout, Smets & Han, 2017), which is defined as "the set of negative and positive psychological responses – cognitive, emotional, and behavioral – provoked by the conscious awareness of ignorance about particular aspects of the world" (p.70). In other words, might psychological responses to – or consequences of (see 3.1.5.2) – existential uncertainty be different from psychological responses to scientific aspects of uncertainty? If so, how might they interact and what are the implications for clinicians?

Secondly, and relatedly, although existential uncertainty is classified within the taxonomy as something that people might be uncertain about (in the way they might be uncertain about prognosis, treatment options, processes of care, etc.), the conceptualisation developed here 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" (Han et al., 2011, p.833) is the closest source of uncertainty in the taxonomy to Spinelli's (2015) conceptualisation of uncertainty, but fails to capture the fundamental and ineradicable quality of the uncertainty generated by our *human* existence. I acknowledge 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" (Han & Djulbegovic, 2019, p.185), 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 emphasise 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. A failure to acknowledge this may lead to patients and clinicians alike persistently seeking answers to unanswerable questions.

Given how pervasive uncertainty is in the cancer experience (Nissim et al., 2012), all professionals involved in cancer care could benefit from a deeper understanding of its different aspects. It was for this reason that I set out to have the Phase 1 concept analysis published as a standalone article (Dwan & Willig, 2021) in a journal focused on the evaluation and development of clinical practice across medicine, nursing and the allied health professions. During the peer review process, I received the following comment:

> 'I think that to conceptualize being-in-the-world as a source of uncertainty is true in a very high-level, abstract sense, but it is not practically useful: it is like saying that the world is a source of uncertainty. Of course being is necessary for uncertainty and thus a 'source': I think the question is whether it is useful to conceptualize it as such [in the context of medical uncertainty], and the authors need to demonstrate this.'

The point, as I argued in my response to this comment, is not just that existential uncertainty is part of living, but that the existential uncertainty associated with the medical context cannot be conceptualised as if it were unrelated to a person's pre-existing uncertainty landscape – in other words, it is not meaningful to draw a distinction between 'medical existential uncertainty' and 'non-medical existential uncertainty'. This exchange with my reviewer reinforced my belief in the need to disseminate counselling psychology research, informed as it is by a regard for the individual's holistic, subjective experience and by a focus on wellbeing rather than cure (Rafalin, 2010), to others in the health professions whose approach to care might be more disease-centred than person-centred.

4.1.2 Psycho-oncology

The strong desire for answers following a cancer diagnosis is something I observed in my clinical work when I was on placement as a trainee counselling psychologist at a specialist cancer hospital. One of the important challenges I faced with clients was trying to decide together whether the questions they had were answerable. This is a key issue for professionals involved in psycho-oncology because the idea that existential uncertainty is fundamental and ineradicable is not to deny that some questions do in fact have answers, and it may be that the most useful thing we can do for our clients is to help them find these answers. If uncertainty exists at various levels of abstraction – whether one chooses to label those levels physical, social, personal and spiritual/philosophical (van Deurzen, 2012) or scientific, practical and personal (Han et al., 2011) – then it is important to ask what the most appropriate psychological intervention might be at each of those levels. For example, if a client who is living with cancer is uncertain about a particular aspect of their medical care (which might be described as a physical or scientific issue), it may be that an informational intervention delivered through improved communication with their medical team is required (Epstein & Street, 2007) – much as in the Phase 2 analysis Jane wanted to have a conversation with her consultant to find out why her tumour was cast as low grade. If, on the other hand, a client is struggling with an issue that is more social or practical, it may be that a solution-focused intervention (Neilson-Clayton & Brownlee, 2002) is what would be most helpful. In the Phase 2 analysis, Liz's uncertainty over when and how to tell her daughter about her diagnosis might fit into this category, or Sam's uncertainty around housing or benefits.

If the uncertainty is what van Deurzen (2012) calls spiritual/philosophical or what Han et al. (2011) call existential, however, an informational or solution-focused intervention would not be appropriate – and may in fact be unhelpful if the person is already feeling overwhelmed by their experience (Persson et al., 2012). In the Phase 2 analysis, when Sam describes their cancer as 'just like a waiting room to death', there is no 'answer' to their 'question', no 'solution' to their ‘problem’. In cases like these, a meaning-oriented intervention might be more beneficial (Lee, 2008; Vehling & Philipp, 2017), and there is growing evidence of the efficacy of such interventions in the cancer context (Bauereiß, Obermaier, Özünal & Baumeister, 2018). The point I am making here is that in order to decide what kind of intervention might be most helpful to clients who are experiencing uncertainty, clinicians must first have some conceptual framework on which to draw. The conceptualisation of existential uncertainty proposed in this research offers a perspective on the uncertainty experience of people living with cancer that may help to deepen clinicians’ understanding of the meaning structure of uncertainty held by their clients, and consequently to inform their choice of intervention.

4.2 Implications for counselling psychology

Brennan (2001) states that in the cancer context “[m]uch of the (non-specific) power of ‘talking therapies’ and other forms of social support may be the result of helping clients to represent their experiences in language” (p.13) – this, he suggests, is how people adjust their “assumptive world” after its constituent assumptions have been challenged by a cancer diagnosis. This is, on the face of it, a fairly uncontroversial and benign-sounding statement, but what does it really mean to help clients to represent their uncertainty experiences in language? We are perhaps more accustomed to thinking about constructing meaning around what is *known* than what is uncertain and therefore *unknown*, and I would like to consider here what the implications of this thesis are for the theory and practice of counselling psychology.

4.2.1 Meaning as co-construction

Spinelli (2001) regards therapy as “the activity of generating meanings which might potentially transform experience through collaborative dialogue” (p.6). While this does not contradict Brennan’s (2001) construal of therapy, it articulates aspects of the therapeutic endeavour that Brennan leaves unremarked and open – that representing experiences in language involves generating meanings in dialogue rather than one boundaried being (the therapist) helping another (the client) to put words on a meaning that already resides inside the latter. Spinelli emphasises the idea that therapy is a *collaborative* dialogue in which both parties play a formative role. Due to the power imbalance inherent in the therapeutic relationship (Proctor, 2017), there is always the risk that the therapist might – inadvertently or otherwise – impose their own theoretically-informed meaning on the client’s experiences. This risk is plausibly heightened when the client is experiencing high levels of uncertainty, i.e. when the client might be trying to make meaning out of *not* knowing, and might be looking to the therapist for answers.

One possible response to a client's grappling for meaning in the context of their own not knowing is for the therapist to adopt a stance of what Spinelli (2014) calls 'un-knowing':

> "The attempt to 'un-know' suggests the counselling psychologist's willingness to explore the world of the client in a fashion that not only seeks to remain respectful of the client's unique way of being-in-the-world, but also to be receptive to the challenges to the counselling psychologist's own narrational biases and assumptions (be they personal or professional or both) that this exploration may well provoke. Put bluntly, un-knowing requires the counselling psychologist to be willing to abdicate, at least for the time being, a great deal of that which might, from the stand point of most psychological models and approaches, be taken as the counselling psychologist's authority, security, expertise and interpretative power." (p.12)

The point Spinelli is making here is that counselling psychologists must cultivate a level of comfort with uncertainty in the therapeutic encounter. They should guard against using theoretical knowledge as a way of assuaging their discomfort at not knowing, which risks foreclosing the kind of meaning making that can emerge from not knowing. This is where the tension between research and practice is evident – how can clinicians use theoretically-derived knowledge to inform their practice without adopting an expert position predicated on having at least some of the answers? Henton (2012) acknowledges the conceptual clarity that research provides, but suggests that "practitioners need research (like jazz musicians need systematic musical learning) to extemporise successfully" (p.15), which echoes Bohart's (1999) conception of therapy as an intuitive and creative endeavour. With respect to the current research, the conceptualisation of existential uncertainty offered above is not intended as a contribution to 'expertise in uncertainty'. Its purpose is to help sensitise us as therapists to an aspect of the meaning structure of uncertainty that might be more or less salient at any given point in the therapeutic dialogue – it is hoped that a unique and creative response appropriate to the situation at hand may emerge from this sensitivity.

I have in mind here Mair's (2012) description of personal construct psychology as:

> "…a psychology 'empty' of facts and data but fully concerned with methods of personal inquiry for undertaking different phases and aspects of making sense of our worlds […] a perspective on psychological inquiry that seemed to be rich and suitably complex, full of unknowns while making engagement with the unknown more possible than before." (p.188)

In other words, the conceptualisation of existential uncertainty proposed in this research does not belong in the realm of facts – rather it offers a perspective that might enable therapists to engage with uncertainty in a different way, and to have more helpful conversations with their clients as a result. This is very much in keeping with the spirit of the Han et al. (2011) taxonomy, which is presented as "a provisional and flexible – rather than a final and fixed – descriptive model aimed at classifying the types and components of uncertainty in a manner that is both logically coherent *and practically useful in different circumstances*" (Han & Djulbegovic, 2019, p,185, emphasis added). It is in keeping too with Bohart's (1999) insistence that concepts are tools that are "made to do work in different situations" (p.292). Finally, it is in keeping with the notion of therapy as conversation, and as the therapist as a "professional conversationalist" (Mair, 2000, p.335) or "a master conversational artist who facilitates the dialogical conversation and works from a position of 'not knowing'" (Spinelli, 2001, p.6).

It seems to me that in order to avoid imposing meaning on clients, we must be aware of and acknowledge the part we are playing in the co-construction of meaning rather than casting ourselves as objective bystanders helping our clients to realise their own meanings. Research such as this can help us to become reflexive conversationalists by sensitising us to conceptual aspects of experience that may be more or less present in clients' awareness, and by helping us to respond in ways that are creative and intuitive rather than diagnostic and prescriptive.

4.2.2 Meaning and language

The question that remains is the extent to which it is possible, as Brennan (2001) suggests, to represent experiences *in language*. The role of language in defining reality is a central concern for counselling psychology (Woolfe, 2016), and although an in-depth exploration of the relationship between meaning and language is beyond the scope of this project, I would like to offer some brief reflections on how existential uncertainty, manifesting as a bodily awareness at cognitive *and* precognitive levels, might be represented in language in clinical work.

The growing evidence that uncertainty is not only a conscious experience but may also manifest at preconscious or unconscious levels (Anderson, Carleton, Diefenbach & Han, 2019) is consistent with the humanistic idea that "fully functioning persons are open to [two] sources of information: bodily felt senses and intellectual-conceptual thought" (Bohart, 2013, p.91).[4] The key question for practitioners is how meaning can be constructed from the existential uncertainty that manifests as a bodily felt sense and that sometimes eludes direct articulation in a conventional scientific discourse. One way to engage with this question is to broaden our conception of language beyond words. Mair (2012) writes:

> "Language is at the heart of conversational inquiry. It is not incidental or peripheral. This sense of language 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)

In other words, it is important for practitioners to be attentive to the different discourses on which clients might draw when trying to articulate their uncertainty, in particular the existential aspect of it, and to develop a facility with as many different discourses as possible so that our responses in the meaning-making endeavour are in harmony with clients' chosen discourses, whether they be scientific, artistic, literary, musical, spiritual, religious, etc.. Taking this a step further, it is interesting to consider whether existential uncertainty might be more satisfactorily expressed in therapeutic approaches such as person-centred expressive arts therapy that bypass the limitations of language in favour of non-verbal modes of expression (Rogers, 2013) – a speculative suggestion, but something that future research might fruitfully explore. I believe the current research can be of practical value to counselling psychologists in drawing attention to the possibility that uncertainty is not always verbal-conceptual, and that the process of constructing a symbolic representation of a client's uncertainty experience, i.e. the therapeutic conversation, may be as important as the representation itself (Bohart & Tallman, 1999).

It follows from this that being a professional conversationalist must involve more than words. There is, of course, an irony in using 45,000 words to make this point, but it is an irony that is well established and explored by writers like Iris Murdoch, who wrestled in her first novel (2002/1954) with the difficulty of trying to get "under the net" of language. Mair (2012) suggests that "[i]n much of psychology, language is an embarrassment. Many seem to think that we would have a much better discipline if we could get rid of words and use statistics and mathematics instead." (p.197) In spite of its shortcomings, however, language is still the most

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[4] In this paragraph and the one preceding it, I contrast 'cognitive', 'conscious' and 'intellectual-conceptual' on the one hand with 'precognitive', 'preconscious', 'unconscious' and 'bodily felt senses' on the other. In doing so, my intention is to be faithful to the terminology of the authors referenced rather than to suggest that the terms in the respective lists are strictly synonymous. The point I am making is about levels of awareness, where the two lists are assumed to point to different levels of awareness.

complex and nuanced symbolic system of meaning we have, and capable of expressing myriad things that statistics and mathematics cannot. It is also by definition central to the practice of talking therapies. This is why it is crucial to be aware of – and honest about – its shortcomings. It is why it is also crucial to engage with those shortcomings so that we can better understand their implications for the discipline.

4.3 Limitations

The shortcomings of language apply as much to this research endeavour as they do to the kinds of meaning that can be co-constructed in the therapeutic dialogue. 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 our use of language that is particularly difficult to escape in psychology – in order to label a psychological phenomenon, we must have some conceptual notion of what the label represents, which is confirmed by the labelling itself. I was most keenly aware of this circularity when I was coding the interviews in Phase 2 – in order to code a passage as ‘existential uncertainty’, I obviously had to have some idea of what ‘existential uncertainty’ is (which of course I had courtesy of the Phase 1 conceptualisation), so the risk was that the Phase 2 analysis would just find confirmation for the Phase 1 conceptualisation, effectively making the Phase 3 synthesis redundant.

I managed this risk in two ways: firstly, by consciously resisting the temptation to code as existential uncertainty only those passages that referred explicitly to the defining attributes specified in the Phase 1 analysis and by remaining open to more intuitive insights – my identification in Phase 2 of ‘control’ as an important dimension of existential uncertainty (absent from the Phase 1 analysis) is evidence that this strategy was to some extent effective; and secondly, by paying particular attention to instances where participants seemed to be venturing into “territories beyond elementary articulation” (Gergen, 2018, p.709) through the use of analogy, metaphor, imagery and other ways we have for deploying language creatively to expand its capacities for meaning.

Concept analysis methodological frameworks are not without their critics – for example, Beckwith, Dickinson and Kendall (2008) argue that concept analysis lacks depth, rigour and replicability. In choosing concept development as a methodology, I was aware that I was embarking on “a formal, linguistic exercise” (Walker & Avant, 2019, p.168), which would mean engaging with – and ultimately accepting – the limitations of language. I would not dispute that my conceptualisation of existential uncertainty lacks replicability inasmuch as if someone were to use the same methodology to develop their own conceptualisation, they could not possibly come up with exactly the same result. No claim is made that the conceptualisation offered here is the only possible conceptualisation or even the most ‘correct’ conceptualisation – indeed, as Rodgers (2000) argues, 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’.” (p.77)

This, indeed, is the nature of language.

I would argue that the concept development described above fulfils its stated aim of establishing a theoretically-informed conceptualisation of existential uncertainty. It is my hope that the establishment of an explicit and rigorous conceptualisation will give future research a firm basis from which to continue investigating its nature and effects. In other words, I conceive of this research project as part of a conversation – a conversation at the macro level of health research that is symbiotic with the conversations that take place at the micro level of the consulting room (Mair, 2000). In keeping with the pluralistic outlook of counselling psychology, I would welcome an alternative conceptualisation of existential uncertainty that might provide a counterpoint to the one offered here, and that might further our understanding of the uncertainty experienced by people living with cancer.

4.4 A broader perspective on existential uncertainty

The shadow that loomed over me as I carried out this research is that of Covid-19, “a novel disease and an unprecedented challenge to individuals, health care and society in the broadest sense” (Freeston, Tiplady, Mawn, Bottesi & Thwaites, 2020, p.12), or – more colourfully – a “vast, cruel sociological experiment [that] has confined people to their homes, radically disturbed their taken-for-granted knowledge and beliefs, and forced them to alter behaviors once casually, even unthinkingly, employed in their everyday personal, working, and social lives” (Goodson & Schostak, 2021). As it became clear in March 2020 that Covid-19 was going to have a substantial (but as yet undefined) impact on all our lives, I became aware of a feeling of unease, a vague nausea in the pit of my stomach, that was accompanied by a difficulty concentrating and a restless boredom. I was not particularly worried about contracting the virus myself, nor was I specifically worried about any family or friends contracting it. The unease I felt was hazy and non-specific, while definitely being connected to the pandemic. There was an incredulity about the way things were turning out, the restrictions on the way of life I took for granted – freedom to fly home and see family, to socialise with friends, to go to restaurants, shops, theatres, etc. What I found hardest to deal with was not knowing when it would all end. There was nothing I could do either to solve the problem or to escape it, and meanwhile the number of Covid-19 deaths climbed to inconceivable levels. In short – I experienced the defining attributes of existential uncertainty.

By the time I came to do the Phase 1 concept analysis in July 2020, Covid-19 had already been around for some months. My response to the pandemic will undoubtedly have influenced what was salient for me in the data I was analysing in both Phase 1 and Phase 2 of the analysis. I think this will have had the advantage of sensitising me to the more 'felt' aspects of the uncertainty experience ('awareness at precognitive levels') and to the difficulty of expressing exactly what the uncertainty was about (which I attributed in part to the limits of language). When I carried out the interviews in July 2020, there were many things in participants' accounts that resonated with what I was feeling. For example, Sam talked about the distinction between the uncertainty they felt after they were stabbed and the uncertainty related to their cancer, explaining that it helped in the former case to have someone to blame. I found myself wondering whether the restrictions under which I was living were difficult to accept in part because there was nobody to blame – just a virus that didn't mean any harm because it didn't *mean* anything at all, as I saw it – it was simply doing what viruses do. Another comment from the interviews that struck a chord with me was Liz's feeling about her cancer: 'it's happened once, it maybe can happen again'. Once the pandemic is over, can there be a return to the cosy certitude of our pre-Covid existence or will the possibility of another virus continue to lurk somewhere in the deeper recesses of our awareness even once things have supposedly 'returned to normal'?

None of this is to suggest that my *experience* of Covid-19 was the same as the experience of participants in the study who were living with cancer (and Covid-19 too, of course) – it is more to say that my own experience of uncertainty may have heightened my awareness of conceptual aspects of existential uncertainty that might otherwise have been less evident to me. It was important for me not to fall into the trap of finding confirming evidence in the interviews for whatever I was feeling, and one way of avoiding that trap was to remain alert to disconfirming evidence or differences. One such difference seemed to be that although Covid-19 posed questions for me around meaning in life (which is to say it challenged my worldview), I didn't question my identity in the way that the participants reported questioning theirs following their cancer diagnosis.

Although I have experienced existential uncertainty over the past year and a half, I did not, as far as I am aware, contract Covid-19, so I was never actually ill. This suggests that one doesn't have to be diagnosed with anything in order to experience existential uncertainty, supporting the idea that it is always available to awareness rather than being something that is *generated* by a medical diagnosis. One of the theoretical implications of this is that the Han et al. (2011) taxonomy could provide a useful template for conceptualising uncertainty more broadly, not just in health care. In my Covid-19 example, one can easily identify scientific issues of uncertainty focused on the virus itself (genetic sequencing, transmission rates, risk factors), practical issues of uncertainty focused on the system, i.e. society (social distancing measures, travel restrictions, quarantining requirements), and personal issues of uncertainty (impact on relationships and meaning in life). A question for future research is whether this template could usefully be applied to any major life event that involves aspects of uncertainty at the scientific, practical and personal levels, e.g. bereavement after suicide.

4.5 Conclusion

Something that has reverberated for me throughout this research project is the famous quote from the poet Rilke (2011/1929), who made the following plea to a young poet with whom he was carrying on a correspondence:

> "I should like to ask you, as best I can, dear Sir, to be patient towards all that is unresolved in your heart and to try to love *the questions themselves* like locked rooms, like books written in a foreign tongue. Do not now strive to uncover answers: they cannot be given you because you have not been able to live them. And what matters is to live everything. *Live* the questions for now. Perhaps then you will gradually, without noticing it, live your way into the answer, one distant day in the future." (p.18)

I have tried to convey in this thesis a love of the questions themselves, and a belief that the way we engage with questions is as important as any answers we might find – a belief that underpins the relationship between counselling psychology and research (Rafalin, 2010).

As concepts are fuzzy, ever-changing things, the development of the concept of existential uncertainty set out within these pages must be seen as a contribution to an evolving conversation rather than anything more definitive or enduring. I offer the conceptualisation as a tentative description of health-related existential uncertainty, which emphasises 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 of meaning in life. I hope that this conceptualisation will spark discussion and continued research that might further our understanding of the personal aspects of uncertainty, which have in past research been overshadowed by the endeavour to quantify and reduce its more scientific aspects.

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6.0 Appendices

6.1 Appendix 1 – Interview schedule

Part 1. Object elicitation exercise

‘Did you manage to identify one or two objects that are linked in your mind to the uncertainty associated with your cancer experience? Can you tell me why you chose these objects?’

[If participant does not have objects to show]
‘Can you tell me what went through your mind when you thought about trying to choose objects that are linked to your uncertainty?’

Part 2. Interview questions

Note: these questions will be adapted to take account of what has already been shared in Part 1. For example, if participants choose an object in Part 1 that is connected to their initial diagnosis, it may not be necessary to ask the first question below as they might already have shared this information.

i. ‘How did you find out that you had cancer?’
ii. ‘What were the biggest questions you had in your mind around the time you were first diagnosed?’
iii. ‘How did these change over time?’
iv. ‘What did it feel like in your body to be living with this uncertainty? How about emotionally?’
v. ‘Who helped you to deal with your uncertainty?’
vi. ‘What did you do to make sense of your uncertainty?’
vii. ‘How aware were you of the uncertainty of life before your diagnosis?’
viii. ‘How has your relationship with uncertainty changed since your diagnosis?’
ix. ‘What does uncertainty mean to you now?’
x. ‘Is there anything else you would like to say about your experience of uncertainty?’

Concluding question

‘Are there any questions you would like to ask me about the research project before we finish?’

6.2 Appendix 2 – Coding manual

Coding manual setting out the eight aspects of uncertainty (column 1) that constitute the coding manual, including a working definition for each (column 2) and the broad question that might be said to underpin the uncertainty from the point of view of the patient (column 3).

Aspect of uncertainty	**Working definition**	**Operative question(s)**
Diagnosis	Uncertainty as to the source of symptoms or the nature of an illness	What is the matter with me?
Prognosis	Uncertainty as to the course and outcome of an identified illness – can pertain to blood test results, scans, etc.	How will this illness develop into the future?
Causal explanations	Uncertainty as to how and why the illness arose and is taking the course it is	How/why is this happening to me?
Treatment*	Uncertainty as to the optimal treatment of an identified illness for a particular individual in a particular context, including questions about side-effects	Is this the best treatment for me?
Structures of care	Uncertainty as to “the competence of one's physician, the quality of care one can expect to receive from a given clinician or institution” (Han et al., 2011, p.833) or the identity of provider responsible for a particular aspect of one’s care – i.e. focusing on externals such as professionals, hospitals, etc.	How much confidence can I have in my medical team?
Processes of care	Uncertainty as to “the responsibilities and procedures one must undertake to access care” (Han et al., 2011, p.833) – i.e. focusing on patient role within the context of structures of care	What role do I play in my care?
Psycho-social	Uncertainty as to relationships and wider social factors, including practical concerns such as employment, money, housing, etc.	How will this affect my life and the lives of those closest to me?
Existential	Uncertainty as to identity and meaning associated with an awareness of the undetermined but finite nature of one’s own being-in-the-world coupled with the necessity of making choices – drawing on different (non-medical) discourses and manifesting at different levels of consciousness	Who am I really? What does all this mean?

* ’Treatment recommendations’ in the taxonomy has been replaced with ‘treatment’ in the coding manual to broaden its purview beyond the recommendations *per se*.

6.3 Appendix 3 – Recruitment poster and tweet

UNCERTAINTY

Are you experiencing uncertainty?

Would you like to be part of a research study exploring the different ways that uncertainty features in the cancer experience?

We are looking for volunteers in the United Kingdom who were diagnosed with cancer within the last 5 years to help us understand better the meaning of uncertainty for them.

Participation in this study would involve a short screening telephone call followed by one interview with a researcher at a later date lasting up to 90 minutes. The interview would take place online via videoconference, so it would not be necessary to leave home.

During the interview you would be asked to describe your own experience of uncertainty and reflect on what it means for you.

To find out more about this study, please contact:

Conor Dwan
Department of Psychology
City, University of London
[redacted]

This research project is supervised by:
Prof Carla Willig
[redacted]

This study has received ethics clearance from City, University of London Research Ethics Committee

If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on [redacted]*. City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk*

[redacted]

6.4 Appendix 4 – Screening call protocol

[The following text is designed to give a sense of what will be covered and said in the screening call, but the exact form will be adapted to fit the conversation as it unfolds.]

Thank you for expressing an interest in taking part in this research study into the uncertainty experience of people living with cancer.

This short call is an opportunity for me to tell you a little bit more about the study and to ask you a few questions about your current situation. It is also an opportunity for you to ask me any questions you may have about the study. Are you happy to go ahead with the call, and is now a convenient time?

Just to give you a bit more detail about the study:

- The aim of the study is to get a better understanding of uncertainty in the cancer experience. Although uncertainty is a big part of many people's cancer experience, we don't understand it fully. A deeper understanding of uncertainty may lead to improvements in the psychological support that is offered to people struggling to deal with cancer.
- If you choose to take part, you will be interviewed by me about your personal experience of uncertainty in the context of your cancer diagnosis. The interview will last approximately 90 minutes, and it will take place remotely via videoconference (either Zoom or Microsoft Teams), so there will be no need for you to leave your home. If you agree to take part, you'll receive a meeting invitation via e-mail which will enable you to join the meeting from your computer or other digital device.
- The interview will be in two parts:
    - For the first part, I would like you to identify and talk about two objects that are linked in your mind to the uncertainty associated with your cancer experience. These objects can be anything at all and there are no right or wrong answers – so they can be anything from everyday objects like clothing and household items to documents, photographs and artwork. The most important thing is that you somehow associate the object with your uncertainty and are able to say something about that.
    - In the second part, I will be asking you a small number of open questions about your experience, but it will feel informal and you will be free to talk about whatever comes to mind. If you're struggling to know what to say, I will give some prompts to help you.
- The interview will be recorded using the videoconferencing software, and later I will transcribe and analyse it. Direct quotes from your interview may be used in the write-up of the study, but your name and any identifying details will be removed to protect your anonymity.

I have a few questions that I would like to ask you, if that's okay:

i. Firstly, can I ask what makes you interested in taking part in the study?
ii. How long ago were you diagnosed with cancer?

iii. What type of cancer do you have?
iv. How do you feel you are coping with the challenges of day-to-day living at the moment?
v. Are you experiencing any thoughts of self-harm or suicide at the current time?
vi. I would like to make you aware that the interview itself does not have a therapeutic aim, and could in fact bring up some difficult thoughts and feelings for you, which may generate more uncertainty for you in the hours and days following the interview. If this were to happen for you, who do you have around you to help support you?
vii. Can I check what age you are?

[If the answer to any of the questions above means the person is not eligible to take part in the study, the researcher will explain to them that they do not meet the eligibility criteria as set out in the recruitment material. In practice, this means: if the answer to (ii) is greater than 5 years; if the answer to (vii) indicates the person is under the age of 18.

If the answer to any of the questions above suggests that taking part in the study may not be in the person's best interests, then the researcher will explain to them that it may be safer at this time to focus on ways of looking after themselves rather than take part in a research project, and signposting will be offered to appropriate support services, including local cancer support services (e.g. Maggie's, Paul's Cancer Support Centre, hospital open support groups) as well as more general services such as Samaritans, GP, A&E, depending on the level of distress discerned. In practice, this decision will be based on the following: if the answer to (iv) indicates the person is having difficulty coping with life at the moment; if the answer to (v) indicates the presence of thoughts of suicide or self-harm; if the answer to (vi) suggests the person is isolated and does not have support available to them should the interview prove unsettling for them.

If the person is deemed eligible to take part in the study, they will be invited to ask the researcher any questions they have, and arrangements will be made as to when the interview will take place.]

6.5 Appendix 5 – Participant information sheet

Participant information sheet v1.1-rem

6th April 2020

Title of study: An exploration of uncertainty among people living with cancer

Name of principal researcher: Conor Dwan
Research Ethics Committee reference number: ETH1920-1358

Invitation

We invite you to take part in a research study. Before you decide whether you would like to take part, it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to get a better understanding of uncertainty in the cancer experience. Although uncertainty is a big part of many people's cancer experience, we don't understand it fully. A deeper understanding of uncertainty may lead to improvements in the psychological support that is offered to people struggling to deal with cancer.

The study is being conducted as part of a doctoral training programme in counselling psychology at City, University of London. The study will be published in the form of a doctoral dissertation and may be published at a later date in an academic journal.

Why have I been invited to take part?

You have been invited to take part because you answered an advertisement asking people who are living with cancer and experiencing uncertainty to be interviewed about their experience. People who were given a cancer diagnosis within the last five years are eligible to take part in the study.

Do I have to take part?

No. Participation in the project is voluntary and you are free to withdraw at any time without giving a reason or being disadvantaged in any way. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form.

You may withdraw your data from the study up to the point at which the data has been analysed. If you withdraw your data before this point, the data will be destroyed.

What will happen if I take part?

If you choose to take part, you will be interviewed by a researcher about your personal experience of uncertainty in the context of your cancer diagnosis. The interview will be done remotely using videoconferencing software (either Zoom or Microsoft Teams) and last approximately 90 minutes. This means that it will not be necessary for you to leave your home in order to take part in this project, but you must have access to a computer or other digital device that allows you to access the internet.

The interview will be in two parts:

- In the first part, you will be asked to identify and talk about one or two objects that are linked in your mind to the uncertainty associated with your cancer experience (as discussed during the introductory phone call). These objects can be anything at all, from documents, photographs and artwork to everyday objects including clothing and household items. The most important thing is that you somehow associate the object with your uncertainty and are able to say something about that.

- In the second part, you will be asked a small number of open questions about your experience, but it will feel informal and you will be free to talk about whatever comes to mind. If you're struggling to know what to say, you'll be given some prompts to help you.

The interview will be recorded using the videoconferencing software before being transcribed and analysed. Direct quotes from your interview may be used in the write-up of the study, but your name and any identifying details will be removed to protect your anonymity.

How will it work in practice?

If, following the introductory phone call, you agree to take part, you will receive a meeting invitation over e-mail, with a link that will enable you to join the meeting at the agreed time. This link will enable you to join via your web browser, so it will not be necessary to download any additional software to your computer/device. However, if you already have the Zoom or Microsoft Teams app on your device, you will be able to join the meeting by entering the details from the meeting invitation into the app.

You will also receive an e-mail with a consent form attached ahead of the meeting. You will need to complete this consent form and 'sign' it by typing your name and the date in the appropriate spaces. You will then need to e-mail the form back to the researcher in order for the interview to go ahead. If you don't manage to do this before the meeting, it can be done 'live' at the beginning of the meeting.

When the time of the meeting arrives, it is best if you can be in a private space with good wifi where you are not likely to be disturbed or distracted.

Further information on Zoom can be found here:
https://zoom.us/about

Further information on Microsoft Teams can be found here:
https://products.office.com/en-gb/microsoft-teams/group-chat-software

What are the possible disadvantages and risks of taking part?

Thinking and talking about objects that are relevant to your experience of uncertainty may lead you to uncover aspects of your experience that you had not previously considered. There is also a chance that talking about your experience of uncertainty may bring up some questions for you which make you feel more uncertain. This can be upsetting. The interview is a research interview rather than a counselling session, but if you decide after the interview that you would like to explore further some of the topics from the interview, we can support you in identifying an appropriate psychological support service that might be able to help.

What are the possible benefits of taking part?

By taking part you will be contributing to psychological research on uncertainty, which may lead to a deeper understanding of this phenomenon and, in time, of how people can be supported to cope with it. You may also view it as an opportunity to tell your own story to someone who is very interested, which many people find beneficial.

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that City is responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information is limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal identifiable information possible. For further information please visit: https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only people at City who will have access to your identifiable information will be the research team. Identifiable information about you from this study will be destroyed once it is no longer needed for the purposes specified above.

You can find out more about City's data protection policy here:
https://www.city.ac.uk/about/governance/legal.

If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (ICO): https://ico.org.uk/

Will my taking part in the study be kept confidential?

- Only the researcher and his supervisor will have access to your personal data.
- All data will be anonymised prior to publication so you will not be identifiable in any of the published materials that result from the interview.
- All data will be stored securely on a City OneDrive and identifiable information will be destroyed once it is no longer needed for the purposes specified above.

What will happen to the results?

The study will be published in the form of a doctoral dissertation and may be published at a later date in an academic journal. If you wish to receive the results of the study, there will be an opportunity to say so on the consent form.

Who has reviewed the study?

This study has been approved by City, University of London Department of Psychology Research Ethics Committee.

What if there is a problem?

If you have any concerns about this study, you should contact the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure.

To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to the Senate Research Ethics Committee and inform them that the name of the project is: An exploration of uncertainty among people living with cancer.

You can also write to the Secretary at:

[redacted]
Research Integrity Manager
City, University of London
Northampton Square
London, EC1V 0HB

Email: [redacted]

Insurance

City, University of London holds insurance policies which apply to this study, subject to the terms and conditions of the policy. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Contact details

If you have any queries about the research, please contact:

Conor Dwan – researcher – [redacted]
Professor Carla Willig – research supervisor – [redacted]

Thank you for taking the time to read this participant information sheet.

6.6 Appendix 6 – Consent form

Title of study: An exploration of uncertainty among people living with cancer

Name of principal researcher: Conor Dwan
Research Ethics Committee reference number: ETH1920-1358

To consent to participating in this study, please click reply to this e-mail, and then tick or initial each box below before typing your name at the bottom of the form (in lieu of signature)

1	I have read and understood participant information sheet v1.1-rem dated 6th April 2020 for the above study. I have had the opportunity to think about the information and ask questions about anything I was unsure of.	
2	I understand that my participation is voluntary and I am free to withdraw without giving a reason.	
3	I understand that I will be able to withdraw my data up to the time when my data will be analysed.	
4	I agree for the interview to be recorded using videoconferencing software.	
5	I agree to City, University of London processing information about me. I understand that this information will be used only for the purposes explained in the participant information sheet and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
6	I want to be informed of the results of this study once it has been completed and understand that my contact details will be retained for this purpose.	
7	I agree to take part in this study.	

Name of Participant:
Signature:
Date:

Name of Researcher:
Signature:
Date:

6.7 Appendix 7 – Debrief sheet

DEBRIEF INFORMATION

Title of study: An exploration of uncertainty among people living with cancer

Name of principal researcher: Conor Dwan
Research Ethics Committee reference number: ETH1920-1358

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

The aim of the study is to get a better understanding of uncertainty in the cancer experience. Although uncertainty is a big part of many people's cancer experience, we don't understand it fully.

By identifying common themes in the way that people living with cancer describe their thoughts and feelings around uncertainty, this study aims to clarify how different *types* of uncertainty relate to one another, for example uncertainty relating to diagnosis, treatment options or the meaning of life. The conversation we have had today is key to achieving this aim.

The hope is that a deeper understanding of uncertainty may lead to improvements in the psychological support that is offered to people struggling to deal with cancer.

If you feel that you need psychological support, charities such as Macmillan Cancer Support (www.macmillan.org.uk) or Maggie's (www.maggiescentres.org) may be able to help. Alternatively your GP may be able to let you know about local sources of support available to you.

We hope you found the study interesting. If you have any questions please do not hesitate to contact us:

Conor Dwan – researcher – [redacted]
Professor Carla Willig – research supervisor – [redacted]

Thank you once again for your contribution to this research project.

6.8 Appendix 8 – Key excerpts from the sources identified through Strand 1 of the search strategy for the concept analysis

Source	Existential uncertainty (definition / indicative quotes)	Keywords	Distinctions (explicit/implicit)	Discipline
Abulof (2009)[1]	"The paper posits 'small peoples' as ethnic communities characterized by prolonged and deep-rooted uncertainty regarding their own existence. I argue that in modern times, 'small peoples' doubt the validity of their past-based ethnic identity and the viability of their future-driven national polity. Empirically, I analyze two distinct ''small peoples''—Israeli Jews and French Canadians (Québécois)—and argue that while the former have been more concerned with the future survival of their polity, the latter have been more concerned with insecurity about their identity." [p.227] "The focus of Israeli Jews' **existential uncertainty** has been and remains the future survival of their national polity (i.e., Israel as the Jewish state). French-Canadians question the validity of their common ethnic identity. The former asks: 'do we have a future?'- the latter: 'do we have a past?' These questions supply the keys to the realm of small peoples." [p.229]	time (past, future); identity; insecurity; survival	existential uncertainty vs security	Politics
Abulof (2014)[1]	"The incomplete (or absent) legitimation for a collective identity or collective polity intensifies its members' perception of insecurity (as **existential uncertainty**) and hence its securitization discourse." [p.402]	identity; collective; insecurity	existential uncertainty vs security	Politics
Adamson (1997)[1]	"Existentialist philosophers maintain that the intuition of nothingness or non-being that comes with the contemplation of one's death is a source of **existential uncertainty** or anxiety. […] I follow existentialist usage in using the term **existential uncertainty** to refer to the individual's awareness that his or her future is open and undetermined. In the medical encounter, **existential uncertainty** is 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." [p.134]	death; awareness; time (future); private; individual	existential uncertainty vs clinical uncertainty	Sociology

	“Whereas **existential uncertainty** is privately experienced, clinical uncertainty is the socially organised realisation by a member of the medical community that the knowledge needed to diagnose a disease and predict an outcome is missing. Whereas **existential uncertainty** is resolved by the individual's freely chosen actions, clinical uncertainty is a problem that invites a collective, intersubjectively verifiable solution. The normative assumption within scientific medicine is that the problem, puzzle, or conundrum which is the source of the clinical uncertainty can, in principle, be solved.” [p.135]	unsolvable;		
	“The clinician confronts the chaotic flux of disease seeking to discover an order within that chaos which will lead toward a cure, while the patient's project involves learning to live with the chaos of lost control.” [p.154]	chaos; control		
Ahmed, Terrill & Sherry (2019)[1]	“Religious communities occupy a particularly important position in the management of identity based uncertainty. In addition to their role in fulfilling personal spiritual needs, religious communities function as internally cohesive social groups. They offer a profound sense of moral guidance and psychological wellbeing as well as a potent defence against the specific cognitive demands of **existential uncertainty**. [...] Those encountering a deep-seated existential crisis are more likely to experience their religious self-construct as a “master identity”—one that satisfies their fundamental need for certainty around the nature and purpose of their individual being by reinforcing an indisputable in-group identity.” [p.91]	identity; cohesion; profound; cognition; purpose; individual; in-group	individual identity vs group identity	Sociology
Belpame et al. (2019)[1]	"Living with **existential uncertainty** In the interviews, all adolescent and young adult [AYA] survivors expressed that their past cancer experience had confronted them with their own vulnerability. Once they had understood the seriousness of their experience, a significant time afterwards, an **existential uncertainty** arose. This became a permanent factor, forever ingrained in their lives. One AYA survivor said in the interview that every time he had to fill out a questionnaire, for instance regarding insurance, he felt the uncertainty of his health status. [...] Digging deeper into the possibility of a future relapse, many AYA survivors mentioned that they had clearly been alerted to the possibility of a relapse in the early years following their cancer experience, but that their concern and fear of this had diminished with the passage of time. Although the uncertainty remained and although all	vulnerability; health status; relapse; fear; resignation; death; pain; discomfort; coping process	death vs survivorship	Nursing

	assumed that a relapse could never be excluded, they experienced a certain degree of resignation. Furthermore, data revealed that a lot of survivors did not particularly consider a relapse as a risk, or renewed risk, of death. Rather, a relapse meant having to repeat the entire cancer experience again: the intensive treatment, the pain and discomfort." [p.e33] Participant quote under 'living with **existential uncertainty**' heading: "I don't think about the fact of dying; that you can die. Because, yes, you can always die and tomorrow, it's true, I could walk out the door and get run over by a car. So, that's not really what it's about. What's worse is that you would have to experience all of that once again, including the consequences (…). It genuinely is a coping process, and the period afterwards is the part I actually find hardest." [p.e32]			
Brothers (2008)[1]	"Although my professional involvements as a self-psychologically informed psychoanalyst have hardly been pain free, my connection to this field has increasingly become a source of pride and satisfaction. My recent investigation into experiences of **existential uncertainty** (or uncertainty about the availability of a relational exchange necessary for psychological survival) and how they are systemically transformed, has helped me form some inklings as to why this is so." [p.502]	relational; psychological survival	n/a	Psycho-analytic
Brothers (2009)[1]	"I found that experiences of the ineluctable uncertainty that attends psychological survival is made bearable by means of the reciprocal regulatory processes that operate within living systems such as those involved in feeling, knowing, forming categories, making decisions, remembering and forgetting, sensing time, and fantasizing. To the extent that they bring some degree of orderliness to a relational exchange, they allow us to feel that our expectation of going-on-being need not even be questioned. Thoroughly dialogic in nature and inextricably embedded in relational systems, language is one of the most important of these processes. I discovered that it not only plays an indispensable role in transforming experiences of **existential uncertainty**, it is itself profoundly uncertain. Rather than being fixed and static, language, as Charles Taylor noted, is constantly being 'recreated, extended,	psychological survival; regulatory processes; relational; language; selfhood; profound; aloneness; exile; hope; taken-for-granted	uncertainties vs certainties	Psycho-analytic

	altered, reshaped'. Consequently, we can never be sure of the meaning of any given word, nor can we fully know the implications of saying it." [p.502] "I would like to take a closer look at that 'something' in terms of what I call '**existential uncertainty**'. In my last book, I pointed out that, because we are profoundly dependent on others for our experience of differentiated selfhood, but we cannot fully know them, or ourselves for that matter, uncertainty about our psychological survival is an inescapable feature of human experience. I believe it is just the sense of naked aloneness that makes our confrontations with **existential uncertainty** so unbearable. Because these devastating experiences are likely to arise when the certainties that pattern psychological life are destroyed by trauma, I have come to think of people who have undergone trauma as exiles. They have lost contact with a once-familiar world in which the availability of a self-sustaining emotional give and take with other people was taken for granted, a world of hope." [p.504-5]			
Brothers (2012a) [1]	"But what most distinguishes Murakami as an analyst after my own heart is that he continually grapples with what I call '**existential uncertainty**', or the unbearable awareness that we can never be sure that others will participate in the relational give and take on which selfhood depends." [p.229]	awareness; relational; selfhood	self vs other	Psycho-analytic
Brothers (2012b) [1]	"In my view, feeling that one is a welcome and familiar member of the human family goes a long way toward mitigating the anguish of what I have called '**existential uncertainty**' or unbearable doubt about one's going-on-being." [p.391-2]	relational; anguish; doubt	belonging vs existential uncertainty	Psycho-analytic
Cohen (1993)[4]	"Uncertainty varies in degree of magnitude, intensity, and saliency - from the overarching, **existential** issues of life and death to the inconsequential contingencies and probabilities that are the substance of everyday life." [p.78]	magnitude; intensity; saliency; life; death; overarching	existential uncertainty vs inconsequential contingencies/ probabilities	Nursing
	"A near total transformation is one in which the individual experiences an abrupt discontinuity with the past and the anticipated future." [p.80]	discontinuity; time; disconnection;	past vs future	

	Quoting Ipswitch (1979): "We moved into another world… It was a world that did not take on reality until you were in it. It was as if Scott and I entered one of those old-fashioned paperweight scenes where we could see out and others could see in, but they could not enter – and we could never completely emerge." (p.45) [p.82] "Suddenly, family relationships take on a temporal quality and thinking about the future seems to invite the threat of loss. Present time becomes discontinuous with past and future time. Mental confusion and behavioral disorganization occur as parents 'switch worlds' and move from the secure world of the known, the familiar, and the predictable to a normless world of ambiguous boundaries, unclear rules, probabilistic predictions, and sinister possibilities." [p.83]	loss; possibilities		
	"Parents and doctors experience the event of diagnostic certainty quite dissimilarly. For the physician, the occasion brings closure to a series of questions and hypotheses and provides reasonably clear direction for his or her subsequent decisions and actions. [...] For the parents, however, diagnostic certainty only answers the question 'What is wrong with my child?' It does not provide any sense of closure nor suggest how they should proceed. Their uncertainty, which until the time of diagnosis had been unidimensional, quickly becomes multidimensional and spreads to every aspect of family life, raising countless unanswerable questions and fears. Parents are now confronted with **existential**, etiologic, treatment, situational, biographical, and social uncertainties." [p.84]	closure; multidimensional; pervasive; unanswerable	closure vs non-closure existential vs etiologic vs treatment vs situational vs biographic vs social uncertainties	
Dellve & Hallberg (2008) [1]	"Described significances for reporting/non-reporting [of occupational disorders] were related to financial compensation, to a part of organizational political game or to an **existential uncertainty**, i.e. questioning if it belonged to their chosen work and life." [p.176]	chosen life	financial compensation vs organisational politics vs existential uncertainty	Health
Friberg & Öhlen (2007) [1]	Participant quote: "You are interested in the other things, not the disease itself." [p.220]	not-disease	disease vs 'other things'	Nursing

	“One important project became the search for a unifying picture, and John reflectively explored the situations he went through and turned to literature in order to get an answer. When his situation deteriorated, he realized that only cancer patients could understand him and his changing body.” [p.222]	search for answers; meaning; art; body (changing)	cancer patients vs non-cancer patients	
	“One striking and important finding was the patient’s need to talk about the uncertain future combined with the health professionals’ vague or sometimes contradictory communication about the same. We interpreted this as a need for **existential** knowing.” [p.224]	future; knowing	patients vs health professionals	
	“Thus, managing and confronting **existential uncertainty** and living existential certainty will both frame, co-create and be co-created by the knowledge seeking behaviour of patients receiving palliative care. […] Perhaps a reluctance to talk about prognosis and future is related to the strict frames of the medical discourse itself. In order to talk about the future with palliative cancer patients, another discourse has to be adopted which involves openness towards existential dimensions.” [p.225]	managing; confronting; search for answers; prognosis; future; discourse	existential uncertainty vs existential certainty	
Furtak (2019) [1]	“One way in which Kierkegaard offers existential guidance to his reader with regard to ‘the uncertainty of earthly life, in which everything is uncertain’ (CUP 1, 86/SKS 7, 85) is to portray unsuccessful ways of dealing with the varieties of uncertainty that are entailed by the finite limitations of our epistemic standpoint. There are cases in which what we long to know is, by its very nature, inaccessible to us - such as the mind of another, or what is going to happen in the future. And there are other cases in which the kind of knowledge that we *can* gain does not remove the fundamental uncertainty of our predicament. Yet the aspiration to arrive at definite answers, to have everything resolved and finished, does not just characterize the Cartesian or Hegelian philosophers from whom we can easily distinguish ourselves. This wish to be liberated from the cognitive limits that are a structural feature of the human condition is one that is liable to plague us all – including those of us who are prompted by Kierkegaard’s writings to *want* to heed his warning against this very wish. He therefore issues reminders to us in various contexts and in a diversity of voices, continually telling his reader: this pertains to *you*.” [p.383]	earthly life; limitations; the other; future; cognitive limits	existential uncertainty vs aspiration to definite answers	Humanities

Gandsman (2009)[3]	"'Do You Know Who You Are?' Radical **existential doubt** and scientific certainty in the search for the kidnapped children of the disappeared in Argentina During the Argentine military dictatorship (1976–83) up to 30,000 people disappeared. Included among them were an estimated 500 children who were handed over to families related (or with close ties) to security forces. The Grandmothers of the Plaza de Mayo formed to discover their fate. During the 1980s, the Grandmothers used newly available genetic technologies as a means of verifying the identities of potential grandchildren to reunite them with their biological families. In the 1990s, custody was no longer an issue because the children were legally adults. Forced to change their strategy, they embarked on public campaigns directing those with 'doubts about their identity' to contact the organization. This article provides an ethnographic analysis of these public campaigns to advance theoretical perspectives on the nature of embodied truth and the transformation of individual concerns regarding personal identity to collective doubt regarding national identity and belonging." [p.441]	personal identity; national identity; embodied truth; belonging	existential doubt vs scientific certainty	Anthropology
Gezentsvey Lamy, Ward & Liu (2013) [1]	"The motivation for ethno-cultural continuity (MEC) scale was developed to capture the agency of minority individuals in the long-term acculturation of their group and their dedication to cultural persistence over many generations. […] As expected, higher values were found among Jews and Māori than Chinese. Together with traditional ethnocentric predictors, MEC predicted intentions for endogamy and in turn selective dating for Jews and Māori, but not for Chinese. Results are interpreted in terms of **existential uncertainty** experienced by "small peoples" and the impact of collective interests on individual behavior." [p.1047] "The results of this study demonstrated that MEC was structurally equivalent across cultures and prevalent across all three ethno-cultural group samples. As expected, higher scores were observed among members of 'small peoples'. This demonstrates that group factors impact individual motivation to ensure ethno-cultural continuity: the **existential uncertainty** experienced by Jews and Māori as groups is reflected in the psychology of Jewish and Māori individuals in these samples." [p.1060]	continuity; behaviour	collective vs individual	Psychology

Gullick et al. (2017)[1]	“Acute coronary syndrome disrupts lived temporality, and the projected potential for carers’ being-alongside. Carers experienced an **existential uncertainty** that arose from difficulty in diagnosis, and situated fear as an attuned, being-towards-death.” [p.393]	time; diagnosis; death	existential uncertainty vs difficulty in diagnosis	Nursing
Hammack (2010)[1]	“Scholars across a range of disciplines have increasingly argued that the intractability of political conflicts is rooted in the proliferation of competing historical narratives. These collective narratives construct the basis of a sense of shared collective identity. Narrative and identity are thus increasingly conceptualized as fundamental to the maintenance and reproduction of political conflict. In this paper, I explore two underlying conceptions of identity that have emerged in the literature on youth and political conflict. One conception views identity as a burden for youth, suggesting that youth 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**. Though psychologically beneficial, this internalization is problematic in the reproductive role it assumes in the larger conflict.” [p.173]	identity; security; solidarity; conflict	security vs existential uncertainty; individual vs collective	Politics
Hoffman (2009)[1]	“A multifaceted contemporary movement aims to correct alleged weaknesses in the scientific foundation of psychoanalysis. For both pragmatic-political and scientific reasons we are encouraged to do and/or study systematic empirical research on psychoanalytic process and outcome, as well as apparently relevant neuroscience. The thesis advanced here is that the privileged status this movement accords such research as against in-depth case studies is unwarranted epistemologically and is potentially damaging both to the development of our understanding of the analytic process itself and to the quality of our clinical work. In a non-objectivist hermeneutic paradigm best suited to psychoanalysis, the analyst embraces the **existential uncertainty** that accompanies the realization that there are multiple good ways to be, in the moment and more generally in life, and that the choices he or she makes are always influenced by culture, by socio-political mind-set, by personal values, by countertransference, and by other factors in ways that are never fully known. Nevertheless, a critical, nonconformist psychoanalysis always strives to expose and challenge such foundations for the participants’ choices. The ‘consequential uniqueness’ of each interaction and the indeterminacy associated with the free will of the participants make the individual case study especially suited for the	ways to be; choice; culture; values	process and outcome vs individual case	Psycho-analytic

	advancement of ‘knowledge’ - that is, the progressive enrichment of sensibility - in our field.” [p.1043]			
Karlsson, Friberg, Wallengren & Öhlen (2014) [1]	“Since suffering is about experiencing a threat to one's existence, uncertainty needs to be related to the existential dimension of life. […] In particular, when a person becomes ill with cancer, the bodily experience involves becoming aware of one's own mortality and this awareness means to live in **existential uncertainties** due to the mortal threat to the body. It follows that the **existential uncertainty** of individuals in this situation is about the uncertainty of the prospect of the disease trajectory, about being able to survive or not and how life will be before death.” [p.2]	suffering; threat; bodily experience; mortality; awareness; disease trajectory; life before death	n/a	Nursing
	“Although **existential uncertainty** prevails in cancer patients, there are studies which show that they can also experience certainty and even existential certainty in the sense of having a fresh take on life, getting to know themselves better and appreciating their families in a different way.” [p.2] “The participants described different kinds of experiences with nature and related that in close proximity to nature they could find existential certainty in their **existential uncertainty**. For example, some of the participants described how they enjoyed walking quickly *or* slowly in the natural environment, and being close to the sea and perhaps going for a swim. Through the power of each person's different senses, nature awakened vivid memories within them. […] The present could be experienced as more certain, as opposed to the future, which appeared more uncertain as a result of living with advanced cancer and receiving palliative treatment. […] Being personally involved in planning important things for the future was described by the participants as providing a greater sense of certainty in their **existential uncertainty**. It was also meaningful to have a goal to look forward to, having something ahead of them that was perceived as meaningful.” [p.5]	take on life; self-knowledge; relationships; nature; memories; time (present, future); goals; meaning	existential uncertainty vs existential certainty	
	Participant quote: “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. I suppose it's not certain I'll die before them, there's no guarantee at all - I could live much, much longer.”	knowing	n/a	

	[p.5]			
	“Living with a life-threatening cancer was highlighted by some participants as having resulted in a completely new attitude to life and self-insight, and they expressed having experienced personal growth in a positive sense during their period of illness. **Existential uncertainty** had raised the question of what was important in their individual lives and promoted the insight that there is no point in wasting time on boring things - it was more important to choose things that were interesting and fun.” [p.5]	self-knowledge; personal growth; meaning	n/a	
	Participant quote: “Yes, you take charge of it. I think something good can come from this, that I've grown as a person too. I have a completely different awareness now.” [p.6]	control; awareness	n/a	
	“Palliative care policy and guideline documents tend to cover existential issues to a much lesser degree than symptom distress. However, when existential questions are not addressed by helathcare professionals, or addressed in an inappropriate manner, patients may perceive a threat to their identities.” [p.8]	identity	n/a	
Kasper, Geiger, Freiberger & Schmidt (2008)[4]	“It became evident in our study that patients are concerned with aspects of uncertainty that, from the physician's perspective, are unlikely to be seen as relevant to the decision-making process. Uncertainty about social integration in a patient's usual life, for instance, or uncertainty about one's ability to cope with disease-related life changes, do not seem to be immediately linked to a treatment decision. However, from the patient's point of view these aspects might be salient.” [p.45]	social; ability to cope	patient uncertainty vs physician uncertainty	Health
Kinnvall (2004) [1]	“The globalization of economics, politics, and human affairs has made individuals and groups more ontologically insecure and **existentially uncertain**. One main response to such insecurity is to seek reaffirmation of one’s self identity by drawing closer to any collective that is perceived as being able to reduce insecurity and existential anxiety. The combination of religion and nationalism is a particularly powerful response (‘identity-signifier’) in times of	identity; existence itself; external world; human life	existential uncertainty vs collective identity	Politics

	rapid change and uncertain futures, and is therefore more likely than other identity constructions to arise during crises of ontological insecurity.” [p.741] “By supplying a consistent structure, religion thus provides order from the chaos and uncertainty in the world. In doing this, religion and nationalism both provide answers to questions concerning existence itself, the external world and human life, the existence of ‘the other’, and what self-identity actually is.” [p.759]			
Kyriacou & Trivin (2020) [1]	“Individuals turn towards identifiable in-groups to reduce uncertainty in social interaction. By reducing **existential uncertainty**, economic development undermines the rationality of in-group bias and, as such, facilitates the emergence of generalized trust. Conversely, income inequality may undermine generalized trust because it makes social interaction less predictable.” [p.26]	in-group; social interaction; trust	existential uncertainty vs generalised trust	Economics
Landau, Greenberg & Kosloff (2010) [1]	“Because the meaning- and value-conferring aspects of death-denying worldviews are fragile social constructions, and confidence in their absolute validity is continually susceptible to threats, people are rendered ***existentially uncertain***: unsure whether their lives have ultimate meaning and significance or whether they are instead fated only to absolute annihilation upon death.” [p.195] “While the exact circumstances of our physical death are indeed uncertain, its inevitability is undeniable and we are aware of the possibility that it signals the self's absolute obliteration.” [p.196]	worldview; threat; meaning significance; annihilation; death; inevitability; obliteration	meaning vs annihilation	Psychology
Landau, Rothschild & Sullivan (2012) [1]	“We introduce a novel account of the role of uncertainty in extremism that builds on terror management theory and the existential theorizing of Ernest Becker (1969). We argue that people are particularly threatened by **existential uncertainty** – uncertainty about life’s significance – because it signals the possibility that they are insignificant and destined only for death. 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. Thus, they may employ fetishism as an ‘extreme’ strategy for minimizing **existential**	life’s significance; death; cultural worldview;	fetishism vs existential uncertainty	Psychology

	uncertainty, reducing their conceptions of the world and themselves to exceedingly narrow dimensions that afford confident (albeit limited) bases for viewing life as significant. We argue that extremism can be profitably understood as the use of fetishism to minimize **existential uncertainty**. To support this claim we review recent research showing that inducing **existential uncertainty** increases people's preference for simplified and concrete conceptions of the social world and themselves in ways that are typically associated with extremism. We then analyze real-world cases of extremism to show that social environments known to breed extremism are likely to arouse acute **existential uncertainty**, and that diverse patterns of extremist thought and behavior can be understood as fetishism." [p.131] "First, we propose that **existential uncertainty** – uncertainty about how, and whether it is possible to, achieve a significant life – is particularly threatening because certain belief in life's significance serves as a shield against anxiety-arousing thoughts of death." [p.132]			
Lewis & Bates (2013) [1]	"The second account of religiosity which we draw on here suggests that religiosity emerges as a source of existential certainty, generating a sense of agency and control, and thus serving to reduce feelings of anxiety." [p.399] "**Existential uncertainty** was measured with the following two items: 'The world is too complex for me'; 'I cannot make sense of what's going on in the world'… […] These items were significantly correlated." [p.400]	agency; control; complexity; sense-making	existential uncertainty vs existential certainty	Psychology
McCoy (2018) [1]	"Through ethnographic description and phenomenological interpretation, this article explores the ways in which the familiar world solicits this individual into reflecting about his sense of self amidst **existential uncertainty**." [p.421] "I borrow the concept of 'solicitation' from Dreyfus and Kelly to describe what happens when worldly phenomena draw responsive activity from the individual. I further suggest that there are a range of solicitations, from those that solicit my basic skills to those that drastically alter my understanding of the world and my self. These more profound solicitations I call 'existential solicitations'.	sense of self; profound	basic vs profound	Anthropology

	Solicitation, in this existential sense, draws from the original Latin sense of the word sollicitare meaning to agitate, arouse, or set the whole in motion. An existential solicitation stirs me to think over my existence, and in a deeply involved way. As Throop notes, varieties of reflective experience may emerge through the ‘dissatisfaction with one’s existential condition’.” [p.423]			
Meranius & Engstrom (2015) [1]	“Prescribed medications are supposed to support future health. However, this study revealed that **existential uncertainty** among the participants was increased by the experience of side effects and by increased doubt that the medication was good for their health.” [p.2759] “The findings provide an understanding of the experience of managing medication and will be useful for both nurses and physicians when caring for and prescribing medications to older people with multimorbidity. It is evident that the **existential uncertainty** involved in self-management of medications is increased by the experience of side effects and fear of medical errors. This creates an ambivalence that can be a barrier for the correct and safe management of medications. It is important that care providers build and maintain empathetic patient relationships. In this way, **existential uncertainty** among the participants seems to diminish, and the patients feel more secure in managing their own medications.” [p.2763]	side effects; doubt about medication; fear of medical errors; ambivalence; relationships	n/a	Nursing
Miké (2000) [1]	“The second imperative of the ethics of evidence is a reminder that there will always be uncertainty. I distinguish between two kinds: scientific uncertainty, essentially dynamic, constantly changing with progress in research, but never fully eliminated, because of intrinsic limitations of the scientific method, and **existential uncertainty**, always present, because the question of meaning, the greatest mystery, is beyond the scope of science.” [p.357] “This view points the way to the synthesis we seek, since in the end we have to deal with more than scientific uncertainty. The source of our deepest anguish is **existential uncertainty**. Beyond physical pain, it is this existential anguish that may drive some people to seek a way out by ending their own lives. To come to terms with the uncertainty of meaning, the ethics of evidence counsels a look at all the evidence, and this includes the insights of religion.”	meaning; mystery; anguish; religion	existential uncertainty vs scientific uncertainty	Technology

	[p.358]			
Mrdjenovich (2019) [1]	“Atheists who experience dissonance between their self-perception and non-belief in God—and agnostic theists who are prone to **existential uncertainty** and have only moderate faith—might experience poorer health outcomes.” [p.1488]	identity; agnostic; belief; non-belief; faith	religious belief vs. religious non-belief	Religion
Parry (2003) [1]	“Although the [long term survivors] in this study discussed cancer as a source of uncertainty, the majority also discussed it as a source of existential certainties and certainty in one's own strength and resilience.” [p.238] “Certainty and uncertainty are linked and dialectic in the sense that the process of unfolding uncertainty (or awareness of uncertainty) simultaneously fosters a focus on and embracing of certainties (appreciation of life, strength, deeper meaning in life, etc.) and the development of faith and hope. It is my proposition that uncertainty and certainty might not be oppositional forces; instead, they might be dialectic, reflexive, and inextricably linked.” [p.239] “Thus, for some [long term survivors], the reconstituted world is not built as awareness of **existential uncertainty** fades over time; rather, it is constructed as uncertainty is integrated into the survivor's worldview and sense of self.” [p.240] “Discomfort with death, so prevalent in many Western societies, might contribute to the development of theories that survivors must repress, cope with, or manage **existential uncertainty**, even when their narratives tell a different story.” [p.243]	strength; meaning; faith; hope; awareness; worldview; identity; death	certainty	Health
Pascal & Endacott (2010)[4]	“Accompanying such challenges is not only anxiety and concern, but also **existential** angst; that is, a confrontation with the limitations of one's own mortality. […] what remains under-researched are the **existential** crisis and subsequent ethical questioning of self, family and place in the social world. Such ethical and **existential** questions focus on the value and purpose of life; that is, how do I lead my life after diagnosis?” [p.279]	limitations; mortality; self; family; social world; value; purpose; meaning;	existential vs non-existential challenges	Health

	"For participants the experience of cancer survivorhood gave life enhanced meaning. That is, the lived experience of cancer survival is not just understanding the cancer experience; it is also making sense of a human life and its ethical and existential challenges." [p.281-2]	sense-making		
Penrod (2001)[4]	"Confidence and control are described as 'feelings' to accentuate that uncertainty is not simply a set of probabilities, but a state of being." [p.241] "Lack of knowledge is often identified as the underlying cause of uncertainty, and many interventions are designed to give the individual the information needed (as determined by an 'other'. Yet, as shown by Dove [1993], this assumption is not always supported; in some cases, bolstering confidence or control mediates uncertainty more effectively." [p.242]	feeling; state of being	confidence/ control vs information/ probabilities	Nursing
Penrod (2002)[4]	"Fleshing out the skeletal framework: concept correction • Uncertainty is a perception of doubt or not knowing that is brought about by cognitive and pre-cognitive ways of knowing. • States of uncertainty are uniquely determined by an individual's perception of being in the world - while opportunities for uncertainty may abound, the state is highly individualized. • Highly individualized perceptions of confidence and control create a dynamic flow of varied types of uncertainty and modes of uncertainty, varying in the intensity of discomfort." [p.60]	perception; cognitive; pre-cognitive; being in the world; individualised; confidence; control; discomfort	cognitive vs pre-cognitive ways of knowing	Nursing
Penrod (2007)[4]	"…whether the doubt is situational (i.e. based on a particular context) or **existential** (i.e. situated as a broader issue of human existence), different *modes* of uncertainty are yielded." [p.661]	broad; issue of human existence	situational doubt vs existential doubt	Nursing
	"Uncertainty is possible only when evidence (cognitive and/or precognitive forms) permeates being to a level of awareness that prompts a tallying and conclusion of doubt or of not knowing that challenges the sense of confidence	awareness; knowing; confidence;	cognitive evidence vs	

	and/or control. This is why distraction and other forms of blocking of authentic being in the world (i.e. a state in which the precognitive and cognitive evidence are embraced into awareness rather than held away from being) are effective barriers to sensing uncertainty." [p.661]	control; distraction; authentic being in the world	precognitive evidence	
	"The derived *modes* of uncertainty specify whether event specific (i.e. situational) or global (i.e. **existential**) issues are dominant in the attribution of doubt." [p.662]	global issues	specific events vs global issues	
	"...it was discovered through phenomenological inquiry that for some uncertainties (particularly in the **existential** mode) probabilities cannot be appreciated; the person simply cannot identify, take in or process evidence." [p.662] "In contrast, during **existential** modes of uncertainty, when different ways of knowing are highly influential in forming perceptions of confidence and/or control, information was not helpful. In fact, during these states of **existential uncertainty** (especially of the overwhelming type), additional or new information contributed to feelings of being out of control and challenged confidence with feelings of being unable to take in or assimilate the information adequately." [p.663]	probabilities; process evidence; ways of knowing; confidence; control; overwhelming	existential mode vs situational mode	
	"This emphasizes the shifting temporality of uncertainty. Uncertainty is a present-oriented state that is influenced by perceptions of the past and future reflected in precognitive sensations (e.g. a feeling in your gut that this is right) or cognitive processing (e.g. consciously choosing a path to meet a desired outcome)." [p.663]	time; sensations; processing; choice	present vs past vs future; precognitive sensations vs cognitive processing	
	"In Nelson's study, the **existential** mode was reflected primarily in the themes that focused on how the women encountered issues when introspectively considering the self with cancer and the self in reference to the world of women with breast cancer. Much like the caregivers in this study, these women were attempting to make meaning that extended beyond the uncertainties posed by	themes; introspection; self; world of women; meaning; grand scale	illness vs grander scale	

	the illness and its treatment into perspectives of life on a ‘grander scale’ (Nelson 1996, p. 73). Introspective processes marked these **existential** modes.” [p.666]			
Persson et al. (2012)[4]	“Lack of information and education often leads to an experienced lack of control that results in uncertainty and causes psychological suffering for the patients. However, the usefulness of information can differ severely. Information was identified as most useful in situational ways of uncertainty but not helpful during **existential uncertainty**, i.e. when knowledge is highly influential for forming one’s perceptions of confidence and/or control. During states of **existential uncertainty** (especially of overwhelming type), additional or new information has in fact been proved to contribute to feelings of being out of control and unable to take in or assimilate the information adequately. Thus, providing information depending on context is essential, and we need to address both situational ways and existential ways of uncertainty. The participants in the present study could be seen living with an underlying **existential uncertainty** throughout their life where uncertainty is a normative state i.e. that people having an increased risk of developing cancer live with uncertainty because they cannot resolve it.” [p.25]	confidence; control; normative state; unresolvable	situational uncertainty vs existential uncertainty	Health
Routledge, Juhl & Sullivan (2009)[2]	“Theory and research derived from the humanistic tradition suggest that in the pursuit of existential meaning and significance, people sometimes pursue goals of personal growth and self-expansion and such pursuits often involve approaching, not avoiding, **personal uncertainty**. People study other cultures and religions, travel to foreign lands, deliberately strive to challenge longheld assumptions and beliefs, engage in self-scrutiny in the service of self-improvement, strive for a sense of uniqueness from others, and pursue intrinsic goals. Such behaviors might provide existential meaning but would not necessarily provide the best means to attain either informational or **personal certainty**. In sum, a compelling theory that offers uncertainty reduction as the core existential motive needs to better consider theory and research that suggests that people’s quests for existential security need not always journey down the road of personal certainty.” [p.236]	meaning; significance;	uncertainty approach vs uncertainty avoidance	
Røysland & Friberg (2016) [1]	“Being physically active while living with unexplained chest pain means balancing between **existential uncertainty** and existential certainty. […] The participants were balancing between doing and avoiding physical activity, and	vicinity; illness; death;	existential uncertainty vs	Nursing

	therein lies an existential dimension. Exposed to existential aspects such as vulnerability during physical activity, the respondents bring themselves in the vicinity of illness and even death." [p.221]		existential certainty	
Røysland et al. (2016) [1]	"An existential dimension exists here in that participants talked about exercise bringing them into the vicinity of illness and even death. […] Being uncertain made the participants vulnerable. Embarking on an exercise training programme seemed to imply a process in which **existential uncertainty** was challenged. Against the background of not knowing enough about the erratic pain in their chests, the participants wondered what kind of exercise they could do, how far they could walk and how much they could carry, for example, when shopping." [p.2010] "…physical activity may have an existential meaning and might influence the way participants experience their own body and abilities." [p.2011]	illness; death; vulnerability; not knowing; physical; body; abilities	n/a	Nursing
Rubin (2018) [1]	"The present research used individual difference measures of the chronic fear of (1) self-annihilation and (2) **existential uncertainty** to investigate the extent to which each of these two different aspects of the fear of death predicted worldview defense." [p.300] "The four items in the Transcendental Consequences scale assess fear about uncertainty regarding what happens after death. Again, the items in this scale start with the phrase "death frightens me because of...," and they end with either "the uncertainty of what to expect," "the uncertainty of any sort of existence after death," "its mysteriousness," or "the unknowns associated with it." Participants responded to the items in these scales and the other scales in this study using a 7-point scale ranging from strongly disagree (1) to strongly agree (7)." [p.301]	fear of death; worldview; existence after death; mystery	existential uncertainty vs self-annihilation	Psychology
Seppola-Edvardsen, Andersen & Risør (2016) [1]	"Serious illnesses confront people with the uncertainty of life itself." [p.367] "Uncertainties that are still experienced in everyday lives of former cancer patients concern dimensions of life and existence, such as expectations of living	life itself; living; dying; health; knowing;	n/a	Health

	or dying, being healthy or not, and knowing how to take part in, enjoy, and fulfil a role in everyday social life. These uncertainties are intrinsic to life itself, but when severe conditions such as cancer are diagnosed, they become more tangible than a vague possibility.” [p.368]	fulfilment; social world; tangible; possibility		
	“Our main understanding of uncertainty and risk in this study does not start from a focus on the risk of cancer recurrence in itself or on whether risk is managed as an objective risk or a perceived risk or whether the approaches to uncertainty are rational or non-rational. Following Jenkins, Jessen, and Steffen (2005) we instead view uncertainty as a state of being, focusing on the symbolic and existential dimension of it - something that a risk discourse departing from clinical risk does not fully encompass.” [p.368]	state of being	clinical risk	
	“The participants talked about the ways in which they trained themselves not to make their worries and concerns a frequent topic of discussion, as this would only serve to validate them and make them more tangible to others, and, at the same time, possibly jeopardise their everyday social life. Drawing on existentialist philosophy, it is possible to argue that the worries or uncertainties acquired a reality through the meaning the participants gave them. When the participants started talking about them, they became much more ‘real’ than when they only existed more implicitly between them. Keeping uncertainties unspoken, became a way to manage them.” [p.376]	social world; meaning	implicit vs explicit	
	“Participants in our study talked about striving to stay in their present, everyday life situations. Central to this was being able to maintain their roles in important relationships to family, friends and colleagues.” [p.380] “We also observed one aspect of 'balancing' which was about including others in one's life, accepting that others were close enough, old enough, resilient enough, about to provide support or simply able to listen to what was shared as a good colleague, friend or relative. Another dimension of balancing was about protecting others from worries and uncertainties that could not be shared without the risk of disturbing their daily life situation.” [p.381]	time (present); relationships; social world; private	private vs shared	

Soroka (2007) [1]	“I argue that Vynnychenko's utopian novel, complex in form and controversial in concept, can be explained as much by his ‘voluntary’ exile in Germany, which resulted in a state of **existential uncertainty**, a feeling of extreme uprootedness, and a desire to overcome this conflict with reality.” [p.442]	exile; uprootedness; conflict	n/a	Humanities
Sperry (2016) [1]	“I will demonstrate how a theoretical knowledge of complexity enables one to grasp the phenomenology of complexity, namely the feeling of living in and with the irreducible complexity of human experience, of being open to novelty, and of embracing the vulnerability that our human **existential uncertainty** entails.” [p.350]	complexity; irreducible; novelty; vulnerability	n/a	Psycho-analytic
Stockl (2007) [1]	“Adamson (1997) describes two uncertainties: one is the **existential uncertainty** of having to deal with the impact of uncertain diagnosis on life strategies, a second is an epistemological uncertainty which afflicts clinicians and patients alike.” [p.1551]	caused by uncertain diagnosis; impact on life strategies	existential uncertainty vs epistemological uncertainty	Health
Tersbøl (2006)[3]	Thus the aim of the present article is first of all to give voice to a group of Namibian men who are either unemployed or in poorly remunerated jobs. […] A second aim is to situate the experiences of men within the context of historical and socio-economic structures and dynamics pertaining to Namibia to attempt to understand how concerns over HIV/AIDS may be marginalised in relation to concerns over identity and **existential doubt**. Finally, the article argues that when attempting to promote reproductive health, including safe sexual practices, in a context where both women and men lack hope for the future, efforts need to go beyond information campaigns. Prevention efforts should take their starting point in experiences of social and symbolic exclusion and **existential doubt**, to promote motivation and agency in the face of socio-economic hardship. [p.404]	hope; future; information; exclusion; motivation; agency	health concerns vs concerns over existential doubt	Health
van den Bos (2009)[2]	“Personal uncertainty is defined as the aversive feeling that you experience when you feel uncertain about yourself.” [p.197] “I argue that although informational uncertainty is important, we should not confuse the concept with personal uncertainty. Personal uncertainty is another	aversive feeling; self-regulation; sense-making; wordview; doubt; instability;	Personal uncertainty vs informational uncertainty	

	type of uncertainty, and I think that, compared with informational uncertainty, it is even more important to understanding self-regulation, existential sense-making, and world-view defense. […] I define personal or self-uncertainty as a subjective sense of doubt or instability in self-views, worldviews, or the interrelation between the two. […] …personal uncertainty is the feeling that you experience when you feel uncertain about yourself.” [p.198] “It is my assumption that personal uncertainty and meaning maintenance processes may be strongly related, at least under some circumstances. Thus, personal uncertainty and existential sense-making may be associated intimately with each other. […] I argue that people have a fundamental need to feel certain about their world and their place within it and that too much personal uncertainty threatens the meaning of existence.” [p.200] “Persons or events that bolster one’s cultural worldviews provide the existential meaning one is looking for under conditions of personal uncertainty; an effect one could label as the **existential uncertainty** effect.” [p.203] “Ironically, it could be argued that the fact that one day we will die is the only absolute certainty that we humans have. This indeed may be the case, but this may confound informational uncertainty with personal uncertainty. That is, this does not mean that there is no social psychological relationship between contemplating death and feelings of personal uncertainty. You can be certain that you are going to die someday, but being reminded about your mortality may trigger feelings of personal uncertainty (e.g., why am I here, what is the meaning of the life I am leading and the activities I am engaged in, etc.). “It is my hypothesis that it is not so much the (informational) uncertainty as to when and how we will die that is important in the relationship between mortality salience and uncertainty thoughts, as Landau et al. (2009) and other terror management theorists seem to propose. I propose rather that an important effect of being reminded of their death is the emergence of feelings of personal uncertainty. After all, being reminded about the termination of their existence probably makes some people uncertain about themselves, their future, or their current personal situation, including their personal cultural worldviews (Van den Bos & Lind, 2009). Hence, reducing **existential uncertainty** or being able to	meaning;		

	tolerate personal uncertainty may be strategies that at least some people use to deal with their awareness of death. This may highlight psychological processes not studied earlier in mortality salience experiments. Thus, at a bare minimum terror management theory should be extended to encompass feelings of personal uncertainty as one of the psychological processes instigated by mortality salience. Personal uncertainty may also be an important concept to study because in everyday life it may be an issue that people are confronted with more frequently than issues terror management tends to focus on, such as death and the utter annihilation of the self.” [p.208]			
van der Merwe & Jonker (2013) [1]	“In this article the authors seek to conceptualize a dynamic and inclusive understanding of personal identity within multicultural democracies such as South Africa, which will draw on both the liberal and communitarian traditions’ respect for the project of self. A preliminary layout for such a project emerges from a literature survey of recent, primarily South African publications on identity and culture, and it suggests that selfhood depends on: a) virtues, cultivated within cooperative communities which allow for effective freedom; b) a venture into **existential uncertainty**, which alleviates that fear of loss of identity that is supposedly central to many multicultural conflicts; c) the hermeneutic construction of identity through narratives that allow for a plurality of voices; and d) the creative transcending and re-interpretation of values and traditions. The authors contend that such an understanding of identity goes some way towards addressing the question of the way that diverse personal and group identities are to be accommodated in South Africa’s multicultural democracy, and to rethinking the unity which underlies diversity without resorting to liberalism’s reduction of personal identity to rational autonomy.” [p.271]	loss of identity	n/a	Humanities
Warran, Fancourt & Perkins (2019) [1]	“The first superordinate theme deals with how the choir may provide support in the face of **existential uncertainty**. For example, participants described the choir as providing a distraction from thinking about death, in addition to an awareness of death in the rehearsal room which heightened the connection between choristers: I think the combination of the music, which is so joyful, and the sense of mortality that must shadow all of us in that room makes it particularly powerful, and I understand people better. (Christopher)	death; connection; mortality; purpose; hope	death/mortality vs connection	Psychology

	Christopher also reported that the choir 'does seem to inject a kind of purpose into the week', which was supported by David, who commented that the choir 'gives hope', and Jason, who stated that the choir provides 'something to aim for, instead of having nothing to aim for'. It would seem that whereas having cancer brings about a heightened sense of mortality, the choir facilitates enhanced connection with others and provides a sense of purpose. This suggestion was reinforced by, and interconnected with, the first subtheme in this category: the dichotomy between the cancer experience and the choir experience (subtheme 1.1)." [p.4]			
Wegleitner, Schuchter & Prieth (2020) [1]	"What does end-of-life care mean in late modern western societies? Generally speaking, this subject deals with the collective coping process with the universal and **existential uncertainty** of dying in – in principle – precarious and fragile liquid modernity." [p.987]	death	n/a	Sociology
Yair (2007) [1]	"Actors are actually driven by **existential uncertainty** and personal anxiety, vying for self-esteem rather than for objective future payoffs. This motive of action appears to be 'warm' and emotional; one that is intimately related to facets of self and identity." [p.683] "A doctor's choice to emulate esteemed colleagues is rational in that conformity allows effective decision-making and the reduction of **existential uncertainty**." [p.688]	self-esteem; emotion; identity; conformity	rational vs emotional	Sociology

<u>Notes</u>

The superscript numbers in the first column indicate the following:

- 1: result from search for 'existential uncertainty' (n=38)
- 2: result from search for 'personal uncertainty' AND 'existential' (n=2)
- 3: result from search for 'existential doubt' (n=2)
- 4: identified from reference lists of articles yielded by searches 1-3 above (n=7)

In the interests of clarity, the in-text citations have for the most part been removed from the quotes above.

6.9 Appendix 9 – Sources supporting the four attributes of existential uncertainty proposed in the Phase 1 analysis

The undetermined but finite nature of one's own being-in-the-world	Brothers (2008, 2009, 2012a, 2012b); Cohen (1993); Gullick et al. (2017); Furtak (2019), Karlsson et al. (2014); Landau et al. (2010); Landau et al. (2012); Parry (2003); Pascal & Endacott (2010); Penrod (2007); Røysland & Friberg (2016); Røysland et al. (2016); Seppola-Edvardsen et al. (2016); Spinelli (2015); van den Bos (2009); Warran et al. (2019); Wegleitner et al. (2020)
Identity, meaning and choice	Adamson (1997); Ahmed, et al. (2019); Brothers (2009); Gandsman (2009); Gezentsvey Lamy et al. (2013); Hammack (2010); Hoffman (2009); Karlsson et al. (2014); Kinnvall (2004); Kyriacou & Trivin (2020); Landau et al. (2010); Landau et al. (2012); Miké (2000); Pascal & Endacott (2010); Penrod (2007); Soroka (2007); Spinelli (2015); Tersbøl (2006); van den Bos (2009); van der Merwe & Jonker (2013)
An awareness that is fundamental, ineradicable and always available	Ahmed et al. (2019); Brothers (2009); Cohen (1993); Furtak (2019); Kinnvall (2004); McCoy (2018); Landau et al. (2010); Landau et al. (2012); Miké (2000); Pascal & Endacott (2010); Penrod (2007); Seppola-Edvardsen et al. (2016); Sperry (2016); Spinelli (2015); van den Bos (2009)
Manifestation at different levels of awareness	Brothers (2009); Cohen (1993); Hoffman (2009); Karlsson et al. (2014); Kasper et al. (2008); Penrod (2001; 2002; 2007); Soroka (2007); Sperry (2016); van den Bos (2009); Warran et al. (2019); Yair (2007)

6.10 Appendix 10 – Number of words corresponding to each code (aspect of uncertainty) after chunking

Aspect of uncertainty	**Number of words**
Diagnosis	6,111
Prognosis	6,102
Casual explanations	903
Treatment	7,532
Structures of care	5,087
Processes of care	5,375
Psycho-social	18,965
Existential	23,804

6.11 Appendix 11 – Section of coded interview with Sam featuring psycho-social uncertainty and existential uncertainty

Mmm. Mmm. You, you, you said there about your body not playing along. Can you talk to me a bit about, about, em, your relationship with your body and, em, you know, how that's evolved over that time?

Yeah, yeah, yeah, yeah, so it's been a weird one because in some ways cancer makes you sort of re-evaluate who you are, which is, you know, tricky, em, I mean, so for me it's like different factors, so one factor is, like, mobility, you know, like, I don't like walking with a stick, I'm embarrassed by it, I think, you know, that's unfortunately a socialised thing, but, you know, it is the way it is, I mean, you're 32, and I think being in the kind of queer world, like I think men that sleep with men can be very, very vapid at points. I think all cultures can, but I think there is a heightened value of it at, at, in certain spaces like bars and areas where you meet people so you can kind of feel excluded from that by having a disability, em, and I should say newly acquired disability, cos that's where the problem is, cos it's newly acquired it's getting used to that, em, and feeling with, with the mobility stuff but also with my health in general, you know, feeling undesirable, feeling like no one's going to want to put up with it or have to deal with it, and even when I have tried dating, they say they will but then there's always a problem around my doctor's appointments or they're annoyed that I can't go out or, you know, on holiday I spend half my day in bed, you know, it's just, you feel like a drag, em, you know, and then there's other things, you know, it kind of pulls out of the works of, like, gender and the way you see your body, and when there's also a national discussion around that, like, I grew up with a lot of gender dysphoria but didn't really know what that meant, you know, I'd just sort of lay in the bath and look at my body and not understand it or not like it, em, as a kid I mean, and then, you know, to then as an adult have this national conversation, and luckily I have a very good like queer circuit to talk through these things with, but then you add the cancer on top and it starts to make you really process your body and, kind of, there are certain parts of it I have come to terms with, which is better, I've been like, you know, non-binary and accepting what that is and still struggling with, you know, social standards of proving that, but, but then there's this other part which is the cancer, so that's completely out of my control really, you know, it's just, and it's, and it's tricky because, you know, people as well can sort of without meaning to devalue the whole thing because they're like oh but you look good, you know, you look fine, and like, well, it doesn't change anything [exhalation, chuckle], like, and it's also this really strange rubric that other people have of what a cancer patient should look like, and if you

Existential

Psycho-social

Existential

Psycho-social

therefore don't have that, you don't qualify for their sympathy, instead you get their curiosity or disbelief. I mean, I've had it in bars where people who I know, em, will tell me, you don't look sick, I don't believe you, and like, I mean, I mean also I'm kind of used to that from being queer, when you first come out everyone's just like oh you don't look that, I don't believe you, you know, this kind of thing, it's just like, I for one don't have to prove to you what's happening in here, but two, your perception of it doesn't change it either, so, you know, it's just kind of noise, but it's noise you have to battle through, and it's, and it's something that's been sort of a weird thing of like, it's that intersectionality of becoming newly physically disabled, being disabled by cancer, you know, and then there's other things of like growing up dirt poor and all that kind of stuff, but being a queer person in that is just a lot of stuff to fit together and sometimes trying to fit it all together and be comfortable with the way they intersect can be a bit of a minefield.

Existential

6.12 Appendix 12 – Section of coded interview with Sam featuring different aspects of uncertainty in rapid succession

Mmm. And if there were, eh, answers to some of your questions, like, what are the questions that you desperately want answers to, if they were available? What are the kind of big questions on your mind?

I think [sigh], 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? You know, like, is this going to be it forever, you know, because, I mean, I remember thinking about a year and a half into my treatment, I remember thinking about a year and half in, thinking, bear in mind I was on a medication that was making, like it was like giving me really sort of psychological impact but thinking like I don't want to do this, I don't want to do this forever, this, it took me a while to, maybe I haven't fully, but it's been a process to let go of who I used to be, you know, and people find it strange when I say that cos, you know, you're the same person et cetera, but in reality people that know me well know that I'm a very different person. Your mood changes, your outlook changes, all that kind of stuff, but beyond that, from a personal aspect, your physical capacity, ability to move in the world changes. You know, I used to be very productive, have multiple projects on the go, walk everywhere, be very healthy, et cetera, so letting that go, it's tough, but then not knowing what the rest of your life is going to be is almost even worse, it's like am I going to get back to that? No, probably not. Em, am I going to survive this? Who knows? Is this new medication actually going to do what it's supposed to do? You know, it's, there are these big questions, I mean, obviously minor questions of like do I have a mutation on this disease, like is that why it's not working, you know, kind of, stuff like that but, em, but those are kind of, you know, they're specifics that I kind of almost have to not entertain because you would hope that the doctor would have considered that if that was an option, you know what I mean, it's like, it's kind of, I have to think on things in my sphere and trust them to do the stuff on their side because otherwise if I start second guessing every decision, it's not healthy for anyone, em, but yeah, but the idea of the big questions that I'd want to know, just am I going to be alright? Because it doesn't feel like it, and it hasn't felt like it, and, and if I'm not going to be alright, even if it means I don't have a good quality of life and I'm still here, like, am I going to be happy? Like, compare that to the life I used to have, you know, I don't feel happy, I don't feel, I don't feel fulfilled, I don't, I don't feel like I have as much of a place in the spaces I used to be in, so yeah, it's just, just want to be healthy and happy.

Existential

Treatment

Causal explanations

Diagnosis

Structures of care

Processes of care

Existential

6.13 Appendix 13 – Immersion/crystallisation process: from key words to themes

Em, so [sigh], you know, so it kind of stems from like I don't really believe in good luck, I believe in opportunities and taking advantage of them, you know, like things just happen if you kind of work towards it. I'm not saying that you know like [inaudible 6 seconds – technical glitch] ... can pass you by, and then I think the not believing in bad luck is because, eh, sort of, eh, [sigh] if I was to believe in some kind of like existential reasoning around all the bad things that have happened to me, then I would have to subscribe to there is some master plan or something, some extraneous variable that has a direct influence on what's happening but I'm, you know, I have cancer, I'm homeless, all these kinds of things, but I've survived, barely survived a hate crime, em, had open chest surgery from it, abuse, child abuse, like all the, all these things that if I was to start believing in these sort of extraneous explanations of or machinations of reasoning around what's happened, I think it just pulls away from the reality that just bad things happen, and I think it gives you a false hope that things will get better without making them better. So yeah, it's just that thing of like when you've had so many bad experiences to believe that there's some kind of uptick when there hasn't been one, I think it's just safer just to think, you know what, it is what it is.	luck agency worldview survival causality acceptance
I guess there's two somatic markers, I suppose. One would be kind of like nausea, to be honest, like if I think about it, it's just, it doesn't feel good, like. But also, cos the anxiety problems I have, nausea is like the one symptom I have tied to my anxiety, so I feel like it's just related to that, but also it just then compounds it, cos when I think about my future, I just feel sick, I'm just like, and there was the kind of additional aspect, going back to what I said before about this isn't the kind of life I recognise or want, I don't want the life that's coming either. You know, what I really want is to go back to how I was, but I can't do that, so I have to fight and work towards a life that I'm not even happy with. Weird. The other thing is 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. I think, I think a lot of it, a lot of that feeling comes down to the fact that I don't feel like I have control over my life at all, you know, I can't go where I want to go, can't take holidays I want to take, no control over my health, no control over my housing, you know, I don't have anything other than small things that I make manage myself, and when, when I think about that, that's when I just kind of have that weight over me, I'm just like [big sigh], you know, this isn't, this isn't fun. [Chuckle]	body nausea anxiety future time past time weight body energy direction control weight

Keywords	**Theme**
Luck, agency, causality, acceptance, control	Questions of control and agency
Body, nausea, anxiety, weight, energy	Embodiment

6.14 Appendix 14 – Themes and indicative quotes

Aspect of uncertainty	Themes
Diagnosis	What are these symptoms (pre-diagnosis)? Is the diagnosis correct? What are these symptoms (post-diagnosis/post-treatment)?
Prognosis	Time and death Variability and unpredictability Direction and recurrence
Causal explanations	How has this happened to me?
Treatment	Side-effects and quality of life Efficacy Weighing up (decision)
Structures of care	Negotiating relationships Transparency Reassurance
Processes of care	Accessing the right help/information Acknowledging the limitations of my role Managing myself
Psycho-social	Practical/material concerns Socio-political/socio-cultural factors Managing relationships
Existential	An undetermined future Questions of control and agency Identity and meaning Living with the spectre of dying Intrusion into awareness Embodiment

Participant quotes

Code:
[1] = ‘Liz’
[2] = ‘Jane’
[3] = ‘Eddie’
[4] = ‘Sam’

[5] = ‘Brian’
[6] = ‘Jim’

Note: some identifying details have been redacted from quotes to ensure anonymity.

Diagnosis

What are these symptoms (pre-diagnosis)?

[1] Oh, it's cancer, it's cancer in my liver, eh, and it's cancer in my brain, that's what I've got as well. And I used to feel the lymph nodes, and I was sure I could feel like swollen lymph nodes as well, you know, em, it was very very, the pain was very very real, em, and then my husb... they rang me and said we've got your results, can you come down, so em, my husband and I went down straightaway, em, and she said yeah, you have got cancer, definitely, em, it's in... it's in both breasts, but both of them are very treatable, you know, I can treat this for you and it will go away, and when she said that, all my pain went away as well [laughing], I never had the pain under my ribs, I never had the pain in my head, em, all the pain just went away as well with the uncertainty, all of this, all of that went, you know, so...

[1] I reckon it was the worry that I might have secondaries, you know, I might... I've got cancer, I definitely, I knew I had cancer in my breasts, I didn't need the biopsy results, I knew that, I think, but what I didn't know was whether I had secondaries anywhere, em, and if I did, secondary breast cancer they can treat it for a while, but, you know, you will die eventually. So I suppose it was the uncertainty of not knowing whether I had the secondaries, but it was, and it wasn't until, she did the biopsies of my breasts first, and it wasn't until she went for my lymph nodes that I thought, oh my God, really, it really hadn't occurred to me that I could have it elsewhere

[2] then having a scan, that was an ultrasound, and then having a cystoscopy where they just have a look up, and she said, oh, that looks just superficial, we could just take that off, that looks fine, if you're going to have something, that looks fine, so we all went, ah-ha [= sound of inhalation, exhalation], you know, that, thank goodness for that

[3] I had my, em, I had my issues for about a year before they decided to chest x-ray me cos I didn't smoke, and then when they did diagnose it, it was, you know, they were very, very apologetic and very kind, but the fact remained it was what I've got, and I'm going to have to live with it, and that's, that's where I am with it now.

[3] Well that's taken on the Lake District, and that was taken on the day when I first realised I was, I was probably ill because whenever we go there we do this walk, and when we walk this walk, em, more often than not, I'm leading the way and I'm having to wait for her to catch up, but this particular day, I mean I'd been complaining to the doctors about this irritable cough, em, like a chesty type thing, em, and stuff like that, but what I didn't realise because I didn't do any physical activity other than the normal things like driving around and shopping, that I really couldn't walk up this hill anymore and I was gasping for breath and I really, really, really, really struggled, em, and of course, when we got down again, I said to [my wife], well I'm not fit, I'm going to have to book into a gym, because this, this isn't , em, this isn't right. And when I come back, I did book into the gym, [my wife] said, well go to the doctors again, because,

you know, cover it both sides, and that's when I, I saw this different doctor, and he got me to have a chest x-ray, and, and, and what they found. And so, I guess, everytime I see pictures of the Lake District now, or if I'm going through my old photos, it sort of brings me back to that day where, em, I suppose I finally realised I was ill, em, you know, so, so something that brings them thoughts into me, that does.

[3] Now, I didn't know that I had but I suspected I had lung cancer, and I was thinking to myself, well, how am I going to cope with that

[4] the situation when I was diagnosed was kind of crazy anyway, just sort of like, I had food poisoning, got a blood test, found out I had cancer basically, after like a month of ops[?], em, and I was in a foreign country, had to come back, like it was all crazy

[5] I'd gone to my GP, eh, with this [?] symptoms and she said, so she took a PSA test, as you would [?], and then, when I came back to get the results of the PSA test and it's only two point two, em, em, but she said, I'm going to give you an examination anyway, if that's alright, and I said yes, em, so she gave me a digital rectal examination, em, and she said, I'm not an expert but that doesn't feel right, I'm going to pass you on to a urologist, and then that, that process started, em, so that was a bit of a surprise because with a PSA level of two point two, that, that is well within the, it's quite low for a fifty-[?] year old man, em, so I wasn't expecting what happened next, which was the urologist gave me the same examination, with her fingers, em, and, eh, said yeah, that's not right, and then the whole process started of going in for biopsies, MRI scans and various scans and stuff, and then the operation

[6] I'd only just come out, em, in the June, em, of that year, 2016, and em, sort of, I was starting a new life and I'd been to the doctor's about certain things and one of the things I'd been to is I'd been to the doctor about erectile dysfunction and, em, the doctor I saw, I'd explained to the doctor about just coming out and everything like that and wanting to, em, eh, improve, you know, sort of, I was first sort of struggling with erections when I was sort of meeting people, and the first thing he suggested he wanted to do blood tests, em, so obviously blood test was done, blood tests, eh, were sent away and, em, then I get a phone call, eh, to go in to the, the doctor, and, eh, I saw another doctor and he explained that, em, all your bloods have come back and everything is fine, but your PSA level is raised to 26.4, em, and we'd like you to, em, you know, I'd like to recommend you have a biopsy, em, which he did

Is the diagnosis correct?

[2] I have some more questions cos mine was a mixed tumour, so it was low grade with a focal point of high, and they told me that's fine we're just casting it as low grade and the more I've thought about it, the more I've got questions which the nurse couldn't answer. Being a pharmacist myself, I can read the papers and understand them, and I know it's subjective, so I just have some questions, em, not necessarily a second opinion, just have some questions, so all of that I feel is uncertain.

[2] I'm saying well yeah, it's low grade, but I've got this kind of small focal point and it's not the very, it is low grade but it could have been a G1, mine's a G2, well actually you read all the stats, it doesn't really make any difference, low grade's low grade, you know, it doesn't come back any more or progress any more, so I'm now looking at the... making it more uncertain for

myself, because I'm looking more into it, whereas if you had a phone call or someone who wasn't medical and just told it was low grade, not to worry, see you in three months, most people would accept that, and I haven't been able to, and it's made me more uncertain

[2] and when then I looked at the guidance, NICE guidance, and I saw the word multi-focal on, and thought well does that mean what I've got, you know, with two different sorts inside, or does that mean you've got a papillary and you've got one something else, or you've got one somewhere else. And she didn't know, so that then increased the uncertainty again.

[2] I think I'd reached the end of her knowledge, you know, I think, I 'm asking her difficult questions that she doesn't know the answer to, and she knows that, and that's fine

What are these symptoms (post-diagnosis/post-treatment)?

[1] The only thing that does happen is if I do get a pain that I'm not expecting, I immediately jump to cancer, I don't think, oh God, that might be trapped wind, or you might just have a bit of a headache because you've got a bit of a headache. I immediately jump to, oh my God, I wonder if I've got cancer there because, you know, when I did find, em, the cancer before, I'd been so well

[2] And I'm speaking to the consultant on Monday anyway, and I know that I shouldn't be worried about [blood in urine], but immediately then it increases my uncertainty again. You know, almost knowing less is better. [Laughing]

[6] It was, yes, I mean, it was, em, it was a thought was well why have I got sort of the blood, but my first thought was well is this yet another thing, a side effect from the radiotherapy, and it was, that was my concern, not that I'd got bladder cancer, that was, that was sort of the second thought was well it could be that.

***

Prognosis

Time and death

[1] When I got the cancer, em, I said to it, you can have a year of my life, and that is it, you know, you started with me in May 2018, May 2019 you're off, you're out of my life. It hasn't quite worked like that, em, but as far as I can I do try and think, I haven't got cancer now, I am cancer free, but it doesn't, it doesn't always work like that, you know

[1] In my mind, I think if I had secondaries, I was going to die. So the question is probably the same. It's just how long will it take for me to die, I suppose – and how much help can they give me, so that, you know, so I do die comfortably, or that I can live for another few years, and see a bit more of what I want, you know, do a bit more of what I, what I want to do really.

[2] I think because we've moved in different stages, em, from, you know, seeing it was a lump and thinking the worst, and I was going to be dead in five years

[2] Everything else, I'm still planning, I'm still talking about the future, still talking about holidays, but there's that little bit there that says, what about this? You know, don't you forget me! [Laughter] And, I'm, what I'm hoping is as time moves on, it will still be uncertain, and I know for the cancer I've got, it's going to be like that cos it's constant surveillance, em, but hopefully living between them, you go back to a normal life rather than spend three months worrying about it, which I'm doing at the moment

[3] the initial diagnosis or the prognosis was very bad because it was stage four and they don't give you long for that , and I remember seeing a form being signed by the cancer specialist nurse off to the, em, PPI, PIP department saying less than a year to live and, em, although she said, em, don't Google anything, everybody's cancer's different, when you, and she said don't, before you even ask, don't ask how long you've got to live because everybody's different.

[3] The biggest question I would ask is the one I was afraid of asking, was how long have I got? Really. Because it's, it's like everything, innit, if you're at work and you need to develop a project, and the first question you ask is, how long have I got to develop it, and then it'll come along, well what's the investment, what resources can I have, em, you know, and everything else. If I'm looking towards dealing with an illness, it's the same thing – how long have I got? Cos that'll help me decide whether I take early pension and get the caravan or, you know, we sell up the house and downsize, em, or whatever we do with our lives. And from a practical side of things, that's what I should have known, but from an emotional side of things, I didn't really want to know or ask that question.

[4] I don't really think I'm going to make it into my forties, I'd like to, I'm 32 now, but, you know, I've gone through treatment after treatment after treatment, we're running out of treatments, the longer that it is detectable in your blood, the more likely there's a mutation which is treatment resistant, you know, there is obviously the chance of a bone marrow transplant, but I don't have any direct siblings that could help

[5] that sort of sword of Damocles, I mean it's been nought point five, nought point six for, for two years, yeah? So that should be fine, but there's always that worry when the next one's coming up, well what if this time it had gone up, you know, what if it's this time? And em, I think well there's a 10 year mark, okay I'm two years into it now, does that mean I've only got eight years left? Maybe that's, maybe that's six, maybe that's 12, maybe that's, maybe that's forever, who knows?

[6] towards the end of the sort of discussions, you know, I asked a very simple question – how long will I live if I don't have treatment? Em, you know, is, you know, if, if you don't treat me, you know, how long will I live? And they said well two, three, five, ten years – it's uncertainty. I said, right, well thank, thanks for letting me know, you know, I, I knew I had got the answer I wanted

[6] At that point I was in a not, eh, I wasn't particularly bothered whether I lived or died at that stage in my life anyway, em, and it was just, eh, just a question I wanted to know the answer to, you know, was well, if I'm going to get, you know, 15, 20 years, and I was, em, what 63 at the time I was diagnosed, 63, 64, so, you know, I was of, hadn't got sort of a whole lot of life sort of in front of me, as I sort of saw it, I said well I'm not going to make it to 70 anyway, and I'm what 67 now and, em, yes I do want to live, em, a hell of a lot longer now, you know, cos

circumstances changed and, em, that, but it was always a sort of, it was a consideration was well if I can get a long time, why go through all the sort of treatment and everything like that

Variability and unpredictability

[1] Well, do you know what, my eye lashes never fell out. [Laughing] Whoop whoop! I mean, it's different for everybody, and the nurses were telling me, oh you know, maybe your eye lashes won't fall out, and I was thinking, oh, they're bound to, you know, I've... at my age, I've got a lot of friends who have had cancer, breast cancer, and I've seen them all with, you know, no eye brows, no eye lashes, but my eye lashes stayed there – how wonderful is that?

[2] I had no doubt that I wouldn't see whether [my grandson] was interested [in music] or not. I'm sure I am now, because, you know, my diagnosis isn't, isn't terminal, you know, my diagnosis is such that I should potentially, you know, I think my, my particular prognosis is time to progression is only 11% of people, so I should be feeling happy [laughter], you know that I've got the best diagnosis of my sort of cancer, but I can't put myself in that place at the moment, other people are getting frustrated with me because I can't put myself in that lucky place. I know, I know it could have been a lot worse, but I'm, I'm predicting the worst of all the outcomes, well, I'll be that 10%, you know, so, and I'm frustrating everybody else [laughter]

[2] And I'm putting the worst prognosis on it all, and you know, he says stop reading papers about it, because all I find is it's very subjective, so there is no right answer, I'm not wanting something else from the consultant really. I just want more clarity

[2] I suppose the thoughts are re..., they do vary because when I get a comment like my consultant told me I'm more likely to be run over by a bus outside the hospital, I think yes, yeah, absolutely, of course it is, of course it is, that's what I've got, but why wouldn't I be that 11 per cent, you know [laughter], so yes, that does make me feel better

[4] The other thing with the, with the blood test results is they're just so all over the place. Because the PCR has a certain amount of variance, you just, you just never really know what, I think the variance can be as much as ten per cent sometimes, so it's kind of wild, because you can have all this anxiety and you want those blood results

[4] my numbers have been going up, which is the wrong direction, have been going up recently, but then we looked at it yesterday or the day before, the day before, and, and they'd gone down again even though I'd come off medication, so, so then there's even more uncertainty of like, well am I getting worse or how does it come down off medication, that like, was the medication bad, like, like was it affecting stuff in a negative way or is the test just messing up again? Because there's a variance in it.

[5] medically they think if you survive five years, you're cured of cancer, yeah? Cos that's the, the, the time horizon they, they, they work on. Cos they think, if you've gone for five years, you could die of something else in five years, so, eh, but, em, which is fine from a medical point of view, but from a, from a real point of view, seeing that, that, that, yeah, things, there seems to be a reoccurrence even in people who've had a radical prostatectomy at around the 10-year mark, some have had 15, still, still completely free, em, some haven't got to 10, you know, they've got about six or seven and it's come back with a vengeance, em, so, eh, so yeah, so

with that, sort of, because that had gone into my mind, you know, why would I want to waste any more time

[6] it was the answer I suppose, em, was, I expect, you know, the kind of answer I expected, and I know that there is always this uncertainty, you know, that, em, you know, people, oh yes, you've got six months to live type thing, and then five years down the line, em, you know, they're still going, you know, there are, friend of ours was, em, diagnosed, em, at the end of May with, em, liver and lung cancer and within sort of two weeks of being diagnosed she was dead, you know

Direction and recurrence

[2] So acceptance, I think, and I think when I can accept that, I can accept the uncertainty of having to have regular, cos this apparently is the cancer that comes back most frequently, but mine I know is least likely to progress, so it's going to be a nuisance, and there's going to be anxiety before each scope, and I think I've got to accept that

[3] I'm certain I've got it, and I'm certain that it's incurable. I'm not certain when it comes back, but I know whatever treatment I'm on, it will do, because I'm a member of this club, which I mentioned to you before, there's 300 in the UK have got this particular rare form of cancer, in the UK, more in the States, and I've been along to their forums, their meetings, and I've spoken with oncologists, and, eh, people from America, you know, cancer leading specialists from America come along and spoken to us as a group and, em, it sort of puts the, puts the cancer to bed, but the body finds a way to overcome the treatment, em, so often, when I go on to the forums, em, you know, someone would say, well my time's come, you know, me, me tumour's grown by this or I've got certain metastases come here and there so I've got to change me treatment and, em, I have to say, more often than not, the treatment that they move on to actually works and it gives them another new lease of life, but there are some very sad instances where it hasn't worked and, and we've lost them.

[4] I've never gotten to near that undetectable stage ever and it kind of just goes slightly towards it and then comes all the way back to sort of a midline zero, and, you know, so I've never really gotten out of the uncertainty of what's going to happen with my health, I've never got to a stable position where it's just like oh, you know, it's like it's not there, which is what you're promised when you first start, you know, within a couple of years, we're not even going to be able to find it, so when you never get to that positive space where there is kind of this safety, em, it's hard to kind of think in a hopeful frame, you know

[4] but then, when it's going the wrong way, you know, that, that result doesn't really make you feel better because it's just a mark on a bad path, and you have these questions of like well maybe it's continuing to get worse? Em, that's why the last blood test was really confusing because it said it had come down despite the fact that before that when I was on the medication it was going up.

[4] So this idea of, okay when I look at a blood test I understand what's going on, this is fine, and it's, you know, you can see the evidence of where it's going.

[5] it's stayed around the nought point six, nought point five, nought point six every six months now, but it's been stable, but as I get close to the date when I have my PSA test done, as I have it regularly done, and then have it done and waiting for the results, that's, that's not a great place to be because there's always a worry that if that number goes up, it's come back.

[6] there's always the sort of the uncertainty, even now as obviously every time I have a PSA test, em, you know, there's always the uncertainty that, em, you know, it's, it's going to be, sort of start rising.

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Causal explanations

<u>How has this happened to me?</u>

[2] I mean, I'm not 60 yet, em, I'm a never smoker, never been around smoking, em, I'm fit, I run, em, three times a week, we're walking 45, 50 miles, you know, during the... and running, we were, em, so I, whereas kind of 1% of women get it, well I'm less than that 1%, so to get something like that makes me angry, but it doesn't, would I feel better if I had breast cancer because that's a ladies' disease [laughter] and common? No, so it's a silly argument, but it makes me angry I've got something I shouldn't have had, you know, as someone's fit and healthy, and so, I can't put myself into that, em, I'm one of the lucky ones in my group, em, and so I think I will do, but at the moment I feel kind of pretty uncertain

[2] we always used to say, you know, we've exercised for... since we were married probably, you know, regular runners, regular gym, I mean, even in the lockdown we've been walking, you know, miles. I had the procedure on the Tuesday, and on the Sunday I walked seven k, you know, em, so I think we all, in my mind, I almost thought I was invincible, I look after myself, I've never smoked, I exercise, I enjoy my job, I don't get particularly stressed

[3] Well it's, I mean, it's a certain stigma about lung cancer anyway, everybody that gets lung cancer seems to be tarred with the brush, well you brought it on yourself because you shouldn't have smoked.

[4] I think the not believing in bad luck is because, eh, sort of, eh, [sigh] if I was to believe in some kind of like existential reasoning around all the bad things that have happened to me, then I would have to subscribe to there is some master plan or something, some extraneous variable that has a direct influence on what's happening but I'm, you know, I have cancer, I'm homeless, all these kinds of things, but I've survived, barely survived a hate crime, em, had open chest surgery from it, abuse, child abuse, like all the, all these things that if I was to start believing in these sort of extraneous explanations of or machinations of reasoning around what's happened, I think it just pulls away from the reality that just bad things happen

[6] As I say, the cancer, it was just something that, you know, I've, I mean, this is just prostate cancer, em, there's other cancers within the family, and eh, because I worked in the building trade from 1970, em, and we used to, em, use asbestos products, em, in the construction industry in those days still and, em, a lot of buildings where we used to go and survey, although I wasn't actually on the tools or anything, I would be in areas where Asbestolux and that was

being cut or spray asbestos was, eh, used for fire insulation on the steel work, em, even in the 70s, it's like they were spraying the fibres, em, in a, a liquid onto steel works so I've always got, em, at the back of, eh, sort of, I suppose it's there that at some point I could end up with lung cancer from that, em, you know, or pneumoconiosis, not pneumo, asbestosis rather.

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Treatment

<u>Side-effects and quality of life</u>

[3] cos one of the first things they did, well the first thing they did, they, they, they gave me some radiotherapy which took away this growth on me lymph nodes near me voice box, which meant I didn't have that irritating cough anymore and I could breathe a bit better, so that was good, but when I went onto the tablets, I mean the very first time I took them, I brought them straight back up, cos they was, they were, they, you know, I vomited them. They gave me a different anti-sickness pill but one of the side effects for these tablets was chronic, em, diarrhoea and it knocked me confidence cos I couldn't go out for fear of having an accident while I was out sort of thing and it took away me taste buds and me sense of smell, and I'm thinking to myself at the time, probably be, into me mindset at that time, well is life really worth living anyway if it's going to be like this all the time?

[3] the other thing that happened was, as a result of taking the treatment, I started getting palpitations in me heart, and, eh, occasionally, I mean they weren't consistent, but I, I would have an, I'd have an affray[?] where it would happen, em, and when they did, me heart beat went up to over two hundred a minute, and the only way they could stop 'em was me going to hospital and having it slowed, you know, not, not by, you know, I, I did come close to being shocked once, but they've generally been able to administer a sort of drug and then it slowed me heart beat down, and then it stayed there, but I started having it quite frequently, about three times a week, sometimes, then I wouldn't have any for a fortnight, and then I'd have it again, and, so I didn't really want to go anywhere for fear of having to be rushed into hospital, you know, it's not a pleasant thought, and again it's saying in the back of your mind, you wouldn't enjoy it because all the time you're thinking, well I hope it don't happen.

[4] if it stops working like the others have, then it's on to experiments, you know, so it's not even road tested stuff, and they've tried to put me on one before but it comes under the fact that I'm really unlucky when it comes to the side effects, I get like all the bad side effects, it's affected my mobility, I struggle to walk, especially up stairs and all this kind of stuff, em, and nap all the time and get dizzy, like, I can't drive anymore, can't work, em, and then they want to put me into trials and studies in the hope that that will be better for me but there's no certainty it's going to be better at all because each medication has been problematic, so instead they want to make me take a risk of another medication that could be just as problematic, but I also have to do bone marrow biopsies for investigation on top, so, and that's just, [sigh] it's, it doesn't seem worth it to me, it's just like, you know, because I've been pretty unlucky and I don't really like the idea of luck but [chuckle] you've got to put it on something

[4] there have been times where I haven't been able to take the pills because they've really screwed me up, they gave me like a really big anxiety problem which developed into OCD, another pill gave me depression, you know, like they have really bad side effects beyond the mobility stuff

[5] so the results of the treatment, which is I've had a radical prostatectomy, so they take away the prostate, they take away the seminal vesicles, em, they did take away all my lymph nodes in my pelvis as well, em, they tried to spare some of the nerves around the prostate, em, and

the surgeon thinks he has spared some, but it's sort of like, they say well it will be at least a year, maybe two years, maybe never before you start to get a natural erection back, eh, and get normal sexual function back, em, and I hadn't really thought about it before the operation, yeah, I was told some things that would happen, I knew, you know, so you can't have children, or I had a vasectomy 30 years ago so children was off the question anyway

[5] So I'm getting to the point now after 24 months, 25 months now that I don't think it's going to come back. Yeah. Em, it's not, there's, there's, there's... yeah, I'm not going to get a natural erection again, that's not going to happen, so, I've moved through the hope, maybe it will maybe it won't, [inaudible] and I'm getting to think it's never going to happen again, so yes. Em, yeah. I suppose, like you know some sort of paralysis that you're hoping to get the sensation back in your leg or something and after this long, you think actually it's never going to happen.

[6] after treatment, right, you've sort of various sort of side effects. I had, em, hormone treatment and radiotherapy and I started getting, eh, blood in my urine, so, em, I had, you know, I was, you know, obviously I was concerned about that thinking yes it's down to the radiotherapy, but, is it? So, so, this, the after effects, em, of the treatment that, em, were, eh, also, so, a concern.

[6] I suppose the concern, you know, there's always that again[?], you know, you sort of, something like that happens now and, you know, you sort of, well is this a side effect, you know, a long-term side effect or is it, em, you know, is it something new, is that, you know, bladder cancer or bowel cancer, you know, and it's always that, you know, hence, you know, the concern about going to the doctor's about that, which is not something I would normally sort of do.

[6] it was a thought was well why have I got sort of the blood, but my first thought was well is this yet another thing, a side effect from the radiotherapy, and it was, that was my concern, not that I'd got bladder cancer, that was, that was sort of the second thought was well it could be that.

Efficacy

[2] What made me less uncertain, or more uncertain, is I should have had a one-off chemo wash in the bladder after the procedure, but basically because I had it done in a private hospital, there was no one available to do it – they didn't tell me that, but I through conversations with people worked that out. And that reduces its reoccurence by about 50%. Not progression, reoccurence. So I was annoyed about that. Em, but yes, I've got some questions. I don't think my treatment outcome will change

[2] but then the more I looked at what mixed grade meant, and looked up, I could see there was no real consensus, and so when I saw the oh if it's less than five per cent you can ignore it or, I'm more tempted to, to ignore what the American says necessarily because a lot of theirs is promoting extra treatment. Or unnecessary treatment. And she'd already said we do not want to overtreat you, you know, we really don't want to, we want to be very careful about this, em, and when then I looked at the guidance, NICE guidance, and I saw the word multi-focal on, and thought well does that mean what I've got, you know, with two different sorts inside, or does that mean you've got a papillary and you've got one something else, or you've got one somewhere else.

[3] Well obviously I spoke quite a bit to the oncologist and, em, on the first TKI he gave us, em, the initial results were fantastic. It more or less got rid of all the cancer, it certainly got rid of all the metastases and the, you know, around the lymphs and everywhere else. It was starting to grow in the other lung, that had gone, and the original tumour had gone down to a

fraction of its size, which is obviously very good news, em, so I said well, you know, how long will I be on these tablets then, knowing, sort of asking the question around the corner, because having done the research, I know that it does stop working, so if I knew how long I was on these tablets, I'd sort of know as a, at a minimum, how long I'd have, you know, before we'd ask the question again.

[4] I'm on my fourth type of treatment and, because they keep failing, so that's the uncertainty element

[4] Em, it's mostly the fact that each medication I've taken, they get less and less sort of, I guess, generic, in medical terms, em, so you're kind of aware as, as you go through treatments that they're getting a little bit more risky, a little bit more untested, a little bit more toxic, and then that impacts your health in different ways, you know, every different form you get for each new one has different levels of death and disease that can come out of it, and then with this one it's been even more pronounced because it's not even in a packet, you know, it's just like a printed out label, em, and, you know, this is the medication that normally goes to people that are sort of in last phase, like, you know, doing really badly, but because I don't tolerate any of them very well, to be honest, and also because they weren't really working, and it's been three and a half years, so, [sigh] to take that many pills for that long and to not really get an effect and now go onto ones that are just in a generic bottle because they are, em, it's weird, and then, and then what comes next is, if, because this, you know, if this works or not, if it stops working like the others have, then it's on to experiments, you know, so it's not even road tested stuff

[4] again with those medication things like, no one really knows, and they, they've said those positive things for every new medication and every new medication hasn't worked

[4] Is this new medication actually going to do what it's supposed to do?

Weighing up (decision)

[3] the side effects get on my nerves more than the fact that I've got cancer, because, em, that's quite limiting, you know, I do get short of breath, me legs swell up, I'm not as mobile as I used to be, em, I get very tired, very fatigued, so that side of it gets on me nerves, but then, I can't really complain cos I'm still here, ain't I? You know, I wouldn't give all them back and get the cancer back

[3] we proposed to change the treatment, and we're going to try a different thing on Friday, so maybe some of these side effects will go away. Well let's hope. I'm not, em, giving up something that's working for something that's not working. That's the only thing I got on me mind. But I'm relaxed about it, I'm prepared to take a chance, because at the moment, an improvement in quality of life with me physical things, worth taking that risk, if I didn't think it was, then I'd..., but I know I'm putting on so much weight each month, I'm probably going to, I'll probably have a heart attack, or diabetes or something [laughter], I can't stop it.

[4] when they changed the medication and they were like talking all about my side effects and how it's going to make me better, but I was looking at my blood tests and they were getting worse, only incrementally, but they were getting worse, I kind of had to ask them, it's like, but it's also because the last medication isn't working, and they were like yes, also because of that

[5] The less radical treatments, so leaving the prostate in but attacking it with, em, eh, brachytherapy or, eh, em, there's ultrasound right now and all sorts of things, em, but they haven't got the, as good a proven prognosis as the physical removal of the prostate, as long as they get it all, so, so if I had caught it earlier, I might have had a different treatment, and

that treatment might be more risky from the treatment I've had. Yeah. Eh, but it wouldn't have left me with, em, erectile dysfunction, so.

[5] Em, it was sort of a, that, making, making the decision had that sort of, em, pit-in-the-stomach feeling that you sort of, eh, not nervous, no, it's a bit sort of, just leaden dread of is this the right thing to do or is that the right thing to do, and I don't know. Or I can make the wrong decision, eh – what is the right decision? It's sort of, yeah. Yes, so, so, em, sort of hollow, empty feeling, that's it. Hollow, empty and leaden, yes.

[5] Em, well to make the decision, you had, eh, oh, the actual making of the decision, em, I think the decision was made when I looked across the information I had gathered [inaudible – 3 seconds] ... that made me make one choice over the other was, em, that if you have a prostatectomy, [?] removal, if that doesn't get everything, you can have, em, eh, radiation treatment to catch what's been missed. If you have radiation treatment and that doesn't get everything, em, they can't do a prostatectomy at that point cos they've, they've stalked[?] you, it's, it, it can't be removed, so it's more radiation treatment and hormone treatment, and, yeah, and it goes on. Em, and I think that was the deciding factor, that, that if I took the operation, I'd get two, potentially two shots at it, yeah.

[6] I'd gone to the doctors about erectile dysfunction, I didn't actually want to come away with it, I wanted it, eh, cured [chuckle], so, em, you know, just reading the literature, you know, it explained what the hormone treatment did, now I, I did reconsider, eh, when it came to, em, sort of finally, em, signing the consent form for treatment, I did actually say at the time, I've, eh, you know, I've changed my mind and then we started, em, doing the hormone treatment at that stage, which was, eh [sharp exhalation], it wasn't pleasant, you know, it's not, eh, something that's pleasant, em, I didn't get sort of the bad effects that some people have, I've, I mean again, I was sort of, I've been sort of lucky or maybe very stupid that I've just sort of, in a way I just sort of sailed through everything

[6] I decided that, you know, reading it a bit more, going to it a bit further, I realised that once I stopped taking the hormones, things would change, that the hormones would sort of go away, and things would sort of, that side of things would sort of stop, em, sort of happening, although there were things from the radiotherapy and that that would never, you know, sort of come back, so the, you know, it's, eh, you don't, em, produce semen and things like that so that when you orgasm it's not as messy, em, so I just reconsidered, em, you know, I sort of look at, I reconsidered and decided that, em, you know, I might as well sort of do it and, em, you know, stand the best possible chance of, em, surviving, if that's the best way to put it.

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Structures of care

Negotiating relationships

[2] I asked the nurse, and then she made me more anxious cos she said well I've been thinking about that, and when I asked her some questions, well what does it mean in the NICE guidance – you know, multi-focal, is that what I've got? – she couldn't answer me, she didn't know. Fair enough, she's a nurse, she's not a pathologist. I've looked into it and I have a question, so she said probably best if you spoke to the consultant. I don't think anything will change. You know, I haven't got any treatment planned.

[2] I said to the nurse, I find it with pharmacy, I find people who have in their mind what they want, and they'll go two, three, four different consultants cos they will find someone eventually that will agree with them, and I don't want to be that person. I could probably go to somebody who would say yes, it should be treated as high grade and you should go on to have six

bladder washes. I don't necessarily want that, but what she told me was the majority of it is low grade, it's fine, the pathologist, really experienced she told me, has been here ages, very experienced [laughter], you know, pathologist, and I'm still saying that they just say the majority, that could be 51 per cent, is it one per cent? – oh they don't use percentages, well why don't they use percentages? She doesn't know. So that's why I'm speaking to the consultant. Will it change my treatment plan? No, because they've had an MDT and they have made a decision and I think I probably agree with them

[3] I don't think it was very professionally delivered, if I was honest, and I found it, em, because, once I had the lung cancer diagnosed at the, em, doctor's, and they actually did, they didn't actually come out and say it. What they said was, we want you to go, eh, see a specialist, very urgently, there's something wrong there, I'm not a cancer specialist, but it might be cancer. That's all they actually told me at the time. And at that time they had a seven day promise where you could go to the NHS, em, and get, em, the, em, biopsies and the tests, or you could go private, and I thought to myself, well, let's go private on this occasion.

[4] I know that cancer, specifically oncology in health, but also health in general is not prepared or suited for someone that comes in who's non-binary presenting, and I know that, you know, NHS statements say it is, and I know that there's the, you know, like there's legislation and everything that protects everyone, but when you walk in and someone comments on something that you're wearing or the way you look, all this kind of stuff, and you're already dealing with so much, you just shed that stuff to expedite your care, you know, because you can't face the uncertainty of the way people are going to treat you at a very vulnerable position, you know, and, and, and it's, I think it's a very big difference between you don't want to feel tolerated, you want to feel appreciated, you just want to be welcome in a space as opposed to, yeah, as opposed to it just being like a novelty for other people.

[4] there's like a personalised care element but the reality is is you're with someone who is dealing with hundreds of people like you, you have five minutes and you just kind of get through it, and to one example, I mean like with my specialist, I don't really think he knows about my sexuality or gender, and there was one time, my CNS does, my CNS is great actually, I'm very lucky to have a good CNS but, the medication before this which they put me on, they were like oh well FYI, it can give you like persistent diarrhoea, and I kind of was trying to hint to them as well, I was just like, with my life and lifestyle and just, you know, trying to like hint, I was like, sexual impacts, vuh-vuh-vuh, and, and they just weren't, they weren't getting it, they weren't getting it, and it was that thing of like you know constantly having to come out et cetera, but you just kind of realise like, I don't want to fight this battle with you guys, like, if I'm leaving you breadcrumbs and you're just ignoring it because you just want to give me the medication

[4] so my CNS is really good, really really good, and we get on on a personal level and I think because of that it's allowed me to sit in that uncertainty a bit because I know that I can trust her that if anything was particularly worrying, she would get in touch, you know, and, and because she's so caring, kind of above her role, I know that I have the safety to do that, but at the same time I know I don't have that all, because I don't have that personal relationship with other members of staff, you know, I don't feel that level of safety, of waiting for a result, em.

[4] in the beginning, my specialist and I had to have conversations about the way he spoke to me because he was being very medical and, for example, with the first medication when it wasn't working, he's like you failed this and you failed that and you failed that, and I had to tell him like I haven't failed, the medication's failed me, and there's a difference, like I've taken it, I've done it, please don't say I've failed, and since then we've been able to talk a bit more levelly and I can ask him things like is it not working, em, so that's been good, but, but yeah, but it's just tough because you need those sort of small moments of [sigh] levelling

[4] trusting the people around you to do their job, you know, it's their job to keep you alive, they're not there to tell you anything that's not going to do that, so it's kind of placing that uncertainty and offset with certain environments or people I can trust, you know, if there's any other uncertainty around other things, I probably won't feel so strong about it, but I know I can sort of trust my health team, they know it more than I do and I just have to let that happen. I mean, there's, you know, but then that's, that bit, because I trust their expertise and, and, and I feel like I can trust them with the uncertainty, I can almost shift that responsibility and then I can just sort of be along for the ride.

[5] so the way these things work is, is that you're given options, you're told, em, well, you, you, you've got cancer, we can operate to remove it or we can, you can have this radiotherapy, em, and sometimes you get other options as well, I only got those two, em, you decide! So, well, you're, you're the radiologist and the surgeon, why don't you know the right answer to this, surely? No, no, we can't tell you, you have to decide for yourself, we can't advise you on what your treatment should be, eh, cos they've both got different side effects and we don't know what's important for you, em.

<u>Transparency</u>

[1] the surgeon was, oh such a delightful lady, such a delightful lady, and the nurse, the breast cancer nurse, but they never quite looked me in the eye once it was in my second breast, do you know, when they were doing the biopsies, they never quite looked at me, em, and they were very, very matter of fact about everything, you know, yes, you've got a lump here, we have found another one here, we're just going to do the biopsy, em, and we, we..., and they did those, em, and then, you know, just turn me over and said right we're going to biopsy you now, your, your lymph nodes, and it hadn't occurred, I knew they would biopsy my breasts, but it hadn't occurred to me that they were going to biopsy my lymph nodes, but they were just very matter of fact about it, there was no explanation or anything about any of that

[1] You see, because you don't know these people, you don't know if that's the style they work in anyway, you know, and although I'm a nurse, em, I've never worked in the cancer arena, old people is, is my passion really, em, and I thought maybe that's the way they do it, maybe that's the way they work in cancer, but maybe, maybe they can't look me in the eye because they know it's bad news, you know, you do, you know, you're not sure why, quite why they're treating you like that really. That's how it felt to me.

[2] being a scientist I would much rather people say I don't know but I'll find someone who can, or I'll find it out for you, very happy with that, I've said that, patients have asked me, what, you know, what would the side effects could this be, and I, I respect people that say I don't know but I can find out for you, so no, I didn't have any qualms about that.

[4] again with those medication things like, no one really knows, and they, they've said those positive things for every new medication and every new medication hasn't worked

[4] And, and I think maybe before all of the experiences I've had with my disease and treatment, I probably would have thought those kind of questions could be entertained because doctors would always say like, oh okay, you're going to do this, and this is how long you'll be on this for, and this is how it's going to work, but with so many assumptions not working out, I think that's also kind of another thing where it's like, I just feel like there is no answer. Like, even when I'm treated at the hospital, it's always a case of oh, that shouldn't have done that or that's not normal for that or that's not that and just like, okay [half-chuckle, sharp exhalation], so, and you become acutely aware that, you know, the doctors don't really know what's going on, they're just trying the tried and true method and hoping that it works, there's no, you know, deep individualistic understanding of your disease unless they do further investigations et cetera, so without that, not saying I want a bone marrow biopsy anytime soon,

but you know, it's just like, yeah, it just kind of has these other impacts, just, these questions that you know your doctors don't have an answer for, and you know they're just shooting in the dark and just hoping something lands and you hope it lands too

[4] it's those bits that are almost like a stop-reset, to be like, okay, I kind of know where we are, but without those moments, and it's just numbers and just positive messages, it just doesn't feel as genuine as when someone sits you down and goes this isn't working.

[4] the other thing is a sense of almost control and understanding, to be like okay, I know what the game plan is, because it just feels good to know like the reality of it, you know, like, rather than being told all these promises, especially because all these promises you've been told haven't come true, but then for it just to sort of, you know, for someone to tell you directly like that didn't work

[5] Em, I then had to go and tell the consultants, so I had to go and see the urologist and say yes, I'd like you to perform surgery on me, go and see the radiologist and say I'm not having radio, radiotherapy, em, and it was only then that they volunteered that, or the radiologist said, yes, I thought you'd choose surgery because your, because of your age, and I thought, why has she said that? And then I found out afterwards it's because if you have a radiation therapy, you can expect in ten years to get a different form of cancer, but that piece of information I hadn't got when I was making the decision, cos I would, in that, if I'd have known that, I would have gone for the surgery without any question at all.

Reassurance

[1] and it was just, right, okay, we should have the results in, you know, less than a week, we hope, and we'll, we'll give you, we'll give you a call when we get the results, and again that was like, there was so much uncertainty around that, when will they call? When will they get to see me? There was nothing, you see I'm obsessed with the bloody diary, there was nothing in my diary that says come and see us at three o'clock next Tuesday, em, and we will have your results, em, so it was all of that as well

[1] I knew the only time I would get an answer would be when I next saw the consultant so she could give me my results really.

[1] I suppose nobody can reassure you cos nobody knows if you are going to get an infection, if your blood, you know, if your blood levels don't recover after the chemotherapy, so that was a huge uncertainty for me, em, and the other thing, I was always, em, uncertain when they didn't give me another appointment for something. Do you understand? Say I went to have, em, all the little tattoos and things that you need for radiotherapy, they never gave me another date to go there to have my radiotherapy, so you're left then, I've been all prepared, but I haven't got a date to go, I just wanted to know that there was some point where it would be starting or, you know, that kind of thing.

[1] And even if you have to change that appointment, at least the appointment would be there, you know, and somebody would contact me to change it, but I always wanted to know there was something, some other point where I would see someone, you know, about whatever pro..., cos there were lots of processes going on in there. Em. So yes, yes, that was a huge thing for me.

[2] NHS for me has been great, and the consultant as well, very positive, you know, I'd be very surprised if this wasn't low grade, you know, very surprised, I see a lot of these, very reassuring, don't panic, it's going to be fine, so I came out very positive out of the operation, or the procedure, it was a day procedure

[2] So that's why I'm speaking to the consultant. Will it change my treatment plan? No, because they've had an MDT and they have made a decision and I think I probably agree with them, but I know it can be subjective, and I kind of want reassurance, that's what I'm looking for, and that will make me less uncertain, I think. And more confident going in, you know, he told the nurse, I'm not expecting to see anything at the three month scan, but somehow that's not good enough for me [laughter]. And that's what makes my husband annoyed, you know – it's good enough for the consultant, he's the expert, but you're still querying, and I think that's where I am at the moment, so I do feel very uncertain at the moment because, em, I still have questions in the air.

[2] I just almost want more clarity and reassurance. Which [the consultant] was very good at, at the procedure.

[3] in the UK at the moment it's so difficult to get a doctor's appointment, they don't make it easy for you, if you're anxious about something, to go get reassured, you know, quite often it's weeks in advance, more often than not they want to have a telephone appointment, em, and, and I can understand why people aren't bothering, em, and probably I was guilty of that, if I'd chased it a bit more rigorously earlier on in that year who knows, I might have got it at a lower stage and I might have had surgery and be cured, but I always have that in me mind, a bit guilty now.

[3] Well up until the point of the Lake District, I thought perhaps it's me being a bit of a hypochondriac? Maybe the doctor's seen me and said that's, that's fine, that'll cure it, and not mention the fact that it's lung cancer, or even investigate for it, and he's the professional, I guess I thought at that time, well, it can't be cos he would have asked me about it or had an x-ray or something if he thought it was, so he can't think it is, so it's not.

[5] the bit where I found out why she'd said because of your age, the cancer could recur, I think, that, I was fairly certain I picked the right one, yeah. Yeah.

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Processes of care

<u>Accessing the right help/information</u>

[2] So that's why I'm speaking to the consultant. Will it change my treatment plan? No, because they've had an MDT and they have made a decision and I think I probably agree with them, but I know it can be subjective, and I kind of want reassurance, that's what I'm looking for, and that will make me less uncertain, I think. And more confident going in, you know, he told the nurse, I'm not expecting to see anything at the three month scan, but somehow that's not good enough for me [laughter]. And that's what makes my husband annoyed, you know – it's good enough for the consultant, he's the expert, but you're still querying, and I think that's where I am at the moment, so I do feel very uncertain at the moment because, em, I still have questions in the air. And I'm putting the worst prognosis on it all, and you know, he says stop reading papers about it, because all I find is it's very subjective, so there is no right answer, I'm not wanting something else from the consultant really. I just want more clarity [speaking slowly] who most people wouldn't need, I accept that.

[2] I'm just hoping that if I get those answers to my questions, it will make me more confident going forward that that's all right, em, and I know, em, you know, this is a life long thing

[2] I think I'd reached the end of her knowledge, you know, I think, I 'm asking her difficult questions that she doesn't know the answer to, and she knows that, and that's fine, and I don't

suppose they have many people like me, and my husband says I'm being silly, but in my mind I've got to get it all kind of straight

[3] in the UK at the moment it's so difficult to get a doctor's appointment, they don't make it easy for you, if you're anxious about something, to go get reassured, you know, quite often it's weeks in advance, more often than not they want to have a telephone appointment, em, and, and I can understand why people aren't bothering, em, and probably I was guilty of that, if I'd chased it a bit more rigorously earlier on in that year who knows, I might have got it at a lower stage and I might have had surgery and be cured, but I always have that in me mind, a bit guilty now.

[3] Well I pursued it, saw the doctor, the doctor said it's that, they didn't perceive that it was lung cancer, I didn't want to raise the fact that it might be lung cancer and ask the question because I was scared of it being lung cancer, and if the doctor's examined me and he hasn't seen it, that's good enough for me, well I can't have it then, can I?

[3] But when I had the Lake District experience, I think I was more determined to push the doctor

[4] in the beginning as well you're just a sponge, you just absorb all of these, eh, ideas and names of drugs and treatments and all this information around you from all these multiple doctors because you're seeing a lot of doctors at once and it's all very new, so you have to kind of just soak it all up and kind of process it later, you know, and I don't really have anyone around me that was coming to appointments with me or anything like that so I had to kind of like process everything at once

[4] so my normal way of being would be to focus on the little individual things because... bit of a control freak, I also have a science background, not in oncology but enough to understand and read papers and all of that kind of stuff, so in the beginning the way that I would reckon with my health was actually to focus way more on that, and what that became was a sort of defence mechanism, that I would try and learn as much about my disease as possible, that I would, you know, understand things, and sometimes it's really beneficial to know like how much variance there is in a PCR test, like that kind of stuff, very helpful

[4] And, the other thing as well, actually, the other thing is I find very frank conversations with my health care professionals very useful, so, you know, if those numbers are not going well, for example when they put me onto this new medication, and they were like oh, but you know, it might help your legs, and it might do this, and it might do that, and they were focusing a lot on the side effects, but I had to kind of ask them, be like, but it's also because it's not working, right?

[5] you've got cancer, we can operate to remove it or we can, you can have this radiotherapy, em, and sometimes you get other options as well, I only got those two, em, you decide! So, well, you're, you're the radiologist and the surgeon, why don't you know the right answer to this, surely? No, no, we can't tell you, you have to decide for yourself, we can't advise you on what your treatment should be, eh, cos they've both got different side effects and we don't know what's important for you, em. Eh, so that was, yeah, that was a difficult period, em, before I decided to have [inaudible] the surgery, em, because, eh, yeah, I, the, the, the two things have quite different prognoses and outcomes and it's sort of you have to work out your own age and how long you, what things are important to you in life and this sort of thing

[5] which one do you decide? Do you flip a coin? What's the, em. And that's, that's when I first went to my first [support group] meeting, before I'd had the operation or made the decision, eh, to help make that decision because it was just, there were too many variables, and I couldn't, I couldn't work out, so I needed to hear what other men, what had happened to other

men and what decisions they'd made. No advice was given, but they just said, you know, I had this, this is what happened to me, this is how it's left me, I had that, these things happened, em, yeah, so, so, but in the end, I had to make the decision, and then having made the decision, you know, was it the right decision?

[5] I just thought, okay, that's just, maybe I missed it in the reams and reams of information I had been ploughing through to help make the decision, maybe I hadn't spotted that, em, I hadn't really spotted the extent of the erectile dysfunction. That had passed me, you know, I hadn't paid, it was probably there, I hadn't really paid attention to it in making the decision. And of course I didn't realise it would turn out to be such a big deal for me, so, cos I didn't think it would be a big deal for me, but it has been.

[6] there was nobody sort of there to support me, and, to be honest, I was happier actually doing that myself. Em, at the time I didn't know about, em, [the support group] em, because, eh, I'd not sort of looked for any support groups or anything like that. I must admit that nothing was particularly mentioned, eh, when I was having the consultation or anything, em, although I think that might actually be changing now, em, but nothing was mentioned about support groups, and I found out about [the support group], em, by chatting with, em, somebody, em, on Facebook , I think it was, em, about sort of life in general and that, and he mentioned, em, that his, em, his partner had had prostate cancer and actually mentioned the, em, the group […]all the, the decisions, all the considerations, you know, were mine, based on the sort of information I had and everything.

[6] You know, and I'd be asking my either the urology department consultant, em, if they hadn't put anything in the letter, I'd be phoning my GP up and speaking to them about it and saying right well, you know, this is the, the results, they're saying this, that and the other, em, right, what are we going to do about it, when can we start getting something, you know, sort of done, treatment or whatever about this, do you need to cut something out, am I going to have to have a, a bag or whatever?

[6] if I felt I was showing any sort of symptoms, anything like that, then I would get straight to the, you know, I'd get straight down to the doctor's and say I believe that, you know, because of past experience I'm getting this breathlessness or pain or whatever, em, you know, I'd like referring for, em, you know, x-rays or that because, you know, I've worked with asbestos in the past and it could be, I, and I also used to smoke, it could be, you know, cancer , I'd, you know, I'd do, I'd do something about it to control it, to be in control, you know

Acknowledging the limitations of my role

[1] I was not in control of that, she [the consultant] was in control of that, em, so there was absolutely nothing I could do about it, there's nothing you can do on your own. […] There is nothing you can do on your own about the secondaries, you know, if you've got them, you've got them

[2] I said to the nurse, I find it with pharmacy, I find people who have in their mind what they want, and they'll go two, three, four different consultants cos they will find someone eventually that will agree with them, and I don't want to be that person. I could probably go to somebody who would say yes, it should be treated as high grade and you should go on to have six bladder washes. I don't necessarily want that

[2] I know I'm reading too much, em, I never thought I'd be that person cos I read a lot of papers with my work, I work with GPs, and I, I, I sit on formulary committees and things, so, you know, I look at papers with evidence, and so I know what absolute risk and relative risk means, you know, I know the difference, so I know what I'm looking at, but I know I'm reading too much, and I should stop, and I think, you know, I will stop now until my cystoscopy

[2] So acceptance, I think, and I think when I can accept that, I can accept the uncertainty of having to have regular, cos this apparently is the cancer that comes back most frequently, but mine I know is least likely to progress, so it's going to be a nuisance, and there's going to be anxiety before each scope, and I think I've got to accept that cos, you know, that's, before anyone has anything done, even if you just go to the dentist, there might be some sort of anxiety, so I've just got to accept that, and I want to be into that place where I've acknowledged what I've got, that's life, you know

[4] in the beginning I was sort of, at one point kind of mocked by one of my doctors for wanting to know what my PCR level was, what my blood was, all this kind of stuff, em, and you know, I like to be involved with my care anyway but then as it's gone on and you go through treatment after treatment, after hospital after hospital, you, you just generate this fatigue that just means that you just [sigh] you just have to go along, it's kind of like a small factor of learned helplessness, you know

[4] I'm just trying to still get to that but just I don't know how to, I think that's the other thing, I don't know how to get to where they want me to be when my body isn't playing along, and there's nothing I can do about that.

[4] so in the past I would have been very on top of it, you know like, want those results as fast as they came through, em, yeah, to the point where some of my doctors were a bit like, like we get it [chuckle], you know, like, you want to be involved, em, and now I just, I've sort of had to kind of stop checking so much because, I, I mean I still look at every single blood test

[4] I think one way that I kind of deal with the uncertainty of the test is to remember the test isn't absolute, and I have to remember that it's about trends between it, and that's kind of where sometimes I'll, you know I'll look at the number and as long as it's not crazy high, I'm just like okay, got it, and then it's, you know, I'll kind of look back over them every now and again and see, like, have we been going up or down? You know.

Managing myself

[1] I always focused on other people but now the focus is going to have to be on me and making myself better, otherwise I was never going to get to the stage where I could help someone again, you know? So, I suppose, yeah, the focus is different, I have to take my focus off that, and just make sure I got all my chemotherapy on time, and you know, I got my radiotherapy on time, and after that year, I would be better, and I would be back to where I was before and focusing on them.

[1] but what I did try and do was when I did think like that was to turn it around as I've said to you before, you know, you know so many people who've come through this, you know that, and you will too, you know and I tried very hard that week to be very positive about it

[2] I want to be into that place where I've acknowledged what I've got, that's life, you know, so I'm going to live with that and I'm not going to let it impact on my day to day. I'm desperate to get back to running, absolutely desperate

[2] what I'm hoping is as time moves on, it will still be uncertain, and I know for the cancer I've got, it's going to be like that cos it's constant surveillance, em, but hopefully living between them, you go back to a normal life rather than spend three months worrying about it, which I'm doing at the moment, you know, I've had one month already, and I've kind of spent that month worrying, so why am I doing that? So I'm hoping if I speak to him Monday, then I can at least have the next two months not worrying about what's going to happen in... [laughter] ...until the

week before when it would be natural to worry. I don't want to worry for three months between every, every appointment.

[3] I sort of tried to strengthen myself, cos I knew they was going to chuck a load of treatment at me, I don't know how I was going to cope with that

[3] between the oncologist and the group, and what the group says, em, that's how I gauge where, where I am really, em. And as I say, the group are very good at finding out what's happening with the latest drugs

[4] probably it would be better mentally to kind of have the hope, but when you've gone through that many treatments in such a short amount of time, you know, and it's like this medication is going to do it, and this medication is going to do it, and this is going to work, it just, or even other things they've offered, you know like, oh we're going to find you someone that's a similar age with a similar disease so you can, you know, meet someone else with it, cos it's super rare, and then these things don't come through, they just don't, so, you know, you kind of learn to lose hope so that you don't end up giving yourself additional fatigue to manage.

[4] I have to think on things in my sphere and trust them to do the stuff on their side because otherwise if I start second guessing every decision, it's not healthy for anyone

[4] So I think that's almost in a way why I sort of focus more on these sort of larger scope questions of, you know, am I going to be alright, because if you focus too much on the details, it just overwhelms you.

[4] in reality I kind of have to just let it happen and then if I'm doing that rather than focusing on details that I can't control, that will frustrate me, I should come to terms with the fact of how they're making me feel and try to share that with people rather than, rather than just tell them about numbers, that's not really what they're asking, you know? They want to know I'm okay, but, you know, I was sort of deflecting by sort of confusing them with the science of it.

[4] I can almost shift that responsibility and then I can just sort of be along for the ride.

[6] Em, you know, and so, try and look at it practically, you know, rather, but eh, let my head rule it rather than my heart and, em, you know, look at, if I'm doing something practical, I don't, I can't, I don't worry about things, it's the control, if I'm out, if I can't control things, I'm more anxious about them than if I can control them.

[6] I believe that, you know, even with that, you know, people, you know, there's help and everything and they're getting support groups, I think support groups are very important, em, you know, especially for some people, you know, that really anxious

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Psycho-social uncertainty

<u>Practical/material concerns</u>

[1] we've moved back to [name of city], because I decided that after the chemotherapy through the winter, I couldn't do another year in the, in the [chuckle], in the countryside, I'm not a countryside person really, you know, so I wanted to come back to the hustle bustle of [the city], so my calendar is now fuller than it was before I had the cancer really, because all of my friends were still in [the city]

[3] and then of course in your own mind you're thinking well how are you going to cope financially, am I still going to be able to work, em, and your mind paints all these things on,

you know, there, there comes through your mind at different times, you don't know, you don't even realise sometimes, then all of a sudden you say, crikey, what happens about that, you know, some people get mets in their brain and they lose their driving licence, and I'm thinking, well perhaps, supposing the next time I go, I'm going to lose me driving licence, how will I cope with that?

[3] we're going to have to cut our cloth now, I only work 20 hours a week and I only work from home, [my wife] only works 20 hours a week now in the hospital, em, because I'm so damn tired all the time, I fall asleep every afternoon, em, but, we get on fine with it, em, so yeah, definitely more uncertainty after the diagnosis.

[3] we've had lots of conversations because, life, life matters really because we've used a chunk of my, em, pension up, we've both gone short time work, we've spent all this money updating stuff, so we haven't got an awful lot of money left in the kitty, and what we're earning now is not allowing us to top it up very much, so we've had the house valued, we've got to make a decision as to whether we downsize, if we downsize we'll move nearer where our children are, em, obviously, then if anything happens to me, [my wife]'s got people local to her, family local to her. […] just recently one of her dear friends lost her husband suddenly, like very suddenly, em, and she has been going through the whole widow thing, em, and [my wife]'s been sort of comforting her, so it's almost like a practice run. She can see [her friend is] coping with it, she must realise that at some point, she'll have to cope with it as well, so I'm hoping that's going to be a good thing for her.

[4] my health has made me homeless and I'm waiting for social housing, so it's the uncertainty of having no, yeah, no, no security.

[4] Like, especially on benefits, like yes, I now have the disability one on top, but I can't afford to pay the London rent, I would have to leave London and I don't have a good relationship with my family, so that would leave me with no support, which is what the council were originally suggesting, I should leave, so it's really hard to have like [sigh] security in your health and this kind of goes back to the idea of hope, but like the mental capacity to think in a positive manner when you're still in survival mode of like I don't have a stable home, I don't have stable health, especially with coronavirus, I don't have stable access to food, you know, it's, it's nuts, so, and also to have to fight for it, that's the other thing, you know

[5] I was off for six months with the operation and convalescing, and I knew there were going to be some redundancies where I was working, so before I, before I went off on the operation I knew that, so I said to my manager, I said if there's any redundancies coming up, you know, I'm going to be off for a long time, I don't know when I come back whether I'll be fully fit, yeah? I don't know what mental state I'll be in, so, em, if you, I, I, I'll take the redundancy, you know, keep the job for somebody else who needs the, who's younger than me, needs to feed their family, so, so I backed out at that point

[5] why would I want to waste any more time, I don't, you don't have to work, em, and, and I stopped wanting to work, that was the other thing, yeah, it's sort of, this isn't relevant to me anymore, you know, I don't, don't, don't define myself by this anymore, it's not, not, I don't, yeah, it's not, it stopped being who I am, yeah?

Socio-political/socio-cultural factors

[1] I've never been terribly political, I do have views, but Brexit I was a very staunch Remainer, and I was so upset when, you know, we were going to... Leave won, em, and I think that was then exacerbated because if we were leaving with no deal, which it looked like at that time, em, and it would have been the end of March 2019, the uncertainty for me there was there was all this stuff about drugs are going to run out, we're going to have to stockpile drugs, but we can't stockpile radiotherapy drugs because they have a very short shelf life, and I knew,

and this is part of the uncertainty of the cancer experience, isn't it, if I couldn't do all my chemotherapies on time, if I got an infection or something stopped me having some of those chemotherapies, my radiotherapy would be put back

[1] [The Brexit referendum is] the one thing, I think, in my life before this pandemic that has made me feel, oh my God, I really don't know what's going to happen, and uncertainty for myself, but uncertainty for young people as well. I think more for young people that what's going to happen to their futures, you know, if we get no deal and the economy and all of that kind of stuff and their jobs, em, so I think yeah, that did leave me with a huge uncertainty

[4] I mean, you're 32, and I think being in the kind of queer world, like I think men that sleep with men can be very, very vapid at points. I think all cultures can, but I think there is a heightened value of it at, at, in certain spaces like bars and areas where you meet people so you can kind of feel excluded from that by having a disability, em, and I should say newly acquired disability, cos that's where the problem is, cos it's newly acquired it's getting used to that, em, and feeling with, with the mobility stuff but also with my health in general, you know, feeling undesirable, feeling like no one's going to want to put up with it or have to deal with it, and even when I have tried dating, they say they will but then there's always a problem around my doctor's appointments or they're annoyed that I can't go out or, you know, on holiday I spend half my day in bed, you know, it's just, you feel like a drag

[4] it's tricky because, you know, people as well can sort of without meaning to devalue the whole thing because they're like oh but you look good, you know, you look fine, and like, well, it doesn't change anything [exhalation, chuckle], like, and it's also this really strange rubric that other people have of what a cancer patient should look like, and if you therefore don't have that, you don't qualify for their sympathy, instead you get their curiosity or disbelief. I mean, I've had it in bars where people who I know, em, will tell me, you don't look sick, I don't believe you

[4] even now as an adult and the way I present, you know, unless I have nice earrings in or I've painted my nails, people don't believe it, which is a very strange thing anyway, I shouldn't have to do that [sigh], but it's still like this weird coming out thing, you know the cost-benefit analysis of it, of like how does it work, and that uncertainty of whether people will change the way that they see about you, whether they're going to close certain doors to you, you'll lose certain cis-passing privileges, like all those kind of things, so it's very weird on the queer side knowing that that level of honesty leads to more uncertainty, but then on the cancer side, where people, it's so much more complicated to understand, but people accept it like that [click fingers], I mean, aside from obviously, you know, looking healthy, em, it's this idea that if I share someone that intimate detail, it's just instant support, you know

[4] people want to treat you like a cancer patient but they don't know how to treat you as an LGBT person, and it's kind of interesting watching those differences kind of play out

Managing relationships

[1] probably about a year before I got my cancer, [my daughter], eh, struggled a lot through depression and anxiety, which came to a head when she was doing her, her master's. I'd always spent a lot of time with [her], em, because her dad and I separated when she was eight, so our relationship is very close, em, but particularly after she went to [university], I was back and forth to [the university town] a lot, spending time with her, she comes home a lot as well, em, so obviously when this happened, there was a lot of uncertainty for me about how I would tell [her], how we would manage that process […] how am I going to feel through all this process, and how, how can I keep supporting [her] because I didn't want to stop supporting her or how can we set something else up, so she was my main worry off my list of things that I have on my calendar

[1] you don't know how long this is, this is, this is going to go on, and at what point do I tell people? Em, you know, because it was only my husband knew, and my niece cos I couldn't go and look after the baby while I was having all of this done, so it was only my husband and my niece knew, there was definitely a point where I was going to have to tell [my daughter], and I had no idea how I was going to do that, but I didn't have any inkling then of when I should tell her, em, because I didn't know what the real news was going to be, you know. So the, the uncertainty around the timing of a lot of stuff for me in this process was huge.

[1] I didn't tell my husband in all that time that I was going to see the GP or, you know, that I thought there was something wrong with me. Em, and then the GP found a lump, and I thought I'm going to have to tell him now, and when I told him, he just looked at me and he went, well I'm telling you, you can't die before me [laughing], so it's like, oh, okay then – we'll have to make sure that I don't die before you, you know?

[1] so I did tell her, just before we went to bed in the hotel, we shared a room, em, but I played it down, you know, oh [daughter's name], I've got a lump in my breast, I didn't say breasts, it wasn't quite [chuckling] an untruth but it wasn't quite the whole truth either, em, and I'm sure it's going to be fine because you know we, we know lots of people who've had breast cancer, em, and I will be fine, and once we get the results, we'll know what kind of treatment I'm going to have, and it will be okay, you know, I'm almost certain I have breast cancer at that stage even though we hadn't had the results

[2] that uncertainty is probably the key thing of having a grandchild, that I might not see him as I would have done grow up

[2] And it's driving my husband mad – he's been very patient, em, and, you know, you can dip for blood, you know, in your urine, and I haven't had any, and I had some yesterday, he was like, it's, it's not even four weeks, you know, it's not going to be healed yet, why are you worried, for heaven's sake?

[2] he says I want some time to myself, he's a [musician], you know, he wants to do other things, he wants to go and lecture at universities, things like that, em, and he wanted me to do the same, and I love my job, I love the people I work with, and I figured I would work til I dropped, and he didn't want that, and he's now saying maybe this will now show you that you can't take things for granted. We want to do travel, we want to travel, and I'm saying, well, maybe I won't be able to, you know

[2] whereas my husband's always of the view, is you don't know what's round the corner, he's, you now, we've lost quite a few friends in flying accidents, one just last year, who crashed a plane in Dubai, em, and so, we, I think he's always been of that mindset, you've got to enjoy life, em, so I think he's now saying, well, if one thing's happened, it's made you think yes, I'm not going to do as much, but I haven't agreed to reduce anything yet. [Laughter]

[2] it's really interesting to see your study because I think I'm affecting my husband, and I think it's really important that people would be able to manage that for the people around them.

[2] I think I lived that life for so long, I was used to it, and in fact, whilst it was dangerous, you know, [husband's name] was running air for NATO, so, you know, he had a responsible job, but for him, it was a job he wanted to do because it was almost like this is a real job that I've been trained to do, and I've had my whole career in preparation for, so, yeah, so he wanted to do it, and I've always told myself that if ever anything happened to him flying, it was, it's his life love, you know, so he was doing what he wanted to do, and I've managed that, you know, you think the anxiety that might come with that, I've managed that, you know, I've had many phone calls in our earlier married life, I'm okay, phone down, cos he's just telling me, I can't tell you any more, but I'm alright, so, and I managed that, so why can't I manage this?

[2] And, and the one thing that did worry me was, em, my son had found a lump, and he'd had his own worries, em, eh, which turned out to be okay, but didn't want to worry me, and that worried me as a mum, you know […] he's always been somebody who wears his heart on his sleeve and will share how he feels with you since he's been a little tot, so it worried me that he couldn't tell me that he had worries, you know, em, his twin brother's always been a bit more inward and reserved, but em, no, he's always been heart on sleeve

[3] I sort of realised, it was a couple of, three months that worrying about it intensely and nothing on me mind other than that, em, wasn't only affecting my state of mind, it was affecting my wife's, my children's, my friends', and everything, and by me being as I am, em, it's making everybody miserable and anxious and stuff, so I sort of, even though I had tablets and I had counselling at that time, I think what really got me out of it was this determination to get the best out of what days we've got left and make, make each day a good day, and we had this conversation, [my wife] and I, and we've tried to do that.

[3] we just had a granddaughter and she's seven months old now, and I don't know how long, you know, I'll be around for her, but probably not when she's a teenager, so what I'm trying to do now is encompass all these good thoughts into a book, which would also be useful for everybody else that's left as well

[3] at that time I probably wasn't a good person to be around [my wife] and the kids, which I regret now.

[3] my counselling I felt I needed was how do you cope with this illness, how do you cope with the fact that some time, sooner than you want to or expect to, you're going to die, and how do you cope with your family around these times, how can they cope, what can I do to help them cope?

[3] [my wife] started crying, em, and I didn't know how to cope with it. Thankfully the cancer nurse was very, very good

[3] [My wife is] a health care assistant herself, she works at the [name of hospital], so she's trained in looking after people like meself, which was handy because she would me blood pressure, and me temperature, and me stats[?], stuff like that, so that I could keep an eye on things every day, and obviously administer me medication, make sure I took the right doses

[3] people are afraid to mention the fact that, they won't come up and say well how's your cancer, how's your treatment, so quite often, you know, I'd do a little e-mail on the, on me Facebook, or I'd go around and talk to me sister, I make sure I give her an update. Sometimes, when I get an e-mail from me doctor, from Dr [name of doctor], eh, after a clinic visit, or after I've had a scan, I'm letting her have a copy of the e-mail as well, you know, just to make sure they understand, em, it's difficult, innit, I know, it's difficult for [my wife] to cope with, I think in some ways it's harder for her.

[4] partly for me but partly because I had to tell other people, and you have to make space for their reactions, which is exhausting, you know, it's not their fault, but it's exhausting, cos you want to be able to be the one to freak out, but you can't because other people are freaking out so you have to deal with that

[4] Em, so, with friends it's tricky because some friends don't want to talk about it, some friends are, em, sickeningly positive, which is fine, it helps them but it doesn't help me because they're not the ones dealing with it every day and going to these appointments and having all this bad news, they kind of take that blind faith thing of like, oh, it'll be fine, it'll be fine, this one will work, and it's like, okay [sharp exhalation / chuckle], you know, that's, that's where you're at,

em, and I have other friends that are just, I have one friend that's Swedish and just is way too Nordic about it, and just you know, she's always tells me that I'm dying so, it's, it's very weird the way that it impacts sort of friend personal things, and I almost feel like I can't talk to them about it, or if I do, I have to limit, eh, how to say this, I think what I, I think I tell them the things that I'm willing to be upset about, as in, upset about their reaction because I don't think they're very good at talking about it, so yeah, I have to kind of tell them stuff that I'm not going to be offended by because likelihood they're going to say the wrong thing and it's going to annoy me, to be fair. Romantic relationships don't really work [sigh] with cancer, I've figured out, you know, people I've tried doing it with, people are super involved with the care, and they still mess up, I started doing it where you kind of pretended like it doesn't exist, that doesn't work cos they get frustrated about why you're tired all the time, you know, I haven't really figured out a way to make the two things come together, to be honest. Em, eh, I don't really speak to my family about this stuff, my dad doesn't speak to me, em, don't know why, and em, my mum speaks to me once, once a week, which is a lot for her, to be honest, it's been since lockdown and she doesn't like to talk about the health stuff, like if ever anything comes up or goes wrong, she just kind of shuts down, always has, em, so the only people I really get to talk about it with is my CNS when I see her, but again that's an appointment, I don't really bother her outside of that cos she is so busy, and then other people are, em, well it's kind of been from setting up this […] peer support network, em, it's a lot of work, but it gives me the ability to speak to people in similar positions, you know

[4] actually you don't have anyone that you can be completely open with, there's no person that you can, that you can relax around and tell them everything because you can't be sure, or certain, that they're going to handle it well

[4] I think the biggest confusion actually is other people who know less about my health than I do are so certain that that is going to be fine, the future, you know, everything's going to work out, and I'm not [half-chuckle, exhalation], you know, and it's like a really weird thing because also they don't want to get on board with the way I'm thinking because they think they're helping in regards to sort of trying to keep positive, em, but I'm sort of, I think I see that rather than trying to take some kind of stab in the dark and some positivity and some projection of what I want to happen, instead I see it as an approximation of everything that has happened so far and that's why there's this huge grey area around it

[4] I think for me personally it comes down to a lot of whether I can trust the person that I'm kind of going through it with, and em, and I trust my specialist and my CNS, they're both great, but do I trust my friends and family with my thoughts and feelings? No. Do I trust the council to appreciate my health and help me? No. Do I trust myself to be good to myself in this? Getting better. [Chuckle] So. Yeah, it's just kind of a, a learning curve of knowing where to place your energy so you don't burn out.

[5] I started feeling a bit low, and, and, em, obviously people, you know, offer support and stuff, but em, the thing that I, that upset me, so, so I had a reaction and it really upset me, it really, really upset me, and it was from my [?]'s daughter, and she doesn't know she really upset me, but she said yeah, but you're still alive to tell the tale, and I'm thinking, well yes I know, but what you're saying to me is just, you know, man up, get over it, you, you, to me it feels like an amputation, yeah, I had something, I had part, if I'd, if I'd had a, a, a, a, em, gangrene or something, and had a leg amputated and I said I'm feeling low cos I'm, I'm, you know, I've got a, I have to deal with this amputation every day of my life, you wouldn't get the reaction yeah but you're alive, you'd get the reaction yeah that's a terrible thing, it's so hard to live with, but for this you don't, it's sort of, that's, you know, it's just dismissed, em, it's, em, and, and that, eh, makes the, the sort of, I suppose uncertainty, how do I react to this, how do I, do I get, do I show that I'm upset, do I, because they didn't mean it to upset me, they meant it to be supportive

[5] that intimacy has stayed about the same level, em, both my wife and, and with, you know, like occasional other partners, em. What has happened though, is, is is, em, that their reaction to my sexuality has changed, so their perception is that I'm not interested in what we're going because I'm physically reacting to it, em, and that, that sort of, so the intimacy tends to, tends to be a one-sided thing where I'm giving and not getting, yeah?

[5] I found that I couldn't really talk to a lot of people about it because they'd try and be helpful without having any knowledge, em, and what happens is they, they, they, they'd sort of try and say something helpful and I'd sort of bite their head off, you know [inaudible], obviously not literally bite their head off, but, but, but you know, sort of implying they were an idiot and they didn't know what they were talking about, which, they'd got completely the wrong end of the stick and they didn't understand, em, cos obviously they had no idea what was going on in my mental or emotional landscape at the time, no matter how well they knew me, em, so it sort of made me shut down a bit, yeah?

[5] I think I pushed people away because, eh, obviously my wife and children were trying to be supportive, and they were supportive, they were very supportive, very helpful, em, but sometimes their concern, they were, sometimes they were more concerned than I actually was, and that was, that was difficult for me cos I got to the point where I felt, eh, am I now supporting you, cos you're, you, you're, you're taking this worse than I am, and, and I'm giving you emotional support, but I'm the one with the cancer […] and I actually said that to my wife at one point, I said I'm not sure if I can cope with this, cos I'm having to deal with this, but I'm having to deal with you dealing with me dealing with this, and that's really hard.

[6] the one thing that sort of really concerned me, when you read through the literature and everything, em, is about, eh, you know, the sort of side effects from prostate cancer on your sex life, and really to me that was the only thing I was anxious about, I wasn't sort of over-concerned about cancer or anything about that, em, I've sort of a philosophical view that, em, well I'm going to die of one thing or another, you know

[6] I was more worried about the uncertainties of moving on, em, rather than the sort of the cancer. The cancer was just a health thing and that was really sort of, whether I survived life I'd still have sort of the other problems, you know, if I die from it, well, I wouldn't really, I'm dead, that's it, you know, I don't have to worry about that

[6] after I finished the treatment, em, I did actually start, em, sort of meeting other people, em, having to explain that, you know, sexually I was, em, you know, I wasn't up for anything, if you're like that and, em, sort of just over 12 months after, em, meeting, eh, what's it, having been diagnosed, em, and having sort of gone through all that and everything, I actually met someone and, em, we eh had a civil partnership in November last year, so, you know, it wasn't, em, quite, you know, the worry about everything wasn't, you know, as bad as, you know, you sort of imagine. But the uncertainty of moving out, I went, until I actually met [name of partner], em, I'd still got that uncertainty, I wouldn't, em, stop out overnight, em, or anything with anybody

[6] I enjoyed sort of being with people, I enjoyed cuddling, hugging and kissing, and that sort of compensated, that satisfied the sort of lack of physical sex, the lack of orgasm, em, especially because of not being able to get an erection

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Existential uncertainty

An undetermined future

[1] I suppose it makes you appreciate that 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, em, and that there are things that will happen to you that will impact on other people as well, other people around you, who you have relationships with, that you were helping out, or were relying on you, that you may not always be able to do that, or able to do it in the same way, I suppose.

[1] I've seen a lot of death, obviously, as a nurse, and I suppose I try not to think about my own […] but I think as you get older you're much more aware of your own mortality, em, and certainly, you know, having cancer makes you even more aware, and I think you know, like I'm probably three quarters of the way through my life, I haven't got that much left, you know, em, I hope I live til I'll be 80 or 90, em, and I do think about it sometimes, and I suppose having cancer does make you think about death more, em, and I do think about it more in terms of my own death

[2] I've got a nine-month-old grandson, and, who loves to make music... noise... and my thoughts were wouldn't it be lovely to see if he developed and had those same sort of interests, so I think the uncertainty is I might not be here to see it, you know

[2] there was a lot of fun and family and good friends and a lot of social life, and that's a very happy time, and maybe it doesn't have to be the cathedral choir, but that's what came to me as something that was important to me, em, you know, whether he did do or didn't do that, but I wanted to be there to see him develop and maybe he would be interested in something like that, I have no desire to force it on him, I want to be there to see, you know, if that, if that happens, so I think that sort of uncertainty, em, is more difficult to put at the back of your mind, you know, you can live day to day, but that's more looking to the future.

[2] I think the difficulty accepting it is, is because of that, I had assumed we would go into our seven… sixties, seventies, pretty healthy. That's not to say I won't be, you know, I feel fine, you know, I'm still me able to do everything I do, I've still got the same energy, I still want to go out and do the garden and, you know, that sort of stuff, so, em, I think that, that's more to do with it

[2] Yes, let's go next year, but there's still a little bit that, that, that bit of me saying, why am I saying, why am I agreeing to book something, you know.

[4] no one really knows

[4] I think the answers to the questions I want are just not answerable

[4] but the idea of the big questions that I'd want to know, just am I going to be alright? Because it doesn't feel like it, and it hasn't felt like it, and, and if I'm not going to be alright, even if it means I don't have a good quality of life and I'm still here, like, am I going to be happy?

[4] my questions are based in the idea of a timeline that you obviously can't access, like, where are we going to go? And, and I think maybe before all of the experiences I've had with my disease and treatment, I probably would have thought those kind of questions could be entertained […] I sort of focus more on these sort of larger scope questions of, you know, am I going to be alright, because if you focus too much on the details, it just overwhelms you.

[4] I personally think that there is a macabre level of human existence where you fantasise about what's going to happen, you know, as you get old, how will you die, will you die peacefully, I mean you see it even in media all the time, you know, like this kind of idea of gold

standard of death is dying peacefully at home, and, and I think a lot of people have those thoughts, and they have that kind of aspect of like, oh, you know how long will I last et cetera. Em, but then when you know pretty much that's not going to be you, I mean, who knows, there might be a tiny chance, who knows what's going to happen, but, but when you do kind of get to that bit where you're like, oh actually, this is an ongoing thing, and it's going to really mess up your body as time goes on, it's hard because you can end up feeling quite defeatist because that kind of yeah macabre wonder of what's going to happen is gone, which is also kind of slightly stupid because you could still walk out in front of a bus, you know, there's still all of that but I think it's just maybe, maybe that when you don't have that there's this kind of field of, eh, invincibility around you mentally cos you don't think you're going to get sick, no one thinks they're going to get sick, you know, nobody takes preventive medicine seriously, no one... so all this kind of stuff, so. So it's this idea that you have the freedom to fantasise about your health, em, and then when you lose that freedom to do so because you are not in this perfect bill of health to have the kind of privilege to think in that way

[5] will I ever get back to normal? 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.

[6] I could walk out of the door and get knocked down by, em, you know, a bus, you know, I don't worry about that, the chances of it happening I think, you know, the odds is just as great as, you know, getting the cancer or anything like that, so we'll just have to see.

[6] There's always uncertainty in life, like I say, with like, you know, the possibility of, em, you know, side effects from working, em, in an environment with asbestos dust in it

[6] I mean, there's, life, life is uncertain, everything in life is uncertain, you never know, even with, eh, things, oh, that's a certainty, nothing is, nothing is one hundred per cent certain, apart from death, so there's everything that you do in life has got some form of uncertainty, and it's how you deal with that uncertainty, how important it is, you know, it's like with a gambler, you know, it's the uncertainty of will the cards go for me, with cancer, you know, will the treatment work for me, this job interview, will I get the job? You know, everything, you know, within life, you know, a professional gambler, then the uncertainty of the cards coming up is far more, em, serious than, em, if you're just playing for match sticks, em, as a family, as entertainment, you know, so there's degrees of uncertainty and whatever uncertainty is within your life, em, I control, I, you know, I deal with it the way I've said, you know, by trying controlling or trying to ai-, you know, trying to aim things if I can't control or put it to the back of my mind.

Questions of control and agency

[1] it's all, it's all out of your control, you know

[1] I suppose when things are uncertain, I like to put control in, which is what I was saying to you about my face and stuff, and I suppose what it's taught me that there are things that I'll never ever be able to control, things that might have a huge impact on me, that I'll never be able to control, and you just have to live with that, and find a way to live with it, really, however hard that might be.

[1] but if you can't control it, you can't control it, you know, you've just got to find a way of dealing with it, haven't you really.

[2] you can only do what you can do, you know, you can only eat reasonably healthy, we're not ma..., you know, and we drink alcohol, but 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, and I think that's, that's the being annoyed thing, angry is probably too strong, irritated is more the..., how dare it, you know, when I've done all of this, and then this is, this is two thirds men, mostly 70 and over, em, and 50 per cent of diagnoses are smokers, so I'm something like between one and three per cent are women [laughter], so that, that's what I'm struggling with, I think

[2] I think I was always a very positive person, I think I've been very lucky in my job that I've enjoyed it, and I've been appreciated where I've worked, and so I've always had that good feeling about working, em, I didn't feel it was uncertain whether I would carry on or not cos I thought I was in control of the decision, em, and the same with many other things in life, I mean I think it's put things in, a little bit more into perspective

[3] I was sat there with me own thoughts really for a while, em, yeah, and, and then, you know, you're in that situation where you can't do anything about it, you've just got to deal with it, haven't you? Em, so I suppose it was almost like frozen shock, eh, for a while.

[3] [The dreams are] 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.

[3] I mean, some people say, don't they, you know, crikey, you're unlucky, you know, of all the people to get it, how come you get it? But the same could be said of anybody in certain things. Some people win the lottery, you know, they get the luck on the other side of the fence, it's just destiny almost, innit. It's what's, what, what, what is, you know, down to happen to you, em, you've just got to live with it cos you can't change it.

[3] Do I see myself as unlucky? No. I could turn it round, I could have died in that truck accident when I was 17, couldn't I, so I could say well I've been lucky to be around for another 50 years sort of thing. Em, you know, it's, I'm a great believer of what goes around comes around, and you get your fair share of luck and unluck, em, I mean, it's just how you deal with it, there's some people who are always bitter and moan the fact that they don't have any luck or, but that's probably the way they look at life really, em, so I've been, I've been lucky

[4] so it kind of stems from like I don't really believe in good luck, I believe in opportunities and taking advantage of them, you know, like things just happen if you kind of work towards it. […] I think the not believing in bad luck is because, eh, sort of, eh, [sigh] if I was to believe in some kind of like existential reasoning around all the bad things that have happened to me, then I would have to subscribe to there is some master plan or something, some extraneous variable that has a direct influence on what's happening but I'm, you know, I have cancer, I'm homeless, all these kinds of things, but I've survived, barely survived a hate crime, em, had open chest surgery from it, abuse, child abuse, like all the, all these things that if I was to start believing in these sort of extraneous explanations of or machinations of reasoning around what's happened, I think it just pulls away from the reality that just bad things happen, and I think it gives you a false hope that things will get better without making them better. So yeah, it's just that thing of like when you've had so many bad experiences to believe that there's some kind of uptick when there hasn't been one, I think it's just safer just to think, you know what, it is what it is.

[4] This big overarching question, especially because I'm not a person of faith, is just, it's very hard to feel okay about that […] it's hard to have blind faith that things are going to work out and I'm going to be fine and I know that's the standard for everybody else but going back to luck, like, even if I don't believe in luck, if bad luck believes in me, there's nothing I can do to stop that, like, just [sigh], like I want to be one of those people that can be certain things are

going to work out and be happy and be cool a bit and just think like it's fine, em, this is the way it goes, but with everything that's happened, it's harder to make that leap.

[4] I just have to kind of find my own physically attainable and manageable milestones in the meantime that give me something to work towards because that end goal, who knows, who knows if it's going to work out? And there's nothing, there's nothing I can do to make it work better, you know, it's not like if I had a physical tumour where we have options, cut it out, radiotherapy, you know, whatever it is, em, it's, you know, it's in my blood, it's in my bones, it's just, it's there.

[4] I start thinking about uncertainty, like with my future or whatever, something like that, and then, and then you get anxiety about it cos you're like, well what am I supposed to do, and you get frustrated

[4] Also it's that idea of, you know, like, control and managing something and exerting that control over it, but at the same time it's hard to know how you're going to even deal with that tiny thing now it's become so ingrained, and then how you're going to get back to that huge one.

[4] when those things happen and like when I get that kind of weight of like oh [sigh], this is my life, you know, I kind of have to just sort of try and stop thinking about it, or you know, although it's not the healthiest thing, just be a bit defeatist about it and just be like yeah, it is, because there is nothing I can control about it, and if I try and control it, I'm going to get stuck in an anxiety loop and, eh, and I definitely in the past would try to do that and like try to be healthy and physical and lead a normal life and it just got nowhere.

[4] 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.

[5] it's that bottomless dread that I used to get before an exam, eh before you got the results of an exam, not so much the exam itself, before you got the results of an exam when you're at school or college or whatever, em, and you worry about what if I haven't made the mark this time, yeah, em, yeah, and, cos there's nothing, nothing, there's nothing I can do about it, I can't, there's nothing I can change in my life that would make it more likely that, that I'll have a good result or less likely I'll have a good result, it's completely out of my hands.

[5] stories are kind of beginning, middle and end, and, and then, em, but I don't think there are stories, I think things just happen, so, so, em, you know, it's [silence – 2 seconds], I find it [silence – 4 seconds], if something, if somebody suddenly dies, em, my reaction to it is often different to other people, so I'll pretend to have the same reaction, em, it can be sort of oh they were, they were taken away too early or this, you know, they hadn't realised their potential, but, but there's no, there's no, em, law that says there is an arc with a beginning, middle and end to your life. It can stop at any moment. And stop quite suddenly. And that is the end.

[6] I've sort of learned that, well, if it's outside my control, I just have to sort of go with it and make the best of it, em, and, you know, I look for, if there are ways I can control things, em, like, you know, changing my mind about the hormone treatment was, you know, sort of sitting

down, and I will sort of sit down and look at things rationally, em, after the first impulse of, well I'm not doing that, sort of thing.

[6] I think because I went into it voluntarily, it was my decision to do it, it didn't mentally affect me say as bad as like the chemical castration of Alan Turing did, where his was forced upon him mentally, I suspect it really screwed his head because it wasn't his choice, with me it was my choice, I'd made a considered decision to do that, and it made it easier for me to deal with, I knew that at the end of this, it had a time limit, I'd set the time limit of six months, em, after the last implant, even if they had said oh you need to do this, that and the other, it was still my choice, em, nobody could, you know, force that on me, I hadn't got any threats hanging over me apart from obviously dying, em, so it made it, em, you know, simple for me.

[6] I'd do something about it to control it, to be in control, you know, I don't want to appear a control freak but I think that if you are in control, if you are, you know, if you, if you can't sort of control something, then you got to accept it, then you've just got to put it to the back of your mind as much as you can, and, em, get on with other things in life, you know

<u>Identity and meaning</u>

[1] 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.

[1] for me gardening, it's such an instant thing, you chuck a couple of seeds in, and it's instant gratification almost, isn't it? And like tomorrow they might have germinated and you've got a few little shoots, em, and you know the produce at the end, it's that kind of thing that I, that I like. And also I used to have an allotment, em, and I like the feeling of community there […] I have started volunteering in, there's a local cemetery, I know that sounds a bit morbid, but it's a very beautiful place, so, em, so I've started volunteering there and clearing away the graves and you can do very old graves, it's the oldest cemetery in [name of city], and you can do archiving as well, you know, so it's, cos I'm aware I'm 62 and I'm not always going to be this healthy, so I've started going there, em, and doing other things, so yeah, yeah, I do like being with people as well.

[1] I thought oh, do you know, that might be a bit more interesting than just going and weeding in the park or, you know, sticking a few bulbs in, and it is actually, you know, there's a lot more and sometimes they focus on one of the graves, and they look into the history of that person, who is in that grave, and I suppose there's something, I, yeah, having said that, you know, death, and, I don't believe in the afterlife, you know, or anything, but it is nice that you can be remembered for stuff, I suppose, and that's what going to the cemetery does for me, is that, especially when you look at, em, you know, one grave, and sometimes it's a young person and, you know, what's happened to them. Em, so yeah, I suppose there is something that, that is carried on, your memory can be carried on.

[2] maybe if I need that, I'll, I'll join in, but it's all a bit too chipper and good luck and all of that, and I don't really want that, I want to be normal, you know.

[2] it almost annoys me when I hear people saying oh well, I'm still alive, you know, like you've got six months left, when I've had this [inaudible]... I don't want to be there, you know, I'm in a different place from that, cos they're being pleased that they've, they've lived six months, whereas I want to live 20 years. So I don't think I'm anything to do with them.

[2] why can't I manage this? I think because I've got my boys worrying about me now, whereas it's my job to worry about them, you never stop being a mum

[2] Yeah, yeah, cos you don't stop being a mum, you're still worried about that, but he didn't want to worry me, and it kind of stops you

[2] I do understand about suicide and that, and I think why are people doing that when everybody else is fighting to, to extend their life span, and people feel so bad that they have to, it's still a tragedy, and it's still an illness, I get that, but in a way it made me a bit irritated the other day, which I'd never felt before […] it made me irritated, and that's not me, you know, why are they, how dare they, you know, they're fine, em, and no they're not fine, so it, it's made me think of things which I wouldn't normally feel like. That's not me normally.

[3] 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

[3] I think it's because I'm a sentimental sort of guy and, em, since the diagnosis, I've not been looking forward so much, but I have been looking back a lot at me memories, and I think the songs try and, em, or tend to bring out the memories

[3] on the whole, when you stop to think about it, you know, I had had a good life, we all have, and it was cheering me up to remember the days and the anniversaries and stuff like that, em, so much so that it's prompted me to start a project where I'm writing a book now because we just had a granddaughter and she's seven months old now, and I don't know how long, you know, I'll be around for her, but probably not when she's a teenager, so what I'm trying to do now is encompass all these good thoughts into a book

[4] I think that in order to create sort of positive ideas of the future, you kind of have to have a level of comfort and security to have those thoughts, you know, like it's, your brain works very differently when it's in survival mode

[4] I think in order to generate hope, you have to have a certain level of stability and comfort to daydream these positive things, and when you don't have that, your brain works very differently, like, you know, when you're in survival mode, that's all you can think about

[4] in some ways cancer makes you sort of re-evaluate who you are, which is, you know, tricky, em, I mean, so for me it's like different factors, so one factor is, like, mobility, you know, like, I don't like walking with a stick, I'm embarrassed by it […] and then there's other things, you know, it kind of pulls out of the works of, like, gender and the way you see your body […] but then you add the cancer on top and it starts to make you really process your body and, kind of, there are certain parts of it I have come to terms with, which is better, I've been like, you know, non-binary and accepting what that is and still struggling with, you know, social standards of proving that, but, but then there's this other part which is the cancer, so that's completely out of my control really […] just a lot of stuff to fit together and sometimes trying to fit it all together and be comfortable with the way they intersect can be a bit of a minefield.

[4] it's been a process to let go of who I used to be, you know, and people find it strange when I say that cos, you know, you're the same person et cetera, but in reality people that know me well know that I'm a very different person. Your mood changes, your outlook changes, all that kind of stuff, but beyond that, from a personal aspect, your physical capacity, ability to move in the world changes. You know, I used to be very productive, have multiple projects on the go, walk everywhere, be very healthy, et cetera, so letting that go, it's tough, but then not knowing what the rest of your life is going to be is almost even worse, it's like am I going to get back to that? No, probably not. Em, am I going to survive this? Who knows?

[4] when you're told there is no cure and the only "cure" can kill you, you know, it's, it's rough, and em, so instead the way I sort of process it is in that uncertainty of what's going to happen and not even knowing if it does go bad when it will go bad, just thinking like, okay, well let's use the time and energy I have, let's use the privilege I have to open doors for other people, 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, and not in some sense of grand design, but just, it would be, I think it would be a waste if I was to go through all of this bad stuff and just sit at home and feel bad for myself, which I could do, you know like I'm signed off, I could just sit at home, just play games all day, stare out the window, but, but what's the point, like there's no point in me revelling in the uncertainty and letting it defeat me and become depressed. I just have to kind of find my own physically attainable and manageable milestones in the meantime that give me something to work towards because that end goal, who knows, who knows if it's going to work out?

[5] 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

[5] it also affects how I think about myself in relation to other people cos I'll, I'll see someone that, that, em, I find attractive and for some reason, I mean I wouldn't have done anything about it anyway, be just oh that, that person looks really, really nice, em, but then it sort of immediately hits me, yeah, but not for you. It's, and it's that sort of all, constant unease that, that's always there.

[5] how long is that going to go on, how long do I have to, do I have to constantly pretend that it's not a big deal when it is a big deal, but people then react to it saying, well it's, it can't be a big deal cos you're alive, and it's, but, yeah. So, so it keeps that sort of churn of, of, em, unhappy emotions and will this ever go, you know, will these ever, will I ever get back to being content with all of this? Or will I ever, or will I just have to be resigned to it as opposed to being content with it?

[5] I stopped wanting to work, that was the other thing, yeah, it's sort of, this isn't relevant to me anymore, you know, I don't, don't, don't define myself by this anymore, it's not, not, I don't, yeah, it's not, it stopped being who I am, yeah? Em, so, so I thought I wouldn't be able to do the job as well as I did anyway, so [half-chuckle].

[5] we all build ourselves up out of a jigsaw of different bits and pieces, don't we, so, so, you know, eh, eh, father, husband, eh, senior manager, eh, [inaudible] things in the community, em, eh, bisexual man, em, you know, there's all sorts of bits and pieces, you think well, that was really, that was one of the big pieces, but actually it's not a big piece anymore, it's [inaudible] but, these other pieces are now much more interesting and more, more useful to me

[5] so, yeah, so, so, so, it was a significant part of me, and I suppose the thing that, that, that possibly is surprising, and possibly surprised people at work was I was, eh it's over now [clicks fingers] – gone.

[5] it's not, it's not a physical thing, it's just that knowledge of I'm a different person now, I'm a different man […] I just get a feeling of sort of inadequacy, that, that's it, that's the, yeah, that's the, that's the feeling, it's quite, it's, it's a horrible feeling, it's a horrible feeling.

[5] there is no, there's, there's no sort of arc of stuff that, that people expect

[6] we dealt with it in the way that we deal with these things, em, 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.

[6] when I first said well I'll do the radiotherapy, I'd read what the side effects were, em, and the long-term sort of effects, and I'd read what the side effects were of the hormone treatment, what the long-term effects were for that, em, my heart, em, was saying well you want a sex life, em, and that, just go for the radiotherapy, the side effects are less effective, you know, not going to be as, em, bad for your sex life as the hormone treatments are, but then when the head kicks in, em, then it was a case of yes, but there's more to life than sex

[6] there was the uncertainty from the cancer and everything, em, I th-, I think it was, I think the uncertainty with the cancer and I sort of dealt with that... helped me, you know, sort of make these changes afterwards, I mean, it was like I say, there was an event that happened that, sort of, switched me from uncertainty to certainty because when that happened, I was able to identify something that I hadn't been able to sort of work out previously, as to why I wasn't moving out, I knew I'd got to move out, and it was the uncertainty, the scared of moving out and that, and then the event of the cat dying, that was, ah, now that's why I was staying at the house, because now I know that I don't want to be here anymore, so that must be why, so I was able to do it, but the whole experience has really sort of helped me, em, organise my life, you know, a lot better. It's not that I don't get anxious about things still, but, em, you know, I do, I hope I deal with things, em, a lot better, you know, than eh, I used to.

Living with the spectre of dying

[1] I used to think sometimes, yeah, I think I will die, I think I have got, you know, especially when I had the pain, em, I think I will die, em, and I wonder how much treatment they can give me, I wonder if they can keep me going for a few years, em, and, em, I suppose in some ways I used to try and keep positive as well and think, look, you know lots of people who've had breast cancer, they've all survived, they've all survived, my best friend had breast cancer ten years before me, she was still here, she was building a job, she was, you know, and I can do this too. I used to, I used to, I suppose, em, flit from being oh my God, yes, I think I am going to die, to no, no, no, I don't know anybody, I know people do die of breast cancer, but I personally don't know anybody, and if they can all survive, then actually so can I. It might be hard work, but I, I think I, I think I will survive this. So I used to flit between total despair, I suppose, and total like, no, I'm going to do this, you know, I'm going to... I never thought, em, and you'd hear a lot of people say with cancer, don't you, don't call it a battle, don't say you're

going to fight this, and I never thought about it like that, but I did think I, I would survive it. You know, I used to flit from no, I'm going to die to I will survive this thing, em...

[3] In my mind, it was almost like the brakes have been put on everything, and I ain't got much time now to finish off what I'd started, so that sort of affected me

[3] when we look forward, I mean when we bought the caravan, I thought, well if we get two years out of it and the children want to use it with their children, em, hopefully, you know, even if I stop wanting to go down there because of my illness or, or for whatever reason, it'll still be with them, you know, still have it there to use, em, so, but we don't plan ten years in advance anymore, more like ten minutes. [Chuckle]

[3] I'm not even particularly concerned about dying, I don't want, I don't want the pain, you know, I can do without that, if, so, as long as I get a painful death and it happens, it happens.

[3] well is life really worth living anyway if it's going to be like this all the time?

[3] at that time I'm thinking to meself, well, do or die really, I'll either go there and hate it and won't go out again or it'll be, em, something to boost me confidence

[3] it was whilst the band was playing, after the third or fourth song, I sort of started thinking, well, I'm enjoying this, and it's probably, had been weeks before I can say I'd enjoyed anything, enjoyed me food, enjoyed doing anything, you know, em, and that's when I probably came around to the fact well, look, you know, this is daft, I'm going to have to get meself in order here, and, and, and, and this sort of traces back to that day in January, the 18th, I think, or something, 2018, so from September to January, that was me worst period. Including Christmas. And when you have things like Christmases and all the kids' birthdays, [name]'s is in November, [name]'s is in January, [name]'s is in January, Christmas, New Year, you can't be human if you don't think, well this might be me last one. And me son was due to get married the following June, and I'm thinking to meself, well, am I going to be around for that?

[3] And from a practical side of things, that's what I should have known, but from an emotional side of things, I didn't really want to know or ask that question [how long have I got?].

[3] I can say, we've done a fair bit of far sightedness by future proofing a lot of the expense, you know, and cutting our cloth accordingly, em, but the focus really is day to day, week to week, month to month.

[3] [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, em, but I suppose before the diagnosis, it would have been a flippant remark, well everybody's got to die sometime, whereas now since the diagnosis, thinking about it, yeah, and it could happen sooner rather than later, em, and that does, that is there's certainly an element of uncertainty that you get which influences the life-changing decisions that you make or even your life decisions. You know, em, but we're happy, put it that way, we're not, we're not unhappy, we jog along.

[4] there's that idea that cancer makes you very aware of your mortality, and how much time you have left

[4] even with my tattoos, like I don't like people asking me about them or talking to me about them, I didn't get them for anybody else, I got them cos it's an interest for me and it's something that I like, but at the same time I'm also acutely aware that you exist in the world and people have opinions, you can't avoid that, so [sigh], in the kind of context of sort of this uncertainty, it's almost like you kind of think, with the time I have left, what do I want to do with it, where do I want to go with it, like how, how, how does that impact the way you kind of want to move in

the world, and I'm getting better with it, you know [sigh], I've been using different pronouns, I'm sort of experimenting with like using different honorifics and stuff, but it's just, it feels like baby steps for a life that I want to be able to lead but I don't know if I have the energy

[4] I think the really big shift of when I sort of came to terms with my mortality as it is now is the concept that the majority of people will live without knowing what's going to kill them, and then I now know what is probably going to be 90 per cent chance will be the thing that does it. And I am reminded of it every single day because I have to take pills every day, so you know I can't say for other treatments, you know, if they get that downtime between things, but for me it's, it's an oral medication every day, you know, and also the appointments et cetera, so these little things [rattling pill bottle] are a constant mortality reminder, and that's [sigh], it's a lot, and, and there's a fatigue that comes with consistently taking the pills, consistently having the blood tests, all that kind of stuff

[4] there have been a couple of times in my life where I've come close to dying, at this point, em, and had to face that, and each one was different circumstances, it's about this kind of, you know, fine, whether it's domestic violence, whether it's attack in the street or now cancer, and I think the cancer's been the most, weirdly, the most impactful one because, because the other ones it's like, you know, it shakes you up, you know, it shakes you up to know that somebody could have killed you, and would have killed you if they had a chance, so that's a weird thing to get your head around, you know, it changes the way you see the world because that's a very big experience, but then when it's this cancer thing, you know, those things were a moment that you survived but you deal with after, but 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

[5] I'm not particularly bothered about being dead, if that makes sense, a bit difficult to describe to people who say yeah but you're alive, but if I was dead I wouldn't care about it, em, so, em, cos I'm an atheist, I don't, if you're dead, you're dead, that's it, I have no, no fear of it at all, em, but I wouldn't like an unpleasant, the act of dying I wouldn't like to be unpleasant, yeah? And dying of prostate cancer is not nice, em, it's not a nice way to go at all. So it's that fear of that hideous decline, em, that, that would, yeah, I, I, I, and not knowing whether that's going to trigger at any point, em, and I'm thinking it probably will trigger at some point but, you know, as time goes on it more likely will trigger, you know, it's that, that sort of, em, but it doesn't make me worried, but it's just, it just sort of sits on a shelf, just sits there, looks at me.

[5] when I say life-threatening, I, I, I, I don't mean sort of in the sense of this could kill me, but this could leave me in a, a, you know, a more diminished state or a crippled state, that, that's, that's of more concern to me than, than being dead, as I said before

[5] the concern for me is the quality of life, how I'm going to live at any moment. So at the moment, I'm, I'm quite healthy and fit, em, and that's great, eh, but I'm also 61, so, so I know, I know it's going downhill, yeah? But I'll keep on trying to be healthy and fit as best I can, em, but I'm not, I'm not frightened of, of, of being, as I say, I'm not frightened of being dead, that's just the, that's just what happens.

[5] I'd say none of [the uncertainty is] related to, to, to death. Some of it's related to the act of dying, yes, that's a, that's, yeah, yes, em, eh, yeah, because I don't, as I say, I don't want to go into that, that sort of, eh, unpleasant decline, yeah, where, where things just, yeah, lots more interventions happen.

[5] the uncertainty that disturbs me when I get a PSA score, or when I'm waiting for that PSA score, em, yeah, knowing I could get on that, you know, do I have to get on the treadmill this time, of the cycle of what to do next?

[6] you know, life, you never get, you know, something you don't get out of alive, you know, you, everybody is going to die, and it, it helps me also deal with deaths in the family, when my parents died, when my son committed suicide, em, you know, death, death is all around us, you know, and, you know, you know you're going to die, why worry about it?

Intrusion into awareness

[1] 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, and I've always been a really healthy person, but now I suppose it makes me think, ah, it can happen again, it's happened once, it maybe can happen again

[1] I'm a nurse, I've seen people die many, many times, I've seen things happen out of the blue to people, em, but I suppose there's an invincibility about yourself, isn't there, we all, you know, you all think you're invincible, especially when you're young, em, and you think it'll never happen to me, and in fact, all the friends I've had with cancer, I always thought it would never happen to me, I always thought, you know, em, that will never happen to me, you know, I am strong, and I'm healthy, em, so I suppose I wasn't as aware of the uncertainties around life as this has made me think now.

[2] I think cos it's hit me that I... I'm not invincible, I think that's why. I thought I'm fit, I'm healthy, why shouldn't I go on, not forever, but you know what I mean

[2] I suppose because it was unexpected, em, eh, and it puts your mortality into focus, which it probably wasn't, I was there thinking I'm fit and healthy, you know, I should be okay. Again, not living forever, but at least, you know, as I say, I'm quite good at compartmentalising, for the next five years, for the next five years, you know, we're going to plan this, we're going to plan that, and I think that's, that's what's brought into focus, my mortality, that we should be doing what my husband's saying, you know, we're lucky enough we can afford a nice holiday next year, we've had to cancel it this year so we were going to go and see our son, let, let's do that, let's travel

[2] And I think it's kind of hit me with this, em, you know, 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, you know what I mean

[3] It's just a feeling, it comes out of the blue.

[3] 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.

[3] in me heart really, you know, it's just wow, in me mind, it's, eh, it is a, it is a feeling, I'd hate not to get that feeling, I'm not complaining about the feeling, em, I wish I had more control over when it would happen and when it won't , but em, yeah, it's just, and then I don't know if it's something to do with the chemo that's made me a more sensitive person, it might be the way emotionally I'm coping with it, em, and this is one form of release, em, it's very, very difficult, when you're, when you get diagnosed with something like this

[3] Well, it's like a clock ticking, isn't it. You know. It's a warning to me to not get carried away because sometimes, like I said to you, I don't think about cancer very often, so I almost forget I've got it and it's only when I realise that other people have had a bit of bad news on their visits and then it's had the change or even worse, you know, it's got worse and they can't offer

anything anymore, it comes home as a, if you like, a warning sign to say, well look, just remember, you have got this. It gets you down for a bit, and then it gets you even more determined to get up and make the most of your life really.

[5] I immediately get hit with that, even though there'll be no, you know, it's not like I see someone attractive and go chasing after them, I just, I see somebody attractive on the TV or I see somebody attractive on the street, and immediately I get that reaction about but you can't, not that I ever would, but you can't, and that, you know, you can't initiate a relationship with this person. Which is kind of weird because, as I say, I didn't think I was that sort of person. I would never think of initiating that sort of, eh, you know, engagement with somebody I just seen on the street or on TV or whatever, em, so I'm surprised that that's what's happening in my head.

[5] the emotions hit me, and that, that just stays there, that, ‘til it, ‘til it sort of wears off […] it's emotion of loss, em, yeah? And em, eh, being, being less than, less than I was, yeah? Yeah. So it's quite odd.

Embodiment

[1] when I got the diagnosis, and breast cancer for women, it's quite a disfiguring thing, all about your body image anyway, isn't it, so for me it was more about this as well, em, and losing, I knew I'd probably lose my eye brows and my eye lashes and, it was, em, I tried to cope with it, I tried to control it, that's what I did with the uncertainty of it, em, I tried to put control in there […] so I did turbans, em, and I always thought that I would cope okay with being bald, but honestly for me that was the worst bit of it, that was the worst bit of the whole experience really, em, I kept a turban on 24 hours a day, seven days a week, I could not stand looking at my bald head

[1] I was always certain it would grow back, em, I think, I'm saying that, but yeah, maybe deep down there was a little bit in me thinking, what if it doesn't grow back? And what if it doesn't grow back to be like it was before? I think it was the not growing back to how it was before that was worrying me more than, I did think it would grow back, em, but some people it grows very curly, some people it's wispy, and I've always had a huge lot of very thick hair, and always been very proud of my hair […] I knew I wasn't going to go back to, em, to how it was before, and I think that, it was more of that than thinking it wouldn't grow back.

[1] I was thinking, yeah, I may not survive it, you know, I don't know anybody else who's had cancer in both breasts, em, I don't know anybody else who's had secondaries, you know, but this could be, it could be me, so that's when the uncertainty started, and I did get my results, it was just under a week, and that week I got such physical pain, em, like I've never had. I got pain under my ribs, like in my liver, I got pain in my head, very, very physical pain

[1] I think physical pain is often a manifestation, isn't it, of your stress and your anxiety and that kind of stuff, and it was, it was so noticeable that as soon as [name of doctor] said to me, you have got breast cancer, you haven't got secondaries, I can treat this, and you will be okay, I never, ever had that pain again […]The pains never came back but yeah, I did feel something immediately, it was like this weight just went, do you know, it was like, oh my God, I said, I thought you were going to say I was going to die, you know, and I really did, when I went in there, I really did think, they're going to tell me I'm going to die, and as soon as she said that it was like this huge weight went from me and I could relax. I didn't think, oh my God, that pain is gone, because probably at that time because I was distracted, the pain wasn't there, do you know [laughing], if I was doing something else, the pain wasn't there, it was as soon as I was on my own or, you know, that's when all this pain would start, so I never thought about it then, oh my God, the pain's gone, but when I reflected on it, it was like after that point I never ever had that pain again.

[1] but it still is like this uncertainty that you've got, oh my God, what if they don't, what if, you know, what if they forget about me? […] I suppose the anxiety would rest here, like your heart would go a bit more, em, and... I, I don't know, yes, it would definitely feel very anxious, you know I'd feel quite tense, em, and definitely, eh, like that sinking feeling in your tummy, like, oh God, they're not going to give me another appointment, they're not going to tell me when they want to see me again, so it would all like sink, you know?

[3] it's sort of like a, a goose bumps, exciting feeling, but then me eyes just go, like I was saying before, as a side effect of me chemo, I do get the watery eyes, em, but I just can't stop them crying really, so it's not a bawling or it's not a, em, it's not like a child crying, it's just I'm silently crying, I get very, very watery eyes , and, em, and I feel, I don't particularly feel sad even, I just feel almost, almost happy because it's, I'm getting that reaction, because music means so much to me, but it can be a bit embarrassing at times [laughter], you know, if you're in mixed company and they might what's the matter with him, but, em, as I say, I can mask it often, say me eyes are watering.

[3] I just had that real happy feeling of being at the band and actually hitting, getting the notes fit, you know, almost vibrating off me chest it was so loud and the adrenaline that you got from going to gigs, so I would say it's probably the songs bring back this adrenaline that I used to have, you know, cos it could be about that rocking song, and I'd still, you know, if there's a particular riff that I liked, it always used to give me, like, cold shivers or goose bumps, instead of that happening now, I sort of get tearful.

[4] it's some semblance of precognition and the idea of like am I going to get better? You know, like, is this going to be it forever

[4] one is obviously the emotional aspect, especially if it's bad news, to be like, ugh, that sucks, and you kind of feel like the pit in your stomach kind of go.

[4] I guess there's two somatic markers, I suppose. One would be kind of like nausea, to be honest, like if I think about it, it's just, it doesn't feel good, like. But also, cos the anxiety problems I have, nausea is like the one symptom I have tied to my anxiety, so I feel like it's just related to that, but also it just then compounds it, cos when I think about my future, I just feel sick, I'm just like, and there was the kind of additional aspect, going back to what I said before about this isn't the kind of life I recognise or want, I don't want the life that's coming either. You know, what I really want is to go back to how I was, but I can't do that, so I have to fight and work towards a life that I'm not even happy with. Weird. The other thing is 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. I think, I think a lot of it, a lot of that feeling comes down to the fact that I don't feel like I have control over my life at all, you know, I can't go where I want to go, can't take holidays I want to take, no control over my health, no control over my housing, you know, I don't have anything other than small things that I make manage myself, and when, when I think about that, that's when I just kind of have that weight over me, I'm just like [big sigh], you know, this isn't, this isn't fun. [Chuckle]

[5] 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

[5] it's a, em, a disfigurement, even though you can't see it, yeah? That's the effect.

[5] making the decision had that sort of, em, pit-in-the-stomach feeling that you sort of, eh, not nervous, no, it's a bit sort of, just leaden dread of is this the right thing to do or is that the right thing to do, and I don't know. Or I can make the wrong decision, eh – what is the right decision? It's sort of, yeah. Yes, so, so, em, sort of hollow, empty feeling, that's it. Hollow, empty and leaden, yes.

[5] I think some of the decisions I've had to make at work have fallen into a similar mental state for me, or emotional state, sort of, you know, the stomach churning, you commit to this, this is a, this is a huge deal, what if I've made the wrong decision? What will the consequences of that be? Em, yeah. But of course none of those are life-threatening, yeah, so, but the emotions were similar, but yeah, it's a material difference.

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