UNIVERSITEIT TWENTE.

A Matter of the Heart: Do Cardiac Patients Experience Existential Anxiety Perioperatively?

An Investigative Study of Patients' and Professionals' Perspective

M.Sc. Thesis (10 EC)
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Date: 23rd August 2020
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"Running Header: EXISTENTIAL THEMES IN CARDIAC PATIENTS"

Abstract

Background. Open-heart surgeries often constitute an unavoidable treatment strategy to alleviate symptoms of cardiovascular disease and to prevent patients from fatal consequences. Despite excellent survival rates, these procedures are life-threatening events for many patients, often accompanied by anxiety and depression. As a result of the increasing awareness regarding psychopathological comorbidities, cardiac rehabilitation now also integrates psychological approaches to improve patients' quality of life and to prevent the recurrence of cardiac events. Yet, even psychological rehabilitation programs based on cognitive-behavioural therapy primarily aim to optimise the patient and devote no attention to presumable confrontations with existential concerns. Therefore, the goal of this study was to shed more light on this issue and to contribute to a more comprehensive understanding of cardiac patients' perioperative experiences.

Methods. Previously conducted semi-structured interviews with a purposive sample of six cardiac patients and six attending professionals were transcribed and qualitatively analysed. By using a structured thematic approach, the interviews were analysed both deductively and inductively. This allowed determining whether cardiac patients are confronted with existential concerns perioperatively, based on the tenets of existential psychotherapy according to Irvin D. Yalom. Beyond that, two separate analyses were carried out to determine if the professionals' perceptions coincide with the patients' experiences.

Results. For the analysis of patients' experiences and professionals' perceptions, the four existential givens (1) *death*, (2) *freedom*, (3) *meaninglessness*, and (4) *isolation* served as overarching themes. Indicative experiences of patients could be distributed over 13 categories and illustrated the overall picture that patients are most frequently confronted with the ultimate concern of death. In descending order, patients were then confronted with the existential givens of freedom, meaninglessness, and isolation. Analysis of professionals' perceptions revealed the same overall order. However, only ten categories could be identified. On an individual level, the distribution differed from the overall picture.

Conclusion. Open-heart surgeries provoke a patient's confrontation with existential givens. In two-thirds of the patients, this evoked anxiety, which manifested itself in pathological symptoms of depression. Attending professionals generally perceive that patients are confronted with anxieties, such as the fear of the unknown, yet their focus tends to be rather biomedical, concentrating primarily on the patient's optimisation. The integration of an existential approach into existing cardiac rehabilitation programs could be beneficial as it responds to the patient's needs and offers a differentiated interpretation and treatment approach for anxiety-related avoidance behaviour.

Keywords: Patients' experiences, Professionals' perception, Open-heart surgery, Existential psychotherapy, Ultimate concerns, Qualitative research. Holistic cardiac rehabilitation

Samenvatting

Achtergrond. Open hartoperaties vormen vaak een onvermijdelijke behandelings-strategie om de symptomen van hart- en vaatziekten te verlichten en om patiënten tegen fatale gevolgen te beschermen. Ondanks de uitstekende overlevingskansen zijn deze procedures voor veel patiënten levensbedreigende gebeurtenissen, die vaak gepaard gaan met angst en depressie. Ten gevolge van het verhoogde bewustzijn over psychopathologische comorbiditeiten, integreert hartrevalidatie nu ook psychologische benaderingen om de levenskwaliteit van de patiënten te verbeteren en om het opnieuw optreden van hartgebeurtenissen te voorkomen. Toch zijn zelfs psychologische revalidatieprogramma's op basis van cognitieve gedragstherapie in eerste instantie bedoeld om de patiënt te optimaliseren en besteden geen aandacht aan vermoedelijke confrontaties met existentiële zorgen. Daarom was het doel van dit onderzoek om meer licht te werpen op deze kwestie en bij te dragen aan een beter begrip van de perioperatieve ervaringen van hartpatiënten.

Methoden. Eerder uitgevoerde semi-gestructureerde interviews met zes hartpatiënten en zes behandelaars werden getranscribeerd en kwalitatief geanalyseerd. Door een gestructureerde thematische aanpak werden interviews zowel deductief als inductief geanalyseerd. Hierdoor kon worden bepaald of hartpatiënten geconfronteerd worden met existentiële angsten, op basis van de componenten van de existentiële psychotherapie volgens Irvin D. Yalom. Daarnaast zijn er twee aparte analyses uitgevoerd om te bepalen of de perceptie van de behandelaars overeenkomt met de ervaringen van de patiënten.

Resultaten. Voor de analyse van de ervaringen van patiënten en de percepties van behandelaars dienden de vier existentiële gegevenheden (1) *dood,* (2) *vrijheid*, (3) *betekenisloosheid* en (4) *isolement* als overkoepelende thema's. Indicatieve ervaringen van patiënten konden worden verdeeld over 13 categorieën en illustreerden het algemene beeld dat patiënten het vaakst worden geconfronteerd met de ultieme zorg van de dood. In aflopende volgorde werden de patiënten vervolgens geconfronteerd met de existentiële gegevenheden van vrijheid, zinloosheid en isolement. Uit de analyse van de perceptie van de professionals bleek dezelfde algemene volgorde, maar er konden slechts 10 categorieën worden geïdentificeerd. Op individueel niveau verschilde de verdeling van het totaalbeeld.

Conclusies. Open hartoperaties confronteren patiënten met existentiële thema’s. Bij tweederde van de patiënten riep dit angst op, die zich manifesteerde in pathologische symptomen van depressie. Over het algemeen beseffen behandelaars dat patiënten geconfronteerd worden met angsten, zoals de angst voor het onbekende, maar toch is hun focus eerder biomedisch, waarbij ze zich vooral concentreren op het optimaliseren van de patiënt. De integratie van een existentiële aanpak in bestaande cardiale revalidatieprogramma's zou nuttig kunnen zijn, aangezien het ingaat op de behoeften van de patiënt en een gedifferentieerde interpretatie en behandelingsaanpak biedt voor angstgerelateerd vermijdingsgedrag.

Sleutelwoorden: Ervaringen van patiënten, Perceptie van behandelaars, Open hartchirurgie, Existentiële psychotherapie, Ultieme zorgen, Kwalitatief onderzoek, Hollistische hartrevalidatie

Table of Content

Abbreviations

APA	American Psychiatric Association
AVR	Aortic Valve Replacement
CABG	Coronary Artery Bypass Graft
CBT	Cognitive Behavioral Therapy
CR	Cardiac Rehabilitation
CVD(s)	Cardiovascular Diseas(es)
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECR	Exercise-based Cardiac Rehabilitation
EP	Existential Psychotherapy
NVVC	Nederlandse Vereniging Voor Cardiologie (Dutch Society for Cardiology)
PAAHR	Psychische en Arbeidsgerelateerde Aspecten van HartRevalidatie (Psychological and Occupational Aspects of Heart Rehabilitation)
QoL	Quality of Life
RIVM	Rijksinstituut voor Volksgezondheid en Milieu (National Institute of Public Health and the Environment)
WHO	World Health Organisation
ZGT	Ziekenhuisgroep Twente. (Hospital Group Twente)

Introduction

Cardiovascular diseases (CVDs) are one of the most severe threats to humanity and remain the leading cause of morbidity and mortality worldwide. Approximately 17.9 million people die from CVDs annually (World Health Organization [WHO], 2017). To put this in perspective, that is comparable with the total population of the Netherlands (February 2020: 17.4 million), where one in four currently succumbs to the consequences (Central Bureau for Statistics, 2020; De Boer, Van Dis, Visseren, Vaartjes, & Bots, 2019). In 2018 alone, CVDs claimed the lives of almost 38.000 Dutch people and were responsible for an additional 1.6 million people living with a specific form of it (De Boer et al., 2019; Rijksinstituut voor Volksgezondheid en Milieu [RIVM] 2019). The most common ones, which together account for more than half of all cases, are coronary heart disease (e.g. heart attacks) and cerebrovascular disease (e.g. strokes) (WHO, 2017; De Boer et al., 2019; RIVM, 2019).

Invasive surgical procedures often constitute an unavoidable treatment strategy to alleviate symptoms and to prevent fatal consequences (Vögele, 2016; Mendonça & Andrade, 2013). Since initial symptoms (e.g. unexplained chest pain or exhaustion) are frequently ignored, many patients are only treated after the occurrence of an acute heart event and require surgery (WHO, 2017; Vögele, 2016). In the Netherlands, with almost 15,000 performed procedures per year, these are primarily open-heart surgeries like cardiovascular bypass grafts (CABG) and aortic valve replacements (AVR) (De Boer et al., 2019). During these highly invasive procedures, the rib cage necessarily is opened to perform surgery on the exposed heart or vein. Furthermore, the heart must not beat during the entire procedure, which is why the patient is connected to a heart-lung machine that takes over its functions (National Heart, Lung, and Blood Institute [NHLBI], n.d.).

Although open-heart surgeries generally have an excellent survival rate around 97% (Beckmann, Meyer, Lewandowski, Markewitz, & Harringer, 2019), it is well established that these procedures are life-threatening events for many patients, often accompanied by anxiety and depression (Sedaghat, Rostami, Ebadi, & Fereidooni-Moghadam, 2019; Vögele, 2016; Pogosova et al., 2015; Mendonça & Andrade, 2013). In fact, elevated levels of anxiety and depressive symptoms are three times more prevalent in this population than in the general, represent the most common comorbidities and occur in 40-65% of patients admitted to hospital for CABG and AVR (Rao et al., 2019; Vögele, 2016; Pogosova et al., 2015; Elliot, Salt, Dent, Stafford, & Schiza, 2014). Open-heart surgery is not only perceived as an immediate risk to life due to the fact that the heart is the essential human organ but also because of its cultural

accentuation as the source of life and emotions (Mendonça & Andrade, 2013). For many patients, this makes it particularly challenging to deal with the situation, even after successful surgery (Mendonça & Andrade, 2013). Depression and anxiety disorders immediately before and after open-heart surgery are associated with higher rates of surgical complications, rehospitalisation, longer recovery and also lower health-related quality of life (QoL), reflecting patients' physical and social functioning, as well as mental well-being (Rao et al., 2019; Pogosova et al., 2015, Dekker, 2011). In contrast to non-comorbid heart patients, they have a significantly increased probability of recurrence of (even more severe) cardiac events within a period of three to four years and almost twice the risk of dying from the consequences of the disease (Vögele, 2016; Pogosova et al., 2015; Elliot et al., 2014).

Increasing awareness of the interaction between CVDs and psychopathological comorbidities has shaped the cardiac rehabilitation landscape in the Netherlands. Since 2004, the guideline 'Cardiac Rehabilitation', formulated by the Rehabilitation Commission Nederlandse Vereniging voor Cardiologie (NVVC, engl.: Dutch Society for Cardiology), has applied with the attempt to ensure and standardise the quality of rehabilitation programs nationwide. Based on the increasing scientific evidence, the guideline was revised in 2011 and now officially devotes attention to psychological factors, too. As a result, the current Dutch guideline no longer focuses exclusively on physical recovery and lifestyle changes but also includes psychological and social aspects for lasting rehabilitation. Additionally, since there is a growing notion that interventions are more effective when tailored to a patient’s individual situation and needs (NVVC, Nederlandse Hartstichting [NHS], & projectgroep PAAHR, 2011; Jansen, Foets, & de Bont, 2010), the emphasis is also placed on tailor-made care to achieve the goal of improving the patient's mental well-being and QoL, ultimately reducing the recurrence of cardiac events as well as mortality and morbidity (Pogosova et al., 2019; NVVC, 2012; NVVC, NHS, & projectgroep PAAHR, 2011). In consideration of the multidisciplinary involvement (e.g. cardiologist, nurses, physical therapist, dietician, psychologist, rehabilitation physician), the guideline therefore provides a decision tree as a tool for determining the individual need for cardiac rehabilitation measures (NVVC, 2012; Kemps et al., 2011) and also recommends various (combinations of) screening tools for the detection of psychological symptoms (see Appendix A) (NVVC, 2012; NVVC, NHS, & projectgroep PAAHR, 2011).

For patients with increased depressive symptoms and anxiety, the Dutch guideline recommends integrating cognitive behavioural therapy (CBT) into the rehabilitation process (NVVC, 2012). CBT is proven to be the most successful treatment approach for depression and

anxiety disorders (Elliot et al., 2019; Vögele, 2016; Dekker, 2011). The theory builds on the premise that there is an interplay between thoughts, behaviours, emotions, and bodily sensations (Elliot et al., 2019; Dekker, 2011). Hence, the way a person interprets a certain situation determines his/her emotional perception and reaction (both physical and behavioural) (Elliot et al., 2019). Crucial in CBT is the fundamental belief that the human mind is biased, which can lead to cognitive errors or dysfunctional thinking. This, in turn, can cause unhealthy behaviour or emotions, whereby the aforementioned interactions quickly become a vicious circle (Elliot et al., 2019; Dekker, 2011). CBT aims to break these circles by addressing dysfunctional behaviour and thought patterns (Elliot et al., 2019 Gebler, 2010). For example, having experienced an acute cardiac event represents an extremely stressful experience for many patients and leads to symptomatic manifestations comparable to those of post-traumatic stress disorder. These symptoms include flashbacks and avoidance behaviour concerning the situation in which the accident occurred (NVVC, 2012). In this case, CBT is used to reassess the meaning of the trauma to tackle the avoidance behaviour (Boos, 2014) and attempts to reconstruct catastrophic thoughts into more desirable ones (ZGT, 2019; Menzies, Menzies & Iverach, 2018). In cardiac rehabilitation (CR), CBT also serves the purpose of promoting and establishing a healthy lifestyle in patients. For this purpose, psychoeducational elements are used to help patients acquire knowledge about underlying, maintaining, and impeding psychosocial factors (NVVC, NHS, & projectgroep PAAHR, 2011).

Despite CBT being the gold-standard in evidence-based psychotherapy for depression and anxiety (Menzies et al., 2018), there are some critical limitations regarding the overall goal in CR to improve the patient's QoL (NVVC, 2012; Gebler, 2010). Above all, this is related to the fact that the complaint-oriented approach primarily strives for the patient’s rapid optimisation so that he or she can resume everyday life without complaints as soon as possible (Pogosova et al., 2019, Vögele, 2016; Van Bruggen, Vos, Bohlmeijer, & Glas, 2013). To achieve this goal and to help patients adapt to the circumstances as well as possible, efforts are made to establish "positive thoughts" (i.e. more helpful and realistic ones) during group therapy sessions (ZGT, 2019; Menzies et. 2018; Van Bruggen et al., 2013; NVVC, 2012; Gebler, 2010), Yet, if a patient does not succeed in sufficiently implementing the intended strategies, studies with chronic pain patients showed that the experience of competence and self-esteem can suffer (Gebler, 2010; Prasko, Mainerova, Jelenova, Kameradova, Sigmundova, 2012). According to Gebler (2010), it is also questionable, whether focusing on positive, accepting thoughts too early or exclusively is advisable, since a solely positive attitude can have a negative influence

on coping with distress, too. In addition, while optimising the patient, little attention is paid to the creation of meaning, although this is associated with a high degree of QoL (Gebler, 2010, Tausch 2008). QoL is a rather vague and ambiguous concept that lacks a uniform definition (Grylka et al., 2017; Gebler, 2010). Generally, however, it can be broken down to the core statement: "*No one is happy who does not consider himself happy*" (Marc Aurel; as cited in Gebler, 2010, p.4), indicating its subjective character. Correspondingly, experienced QoL depends on the individual's assessment and evaluation of one's own life (Gebler, 2010). According to Tausch (2008), high QoL relates above all to experienced and realised personal values and thus individual experiences that give life meaning. At the same time, loss of meaning is a predictor for hopelessness, stress, depression, and anxiety (Gebler, 2010; Tausch, 2008), typical psychological symptoms that are known to be common in heart patients (Sedaghat et al., 2019; Vögele, 2016; Pogosova et al., 2015; Mendonça & Andrade, 2013; NVVC, 2012). Beyond that, studies of patients with chronic and life-threatening diseases, e.g. cancer patients and patients with chronic pain or fatal heart disease, have shown that they were significantly less mentally impaired when they were able to find meaning in their lives or diseases (Vos, 2015, Van Bruggen, Vos, & Glas, 2014, Tausch, 2008; Yalom,1980).

In conclusion, classical CBT has its limitations when it comes to more philosophical questions, for example, concerning the meaning of life, death, or suffering (Gagnon et al., 2014; Bruggen et al., 2014, Prasko, et al., 2012; Koole, Greenberg & Pyszczynski, 2006). In contrast, these very concerns represent central themes in various strands of existentialist psychotherapy, such as Logotherapy or Daseinsanylse (Grober, Heidenreich, & Rief, 2016; Van Bruggen et al., 2014; Prasko, 2012). Although the different approaches of existential psychotherapy can be clearly distinguished from each other, they have something in common, namely that they are all deeply rooted in existential philosophy (Grober et al., 2016; Van Bruggen et al., 2014; Dela Cruz, 2013). Well-known persons that are commonly associated with this philosophical movement are Kierkegaard, Nietzsche, Heidegger, Sartre, Camus and also Russian novelists such as Dostoevsky and Tolstoy (Van Bruggen et al., 2014; Dela Cruz, 2013; Cooper, 2003). Although it should be noted that some thinkers like Camus, Heidegger or Sartre refused to be labelled as existentialists (Kaufmann, 2016; Van Bruggen et al., 2014; Cooper, 2003), their ideas and works nevertheless fundamentally influenced the probably most widely known contributor to the field of psychotherapy and founder of existential psychotherapy (EP) Irvin D. Yalom, Professor Emeritus of Psychiatric at Stanford University (Huguelet, 2014; Zafrides, 2013; Berry-Smith, 2012; Cooper, 2003). The present thesis will be written within the

contextual framework of EP, according to Yalom and his book *Existential Psychotherapy* (1980).

Existential Psychotherapy is considered as a dynamic approach which focuses on individual's conflicts with the four givens of existence: *death*, *freedom*, *isolation*, and *meaninglessness*. Yalom (1980) refers to these givens as "*ultimate concerns*" (p.8) since they are inherent to human nature, whereby the confrontation becomes inevitable. The confrontation is especially provoked by so-called "*boundary or border situations"* (p.8) (e.g. having an accident or terminal illness), which unavoidably draw the individual's attention to one of the givens, which will be outlined in the following paragraphs.

Death. The first, and most apparent, existential concern of death centres around the

> *'tension between the awareness of the inevitability of death & the wish to continue to be' (Yalom, 1980, p.8)*

The unique cognitive development of the human being and the ability to think, plan and reflect, burdens the individual at the same time with the consciousness of eventual death (Van Bruggen et al., 2014; Zafrides, 2013; Koole et al., 2006). The individual, constantly, however, not necessarily consciously, faces the undeniable reality of mortality, while having the desire to live (Yalom, 1980). The confrontation of the ultimate concern *death* most frequently can be observed in the aftermath of negative border experiences, such as the confrontation with a fatal illness, the loss of loved ones, and accidents. Due to correlated symptoms like catastrophic thinking and ruminating, it is well understood that anxiety and depression can increase the awareness of death, which in turn can cause uncertainty, confusion, as well as severe distress (Yalom, 1980). However, from practice, it is known that patients who ask themselves about the purpose of suffering were more confronted with the existential concern of death. Here, fantasising of death was also observed as an emotional relief-valve serving to mitigate pain and suffering. In therapy, the confrontation with death exemplifies in comments such as *"I am not sure how long I can go on like this*" and *"I wish I could go to sleep and not wake up"* (Zafrides, 2013, p. 6). According to Yalom (1980), a person who is unable to confront the possibility of dying might attempt to assuage the terror of death by either believing in the own specialness (i.e. the belief to be an exception to the norm) or in the existence of an ultimate rescuer.

Freedom. The term freedom is somewhat misleading, as it usually refers to something positive. In an existential sense, the individual is indeed free but rather "*doomed to be free*" (Yalom, 1980, p. 220) as it indicates the individuals' sole responsibility for his life. This implies

authorship and becomes especially dreadful when the individual must decide or choose, as it is impossible to predict the outcomes. Yalom (1980) defined freedom as the *"absence of external structure"* (p.8). Having the freedom to give life a direction, meaning or values against this background can evoke the experience of groundlessness and anxiety. The existential conflict of freedom, therefore, refers to the

> *'tension between our confrontation with groundlessness & our wish for ground & structure.' (Yalom, 1980, p.9)*

Being confronted with the conflict of freedom can also cause severe distress and existential guilt, as it brings the individual the awareness of being responsible for not living their life to their full potential. Yalom (1980) even states that *"the discrepancy between what one is and what one could be, generates a flood of self-contempt with which the individual must cope throughout life"* (p. 279). The confrontation with the ultimate concern of *freedom* may manifest itself as anxiety, depression or even boredom. In attempts to deny the responsibility of freedom, individuals can avoid personal responsibility by displacing it upon others, or even by procrastinating, which, according to Yalom (1980) is the most obvious method of avoiding a decision.

Isolation. The third ultimate concern refers to existential isolation. In contrast to separation from others (interpersonal isolation) or the closure of parts of the inner self (intrapersonal isolation) (Van Bruggen et al., 2014), existential isolation reflects an individual's separation from the world and his 'true aloneness' (Yalom, 1980). When confronted with existential isolation, the individual becomes aware that there is a fundamental, unbridgeable gap between him/her and others despite feeling close to others or having relationships with others. The individual will become aware that he/she enters and departures the world alone. Moreover, he/she will become aware that no one ever will experience the same feelings he/she experiences. The awareness will eventually evoke a sense of fundamental loneliness (Yalom, 1980). In this sense, the existential conflict regarding isolation refers to the

> *'tension between our awareness of our absolute isolation & our wish for contact, for protection and our wish to be part of a larger whole.' (Yalom, 1980, p. 9)*

Being confronted with existential isolation, most frequently manifests in emotional distress. Apart from physical suffering, for example, emotional pain can also bring awareness of the fundamental aloneness. Yalom (1980) also pointed out that it is a common theme in depressed and anxious patients, in the sense of feeling isolated through a lack of external understanding.

According to Yalom (1980), individuals most frequently try to deny their existential isolation through the fusion with others (e.g. marriage). Yet, he adds, that no relationship can eliminate or ward off existential isolation (Yalom, 1980).

Meaninglessness. At the bottom line: An individual must die, is doomed to be free, and ultimately alone. Naturally, the awareness of these existential givens can cause an existential crisis, where the individual has to ask himself or herself questions like: "What is the meaning of existence?" or "Which purpose serves existence?" Given the fact that an individual is ultimately free, and there is absolutely no predetermination, then the individual is solely responsible for creating his/her own meaning and purpose in life. This confronts him/her with the fourth ultimate concern of meaninglessness, which refers to the:

> *'dilemma of a meaning-seeking creature in a world without meaning'*
> *(Yalom, 1980, p.9)*

When people attempt to avoid the confrontation with the fourth ultimate concern, this can manifest in typical psychopathological symptoms of depression, including apathy or a sense of emptiness. To cope with this reality, an individual may devote his life to a cause he finds meaningful or tries to believe in some form of a higher order, for instance, becomes religious or spiritual.

Yalom (1980) argues that the awareness of each of these givens, either conscious or unconscious, evokes anxiety, which will become pathological when using non-adaptive defence mechanism in the attempt to ward off existential anxiety, especially by avoiding the confrontation entirely. However, Yalom (1980) emphasised that experienced anxiety not necessarily needs to be pathological. With his famous words: *"Although the physicality of death destroys man, the idea of death saves him",* Yalom (1980, p. 30) stresses that the experienced anxiety also offers the opportunity to grow and to live an authentic life. The overall aim of EP, therefore, is to help and to guide the individual in confronting and becoming aware of the four givens of existence (as well as dysfunctional defence mechanisms) by asking deep questions about the nature of anxiety, grief, and despair (Yalom, 1980). Faced with the same existential questions as the patient and without any universally valid answers, the therapist does not adopt the role of either a superior or instructor **(**Huguelet, 2014; Zafrides, 2013; Gebler, 2010). Instead, therapeutic work is characterised by a close, non-hierarchical relationship in which the therapist tries to encounter the patient's inner world through *"disciplined naïvety"* (p. 25), an

attitude that encompasses genuine listening, presence, empathy and non-judgmental acceptance (Yalom,1980).

In summary, the pragmatic cognitive behavioural approach naturally pays less attention to underlying, more philosophical questions that come with the confrontation of a life-threatening event (Van Bruggen et al., 2014, Yalom, 1980) and thereby neglects patient's needs. This, in turn, also questions the intention of providing tailor-made CR. The integration of Yalom's non-dogmatic existential psychotherapy approach could compensate for CBTs existing limitations and contribute to the practical implementation of the intended approach of a holistic, person-centred CR (Van Bruggen et al., 2013; Prasko et al., 2012; Gebler, 2010; Yalom, 1980). However, apart from cancer and palliative care, little is known about how patients who are struck by a severe illness (Grober et al., 2016, Schaufel, Nordrehaug, & Malterud, 2011; Gebler, 2010) experience life-threatening events, such as open-heart surgery, and whether they are confronted with existential challenges. To contribute to a more comprehensive understanding of patients' experiences in the period around an open-heart surgery, this research study aims to answer the question:

1. Do cardiac patients experience existential anxiety perioperatively?
    1.1. If so, which ultimate concerns occupy them predominantly?

Although patients' confrontation with the existential givens not necessarily causes psychopathological manifestations (Yalom, 1980), it is crucial that attending professionals are able to identify and adequately address the issues that concern patients to prevent possible negative consequences (e.g. anxiety and depression) and to promote well-being (Schaufel et al., 2011). However, a study by Buser (2003) on communication with cancer patients indicated that health-care professionals are often unable to operate in a person-centred manner if they cannot put themselves in the patient's disease-related perspective. Additionally, a study by Novaes et al. (1999) on the perception of patients' stressors in intensive care unit even revealed that professionals have their own perceptions of patients' experiences during hospitalisation, as their evaluation is affected by personally experienced stress and daily work routines. Consequently, this study further attempts to gain insight into the professionals' perception of patients' confrontation with existential anxieties and attempts to answer the question:

2. Do cardiac patients experience existential anxiety perioperatively according to their attending professionals?

2.1. If so, which ultimate concerns do professionals consider to be at the forefront?

Since professionals are primarily responsible for interventions on patients and the content often relies on their perceptions (Sedaghat et al., 2018; NVVC, 2012; Udo, Danielson, & Melin-Johansson 2012; Novaes et al., 1999), it is particularly important to investigate whether these correspond to the patients' experiences and needs. Studies have shown that professionals' misconception, for example, led to the provision of less effective interventions to eliminate stressors in open-heart surgery patients (Sedaghat et al., 2018) and that the failure to address existential experiences in terminal cancer patients both impeded recovery and contributed to the patient's overall suffering (Mako, Galek, & Poppito, 2006). In the context of holistic care, Kooslander, Da Silva and Roxberg (2009) even go so far as to consider the failure to meet patient's existential needs as a potential violation of human dignity, worth and fundamental rights. Therefore, the two perspectives will be compared to answer the question:

3. Do the professionals' perceptions coincide with the patients' experiences?

Methods

Design

The current study is based on previously conducted semi-structured interviews with patients and attending professionals from a cardiac surgery centre in the Netherlands. For the qualitative analysis, a structured thematic analysis approach was used, as described by Braun, Clark, & Hayfield (2019). The Ethical Committee of the University of Twente approved the study (no. BCE15309).

Participants

A total of twelve participants were recruited at the cardiology department of a hospital in the Eastern part of the Netherlands via purposive and snowball sampling. Of these, six participants were patients, and the other six were attending professionals from the multidisciplinary team.

On behalf of the researcher, patients were informed about the ongoing study by a specialised nurse during consultations on one day. Since the researcher has previously recruited the nurse, this is a clear demonstration of the recruitment strategy of snowball (or chain)

sampling (Naderifar, Goli, & Ghaljaie, 2017). All initially approached patients (N=10) gave positive feedback to be willing to participate, which the nurse forwarded to the researcher. To meet the inclusion criteria, patients had to be at least 18 years old, and either has had open-heart surgery within the past year or were waiting to undergo it at the time of the interview. Based on these inclusion criteria and an additional selection regarding age distribution, six patients were subsequently contacted and received an information letter (Appendix B.1.), reflecting the purposive element of recruitment. The letter outlined the objective of the investigation, who carries it out and to which institution it is affiliated. All patients contacted agreed, which is why the remaining four, who had also expressed their willingness, received a letter of thanks in March 2016 informing them that their participation was no longer necessary. Table 1 provides an overview of the patients' characteristics. The sample consisted equally of men and women with an average age *of* M = 69.33 years *(*SD = 7.20*),* ranging from 61 to 78 years. All participants were retired and had already undergone open-heart surgery (CGAB and AVR in equal measure). Also, the majority were widowed and to some extent religious.

Attending professionals were recruited similarly. Via purposive sampling, different professionals from the multidisciplinary team were recruited, including one cardiologist, two physiotherapists, two nurses and one specialist nurse. In advance of the interviews, they also received an adjusted letter of information (Appendix B.2.). The professionals' characteristics are presented in Table 2. The sample also consisted of equal numbers of male and female participants with an average age of M = 48.33 years (SD = 13.60), ranging between 25 and 60 years. Beyond that, the participants of the predominantly highly educated sample worked on average M = 8.5 years (SD = 5.16) in their current position.

Table 1

Patient's characteristics at the time of the interviews

	Sex	Age in years (M[1] = 69.33; SD[2] = 7.20)	Type of Surgery	Education Level[3]	Occupational Status	Marital Status	Children[4]	Religious
P1	Female	61	AVR[5]	Low	Retired	Widowed	Yes	Yes
P2	Female	73	CABG[6]	Middle	Retired	Widowed	Yes	Yes
P3	Female	65	CABG	Low	Retired	Widowed	Yes	Yes, not practicing.
P4	Male	76	CABG	High	Retired	Married	Yes	Yes.
P5	Male	78	AVR	Low	Retired	Married	Yes	No
P6	Male	62	AVR	High	Retired	Single	No	Yes, not practicing.

Note. [1]M = Mean; [2]SD = Standard Deviation; [3]Low: primary and lower secondary education; middle: upper secondary education; high: higher vocational training and university; [4]All patients with children indicated that those do not live with them at home; [5]AVR: Aortic Valve Replacement; [6]CABG: Coronary Artery Bypass Graft.

Table 2

Professionals' characteristics at the time of the interviews.

	Profession	Sex	Level of education[1]	Age in years (M[3] = 48.33; SD[4] = 13.60)	Occupational Status[5] (hrs. a week)	Work experience (years) (M =23.00; SD=13.27)	Work experience in current position (years) (M = 8.50; SD = 5.16)
Pro1	Cardiologist	Female	n.a.[2]	58	>20	25	15,5
Pro2	Physio-therapist	Male	High	60	>20	36	10
Pro3	Physio-therapist	Female	High	54	36	32	3
Pro4	Nurse	Female	Middle	39	>28	7	6
Pro5	Nurse	Male	Middle	25	>36	6	3.5
Pro6	Nurse specialist	Male	High	54	>36	32	13

Note. [1]Low: primary and lower secondary education; middle: upper secondary education; high: higher vocational training and university; [2]n.a. = not asked by the interviewer; [3]M = Mean; [4]SD = Standard Deviation; [5]since all professionals are doing 'paid work', the occupational status indicates the number of hours worked per week.

Procedure & Materials

Semi-structured interviews were conducted in the period from February 2016 until April 2016 as part of an ongoing doctoral thesis. Aim of the study is the development of a psychological online intervention to improve the recovery process after open-heart surgery, considering the needs and wishes of both patients and professionals. Therefore, the PhD-candidate (A.H. - a trained M.Sc. in Health Psychology) took the interviews either at the patients' home or, in the case of an attending professional, at one of the hospital's two associated cardiological facilities. Prior to the interviews, however, the participants had to give their written consent. Therefore, the patients received a letter of consent (Appendix C.1.) informing them about their right to withdraw their voluntary participation at any time and for any reason. They were also assured that their sensitive data would be handled anonymously, confidentially, and respectfully, and that their involvement would not have any consequences concerning their operation/treatment. The participating professionals received an adjusted version of the informed consent (Appendix C.2.) where they were assured that their participation would not affect their work at the hospital. All interviews were then conducted in Dutch and under some circumstances in the presence of the patient's relatives.

During the 40-45-minute conversations, a self-developed interview scheme (Appendix D) served the researcher as a guideline. The interviews consisted of three consecutive parts. The first part focused on the period prior to the operation: how the patient felt, what complaints he/she had and how he/she dealt with them. In the second section, the patient's experiences with the operation itself were discussed and how he/she experienced the rehabilitation phase afterwards. During the third part, the researcher then asked about the patient's wishes and needs for an online intervention. The participant was presented with initial ideas and a draft version on which he/she was asked to comment. The professionals were asked to answer the questions mentioned above from their point of view and were additionally asked how a novel intervention could be implemented in their daily work without becoming an additional burden. Finally, general data were collected (e.g. age, gender, occupation, etc.), and the participants were allowed to ask questions or make further comments.

To fully engage in the conversation with the participants, A.H. made no field notes but recorded the interview with an audio recording device. For further analysis, the audio files were then transcribed verbatim using the transcription software *Express Scribe.*

Data Analysis

To interpret the experiences of patients and professionals, a hybrid method of inductive and deductive thematic analysis was used, which is an appropriate technique in a clinical context (Braun, Clarke, Hayfield & Terry, 2019; Fareday, & Mui-Cochrane, 2006). The methodological approach integrated data-driven codes with theory-driven ones (Fareday, & Mui-Cochrane, 2006) based on the tenets of existential psychotherapy according to Yalom (1980). This allowed to determine whether cardiac patients experience existential anxiety perioperatively, as discussed in the existing theory, but also to work out inductively how existential anxiety manifests itself in this target group (Fareday, & Mui-Cochrane, 2006). All subsequent analysis steps were executed in two separate versions, to ensure that the two perspectives could be analysed independently. Hence, two coding schemes were developed, one for the analysis of patients' experiences and one for the perceptions of the treating professionals.

In a first step, the interviews were re-read to familiarise with the content. For this purpose, the transcribed interviews were printed out and already provided with first annotations. In a second step, it was made use of deductive coding by linking relevant sentence fragments or entire statements/responses (consisting of more than one sentence) into one of Yalom's (1980) four themes: (1) *Death*; (2) *Freedom;* (3) *Meaninglessness*; and (4) *Isolation*. However, depending on their content, fragments could also be assigned to several themes.

In the following step, the fragments of the main topics were examined more closely and arranged into sub-themes through inductive analysis. During this step, a constant comparative analysis was performed, and accordingly, new codes continuously compared with already existing ones to reduce redundancy. This step was also repeated until no new codes or sub-codes could be extracted from the raw data. The resulting preliminary coding schemes were then expanded with definitions, variations within codes and exemplative (translated) quotations. These versions were then discussed with another researcher (N.K.), adjusted and used as the final coding schemes (Appendix E.1., E.2.). Subsequently, all the data was coded anew using the software Atlas.ti (version 8.0). A condensed version of the particular coding scheme with additional information on occurrence is given in Table 3 (for patients) and Table 4 (for professionals) in the following section.

Although all parts of the interview were considered, it should be noted that the focus of the analysis was primarily on the first two parts of the previously collected interviews, since the

third part (concerning the development of a new intervention) was formulated mainly in the subjunctive and provided little information about the patient's actual experiences.

Results

In the following section, the results of the data analysis are presented in the order of the research questions. Accordingly, this section is divided into three parts. In the first part, the findings of the patients are presented and in the second part, those of the professionals. Finally, in the last section, a comparison is made of the extent to which the two perspectives coincide or diverge.

1. Evaluation of patients' experiences

In this first part, the analysis results of the patient interviews are presented, whether they experience existential anxiety perioperatively and which ultimate concerns occupy them predominantly during this period.

The evaluation of the interviews showed that the majority of patients were confronted with existential anxieties in the period around open-heart surgery. All patients mentioned experiences or thoughts that could be clearly assigned to one or more of the four ultimate concerns (1) *Death*, (2) *Freedom,* (3) *Meaninglessness*, and (4) *Isolation*, that served as overarching themes. In total, 493 fragments were identified and by means of 13 codes assigned to the four themes (see Table 3). The aforementioned order of themes also reflects their overall occurrence in a descending manner. Experiences, indicating a confrontation with the ultimate concern of death (n = 213, 43.2 %) were mentioned most frequently, while those concerning the issue of isolation (n = 29, 5.9 %) were mentioned scarcest. On an individual level, the distribution varied considerably and also differed from the overall picture. For example, while patient no. 1 most frequently made statements that pointed to a confrontation with the ultimate concern of freedom (almost 48% of all her statements), patient no. 6 most frequently mentioned experiences that pointed to a confrontation with the ultimate theme of death (55%). In total, four out of six patients (n = 4) described themselves as depressed and emotionally affected by the operation and additional experienced consequences such as the loss of ability and dependency. The two remaining patients (P4 & P5) considered themselves as unaffected by the operation and reported on average only half as many experiences indicating a confrontation with the givens of existence. The majority of their statements were also attributed to defence mechanisms associated with the themes of death and freedom. In addition, the interviews revealed that no patient participated in a psychological rehabilitation intervention after cardiac surgery.

Table 3
Occurrence of Ultimate Concerns in Interviews with Patients (N=6)

Theme	**Patient**						**Total**	
Category • Sub-category	P1 (n=84)	P2 (n=96)	P3 (n=89)	P4 (n=46)	P5 (n=48)	P6 (n=127)	n (N=493)	%[1]
Death	24	43	33	18	25	70	**213**	**43.2**
Confrontation with Severe Illness	16	23	21	11	17	33	**121**	**56.8**
• Confrontation with Physical Complaints	9	6	12	4	10	16	**57**	**47.1**
• Past with severe Illness	4	7	6	1	3	2	23	19.0
• Denial of Illness	1	5	-	4	4	8	22	18.2
• Need to take Medication	2	5	3	2	-	7	19	15.7
Fear of Unknown due to a Lack of Knowledge	4	15	4	3	2	22	50	23.5
Confrontation with own Death	4	2	5	4	6	14	35	16.4
• Awareness of own Mortality	4	1	4	2	3	14	**28**	**80.0**
• Awareness Natural Decay	-	1	1	2	3	-	7	20.0
Lack of Safety	0	3	3	0	0	1	7	3.3
Freedom	40	42	42	13	21	42	200	40.6
Experiencing Existential Guilt	21	21	25	3	7	15	**92**	**46.0**
• Feelings of Guilt against Oneself for the "Unlived Life"	18	11	21	1	6	13	**70**	**76.1**
• Feelings of Guilt towards Others	3	10	4	2	1	2	22	23.9
Loss of Autonomy	10	13	12	4	5	16	60	30.0
• Loss of Control	2	4	3	2	3	14	**28**	**46.7**
• Being Dependent	8	4	3	1	1	2	19	31.7
• Being Patronised	-	5	6	1	1	-	13	21.7
Avoiding taking Responsibility to make Decisions	9	8	5	6	9	11	48	24.0
• Displacement of Responsibility	7	3	4	5	7	2	**28**	**58.3**
• Avoidance of Autonomous Behaviour	2	5	1	1	2	9	20	41.7
Meaninglessness	9	8	10	12	2	10	51	10.3
Loss of Meaning	8	5	8	1	1	5	**28**	**54.9**
Cosmic Meaning	-	3	2	7	1	2	15	29.4
Experiencing an Existential Crisis	1	-	-	4	-	3	8	15.7
Isolation	11	3	4	3	**0**	5	29	5.9
Experienced Loneliness/Isolation	10	1	2	-	-	3	16	55.2
Fear of Loneliness/Isolation	1	2	2	3	-	5	13	44.8

Note. [1] depending on the code level, it either reflects the percentage distribution of themes (dark blue background), categories within the theme (light blue background) or the distribution of sub-categories within the categories (no background colour).

1.1. Death

Without exception, all patients (*n* = 6) indicated that they were confronted with existential anxiety related to the tension between the undeniable reality of finiteness and the desire to continue to be. As mentioned before, information on the theme of death anxiety occurred most frequently and was further divided into four categories: (1*) Confrontation with Severe Illness* (*n* = 121, 56.8 %), (2*) Fear of Unknown due to a Lack of Knowledge* (*n* = 50, 23,5 %), (3) *Confrontation with Own Death* (*n* = 35, 16.4 %), and (4) *Lack of Safety* (*n* = 7, 3.3 %).

1.1.1. Confrontation with Severe Illness. Of all experiences associated with death anxiety, almost 57% (*n* = 121) were caused by the *Confrontation with [a] Severe Illness.* This category comprises four further sub-categories that reflect the confrontation in a more differentiated way. The relation between death anxiety and the confrontation with the severe illness was most frequently associated when patients referred to the distressing *Confrontation with Physical Complaints* (*n* = 57), which represents the first sub-category. Due to the illness/surgery, all patients were at a certain point confronted with physical complaints and side effects, including increased fatigue, memory impairment and shortness of breath. More severe complications, like urine in the kidneys or excessive fluid accumulations even prolonged the hospital stay for patient no. 3 and no. 6. In addition, almost all patients mentioned chest pain and associated feelings of pressure on the chest. Patient no. 1, who according to her own was *"deep in the pit"* after surgery, gave an insight into the extent to which the experienced chest pain was also mentally stressful:

> *Cause it's not a piece of cake (org. dutch: Huppekee). When you know that they have detached the whole thing [ribcage] there […] and they just put it back together, and good is, but the muscles in that spot, everything hurts. (P1)*

The second sub-category, entitled *Past with Severe Illness* (*n* = 23), includes information that all patients (*n* = 6) became aware of the inevitability of dying due to a life-threatening disease, they either experienced themselves or as a relative. Especially in the latter case, they reported the loss of loved ones or family members and emphasised the experience as particularly threatening when the deceased succumbed to the disease, with which the patient was also confronted. Moreover, patients noted that this fact drew their attention particularly to the deadly aspect of the disease. In case of patient no. 1, i.e., the sudden loss of her son due to a cardiac arrest was the initiating event that led to her diagnoses. The possibility of dying became further threatening to her, as other family members also succumbed to the shared diseases:

> *Yes, it was [an intense period]. It was very hard. And then we all went to the hospital […]. My sisters went too. All my sisters had it, too. One of my sisters died. […] I guess it runs in the family. (P1)*

The same patient also decided at a certain point, regardless of the chronicity of her illness, that she was no longer ill:

> *Yes, I am done with it since January, yes. Since January I've been going back to clubs, bridge and tennis and [silence] I said to myself 'I am just going to do everything normal again'. (P1)*

This statement was assigned to the third sub-category, called *Denial of Illness* (*n* = 22). In total, five out of six patients (*n* = 5) made statements indicating that they were trying to deny their illness, and thus the inevitability of death. Preoperatively, for instance, patients ignored or trivialised their symptoms for this purpose, as illustrated by patient no. 6, who even reflected on hiding or avoidance strategies:

> *I got respiratory complaints with retrospective effect, and I fantasised a little, but I have no sense of fantasy. I have honestly been bothered by that for a few years. I had a feeling for some time that something might not be right, but the hiding strategies worked reasonably decent. (P6)*

Beyond that, patients also tried to avoid thinking about the illness by searching for distraction: *"Yes, you have a distraction, but if you are alone with it, then you are very occupied with it in your mind."* (P1) or by avoiding provided information: *"No, the less you know, the happier you are […] at least I think so."* (P1) Due to the illness/surgery, five out of six patients (*n* = 5) were also confronted with the necessity to take medication. Statements in this regard were captured in the last sub-category *Confrontation Need to take Medication* (*n* = 19). The drugs mentioned included sedatives such as sleeping pills or oxazepam, painkillers like paracetamol, and diuretics. While some patients took the prescribed medication without further ado, it caused considerable distress and frustration to others. Patient no. 2, who has had several invasive procedures in the past, found open-heart surgery much more stressful and emphasised that she was "*a little depressed"* afterwards. When asked what made the heart operation different, she answered: *"Those drugs. Taking those drugs every day."*

1.1.2. Fear of Unknown due to a lack of Knowledge. In total, almost 24% (*n* = 50) of all experiences associated with the theme of death was assigned to the category *Fear of Unknown due to a lack of Knowledge*. Patients' experiences indicated that the lack of knowledge regarding medical procedures, bodily functioning and medication caused feelings of fear and uncertainties. For example, patients hesitated to take medication, as they suspected them of

causing feared side effects or even make them addicted. Particularly after open-heart surgery, four patients (n = 4) also lacked information about which bodily functions are normal or sequelae, making them uncertain and overly alert on physical signals: "*The irregular heartbeat really has bothered me, and it is difficult for me to estimate whether that is a consequence of being a heart patient."* (P6)

1.1.3. Confrontation with Own Mortality. Roughly 16% (n = 35) of all statements associated with the ultimate concern of death were assigned to the category *Confrontation with Own Mortality*. The category comprises the two sub-categories (1) *Awareness of own Mortality* (n = 28) and (2) *Awareness of Natural Decay* (n = 7*).* At some point, all patients (n = 6) were confronted with their own mortality and gave information that they became aware of it either before or after surgery. Before surgery, this was often accompanied during the diagnosis. Two patients (n = 2), for example, were confronted by their doctor with their remaining time. Patient no. 5 remembered: *"he said 'maybe two more years, and then that's it'."* A similar experience made patient no. 1, who described the necessity to have an operation with the following words: *"I had to do it. Otherwise, I wouldn't have had two years to live. Within two years, it would have been over."* Especially chronic patients (n = 4) thought about death and the likelihood of dying while waiting for the operation. The attention was also drawn to the possibility of dying, through pre-surgical education from professionals. Patient no. 6, for example, stated:

> *Well, it was constantly said 'it might also go wrong' and that's true […]. You know that the chance of your death is present, and the probability of death was estimated at 5% for me. […] So, you know that's a real thought, and then you start thinking about it. (P6)*

The same patient also gave a very vivid insight into how distressing the tension between the inevitability of death and the will to live is preoperative:

> *The nearing of doomsday was on the one hand: 'well, it had to be done', on the other hand, you thought of 'well, let it just take a few more days'. I said to one of the nurses: 'I prefer it when I am picked up that I only find out [when the operation happens] the same day.' Pick me up right away so that I can't think about it anymore. (P6)*

Patients who underwent surgery due to an acute cardiac event, or where surgery was not without complications, subsequently became aware of their mortality through near-death experiences, resuscitations, or the awareness of having survived. Besides, four patients (n = 4) also became aware of the inevitability of dying, when reflecting on their age and realising that the process of ageing is ultimately accompanied by death.

1.1.4. Lack of Safety. Through the illness and related (traumatic) experiences, 50% of all patients (*n* = 3) became aware that the world is an unsafe place where they have no certainty that the life-threatening event won't happen again, which represents the category *Lack of Safety* (*n* = 7, 3.3%). The awareness led to uncertainty, and a preoccupation of mind with the terror of death as a statement of patient no. 2 demonstrated: *"If I went for a walk and I think 'here it comes again'. And I was not sure either; then you will become very uncertain of yourself."*

1.2. Freedom

Experiences that indicated a confrontation with the ultimate concern of freedom were mentioned second most frequently (*n* = 200, 40.6%). Information concerning the 'agony of choice' could be divided in three categories: (1) *Experiencing Existential Guilt* (*n* = 92), (2) *Loss of Autonomy* (*n* = 60), and (3) *Avoiding taking Responsibility to make Decisions (n* = 48).

1.2.1. Experiencing Existential Guilt. Almost half of all with freedom associated information (46%) could be linked to the category *Experiencing Existential Guilt* (*n* = 92), which was further divided into the sub-categories (1) *Feelings of Guilt against Oneself for the "Unused Life"* (*n* = 70) and *Feelings of Guilt towards Others* (*n* = 22). Due to the illness, all patients (*n* = 6) indicated that they were confronted with limitations that affected their daily life. Everyday tasks such as cooking, taking out the garbage, emptying the dishwasher, gardening or even sweeping away crumbs proved to be a challenge. Patient no. 5 even described the ordinary nightly rotation in bed as one of the *"things that [he] immediately regretted*". He said: *"I mean, you can't lie on one side for too long. You want to distribute [the pressure on the chest] once in a while, very carefully. You can't turn around all at once or anything."* Since they could not live their lives as usual and could not fully realise their potential, they experienced existential guilt against themselves for the "unused" or not authentically lived lives. This experience manifested in feelings of shame and frustration:

> *I can't take the mail off from the street. Then I will be lost for years. I can't breathe. [...] I still try to walk, but I couldn't do it either. Then I went to the barn and sat in the chair [...]. I grabbed the bike; I think: 'I'll cycle'. I took the bike; I couldn't do it at all! I'll get to the fence. I went back. And my mother-in-law takes the walker and walks to the road, 91 [years old], and she still runs, and I'm 64 [years old], and I can't walk to the road. That's a real shame. (P1)*

Two patients (*n* = 2), who experienced more limitations after the operation than before, even regretted the decision to have undergone the procedure: "*If I would have known that I wouldn't*

have done it. No, really, I wouldn't." (P1) Also, four patients (*n* = 4) experienced an increased emotionality in this context. They felt more irritable and perceived emotions generally as more intense, while at the same time more transient and alternating faster. To a certain extent, all patients (*n* = 6) also experienced *Feelings of Guilt towards Others* (*n* = 22), as their illness-related limitations affected the lives of loved ones and relatives. Their feelings of guilt became apparent by statements that emphasised their aversion of being a burden to others: "*I don't want to be so dependent on the children. I think that's terrible. I think they are all busy, and I don't want that."* (P3*)* or that demonstrated their relief of not having become a burden in the aftermath of an acute cardiac event:

> *I'm so glad I didn't get on the other side of the road so that nobody had an accident or anything because of me. Or, that I don't sit at home on the couch like a zombie, and my wife has to take care of me. (P4)*

Half of all patients (*n* = 3) even experienced feelings of guilt towards attending professionals and avoided to bother them "*for stupid things*" (P2). Beyond that, four patients (*n* = 4) stated that they felt guilty for triggering negative emotions (e.g. fear or worry) in relatives and wanted to protect them from these by withholding disease-related information.

1.2.2. Loss of Autonomy. All patients (*n* = 6) mentioned experiences that indicated a confrontation with the ultimate concern of freedom, due to an experienced *Loss of Autonomy* (*n* = 60). The information regarding this category was further divided into the three sub-categories: (1*) Loss of Control* (*n* = 28), (2) *Being Dependent* (*n* = 19) and *Being Patronised* (*n* = 13). Most frequently, patients experienced a loss of autonomy and freedom while waiting for the operation. They experienced a complete lack of control regarding the timing of the procedure and the hospital stay in general, leading to feelings of helplessness and despair:

> *Before the operation, I had to wait, of course. [...]. [While waiting] you observe a lot. You have time to think. Well, I guess you can't remember your despair. You cannot remember the desperation you feel, luckily, when you are waiting. [...] I think at that moment I already felt so intensely that I had nothing under control. (P6)*

Also, all patients (*n* = 6) gave information that they became dependent on others in the time after the open-heart surgery. Due to the slow wound healing process of the thorax, patients were also reliant on family members and home care assistants for a relatively long time, which led to considerable frustration and resentment in four out of six patients (*n* = 4). Patient no. 3, for example, clearly expressed her need for self-determination with the words: *"I want to get rid of the dependency. I must. I always was independent. […] I want to do my own thing. I don't want*

to be so dependent [...]. I think that's terrible". Especially the patients, who were used to being entirely on their own, found the loss of independence difficult:

> *You have to ask for everything. Do you want me to help with this? Can you do this for me? I don't recognise that part of myself, because I used to be able to do everything on my own. (P1)*

Four out of six patients (n = 4) also experienced a loss of autonomy through the patronage of concerned relatives: *"Everybody has got an opinion about me. They think my yard is too big, and since I am a heart patient, my yard is way too big. Everybody is keeping an eye on me."* (P2) Patient no. 1 even stated: *"I didn't feel free at all."*

1.2.3. Avoiding taking Responsibility to make Decisions. 24.0% (n = 48) of all experiences that could be associated with the ultimate concern of freedom provided information that patients avoided taking their responsibility to make decisions. The information could be further divided into the sub-categories (1) *Displacement of Responsibility* (n = 28) and *(2) Avoidance of Autonomous Behaviour* (n = 20). In the majority of cases, patients avoided personal responsibility by shifting it upon others, including significant others and family members*: "If there is anything, I have my children, they will do it. […]. At least I don't need anything to do. Everything is done automatically. […] So, that is so easy."* (P3) Especially regarding medication management and other health-related issues, patients indicated to blindly trust professionals and informal caregivers without questioning anything:

> *Very briefly: I was given medication, and I did not understand it at all. I never took a pill, so. At first, I didn't delve into this either. Luckily, I had a sister-in-law who prepared everything for me. I also said [name]: 'do whatever you need'. (P6)*

When patients experienced insecurities and were unable to displace their responsibility to make decisions, they tended to avoid autonomous behaviour at all. Due to the previously mentioned lack of knowledge regarding bodily functioning and the associated experienced uncertainties, four patients (n = 4) expressed a particular fear of movement:

> *I slept here in the chair for a few days. I don't exactly know the time span between things, but the period ahead of the water-pills I got …well, first to my feeling: I couldn't lie anymore either – then I thought: 'you imagine something' […] 'it gets worse'. And later, when I was lying down, then at once I became oppressed. I shot away and then it was over again. After a while, I did not even dare to lie down. Since that moment I also went to sleep in the chair for a few days. (P6)*

Additionally, two patients (*n* = 2) experienced uncertainties regarding medications, which also resulted in their aversion to take them.

1.3. Meaninglessness

Experiences that indicated a patient's confrontation with the dilemma of seeking meaning in a meaningless world (Yalom, 1980), were captured a total of 51 times (10.3%) and could be divided into the three categories: (1) *Loss of Meaning* (*n* = 28), (2) *Cosmic Meaning* (*n* = 15) and *Experiencing an Existential Crisis* (*n* = 8).

1.3.1. Loss of Meaning. All six patients (*n* = 6) stated that after surgery and due to the experienced limitations, they were no longer able to do the things that gave their lives meaning previously, like "*playing tennis"* (P4) or "*working voluntarily"* (P2). Four patients (*n* = 4) described the loss of meaning with the words *"I can't do anything/it anymore"* and additionally related feelings of sadness or frustration*: "But you're so deep in the pit. You can't do anything. You can't drive a car. You can't do anything. That's the worst part."* (P1) Four patients (*n* = 4) also mentioned to feel worthless or unimportant in connection with professional care in the hospital. According to the patients, professionals had little time for them, but they did not want to draw attention to themselves and steal their time as Patient no 2, a former nurse herself, indicated:

> *They're busy, they are. I'll kept quiet over there. You know, at some point, a physical therapist came in, and he was gonna practice with me. And um... I had a little talk with him. And other than that, I didn't have a conversation with anyone. And that, yeah, that's not how I was in nursing. [...] And, I didn't bother them, I haven't even told them that I've been in nursing, too. I just, yeah, left it that way. (P2)*

The loss of meaning was also associated with a loss of structure in life and caused feelings of emptiness and boredom*: "I always had the grandchildren on the weekend. The little boys from my son. They came every Friday evening and returned on Sunday evening. Nice distraction, and now that is gone"* (P1) In two patients (*n* = 2) the confrontation with meaninglessness even resulted in suicidal ideation:

> *Well, I wasn't able to walk anymore, and I said 'I have to walk! I don't want to become 100 [years old] like that. I want to be 100 [years old], but not like this'. I do want to be able to walk around, but that was not possible anymore. […] I couldn't do anything. (P2)*

The son of patient no. 1 even interrupted the interview and stated slightly annoyed*: "If that continues, I call a doctor. I don't want to sit there constantly about 'I don't want those pills', or 'I am going to hang myself in the shed'*."

1.3.2. Cosmic Meaning. Five out of six patients (*n* = 5) made statements indicating that they were trying to find meaning in life by believing in some form of a higher order. Three patients (*n* = 3) found (spiritual) meaning and support in their religious belief. Patient no. 3, a catholic who believed in the concept of heaven, stated*: "It certainly gives you support. […] It is a very nice one "upstairs" […] I am quite convinced.*" Patient no.3, on the other hand, indicated to belief in fate while patient no.4 had a more fatalistic attitude towards life : *"I wanted to prove something to myself in the sense of 'OK, I'll go and then I drop dead, then that's how it is, but then I know it in any case', something like that."*

1.3.3. Experiencing an Existential Crisis. Due to the open-heart surgery, 50% of all patients (*n* = 3) indicated to experience an existential crisis and consequently questioned their lives, whether it has meaning, purpose, or value. In two of these patients (*n* = 2), conflicts with family members played a crucial role, and let them think about the realignment of their values. In patient no. 4, even a long-suppressed conflict from the past with the daughter came to the surface after surgery: *"I thought I was over it, but that came up again at a certain point in the whole process at night when I thought: 'oh dear'."*

1.4. Isolation

Experiences that indicated a confrontation with the ultimate concern of isolation were mentioned scarcest and reflected only roughly 6% (*n* = 29) of all mentioned experiences and were further divided into the two categories: (1) *Experienced Loneliness/Isolation* (*n* = 16), and (2) *Fear of Loneliness/Isolation* (*n* = 13).

1.4.1. Experienced Loneliness/Isolation. As the title suggests, this category includes information that patients already experience loneliness and are confronted with isolation. Four out of six patients (*n* = 4) experienced loneliness due to the loss of their partner: *"And now, now that my husband has died before the operation […] Well, I am always alone. Night and day, you are alone."* (P1) Two patients (*n* = 2) also experienced isolation as a consequence of interpersonal conflicts with family members. In this context, especially patient no.1 complained above all about the lack of attention and emphasised their frustration with existing social contacts:

> *My son? I don't get any support from him. Otherwise, I have no one else. And I think that's a shame. […] And I never get a visit, too. I have six brothers, and they never come either. So, the family is not coming. (P1)*

1.4.2. Fear of Loneliness/Isolation. In contrast to the previous category, this one captures experiences that indicate the patients fear of isolation and loneliness while not yet facing it. The fear of losing social contacts became evident by a statement from patient no. 6, who indicated that he had primed his surroundings for possible illness-related behavioural and character changes in order not to scare them away:

> *I spoke to my surroundings that I could behave oddly for a year, and that includes things like that [increased forgetfulness], and it doesn't have to be made a big deal out of it. [...] At first, I only got half a year. I said: 'that's not enough'. (P6)*

Two patients (n = 2) also indicated the fear of being stigmatised: *"And when you got somewhere, everyone asked:' Gosh, how are you?' Oh god, you know. Well, at least I experienced it like that."* (P2), which could be associated with the fear of becoming isolated. Finally, the patient no. 6, who was well aware of his possibility of dying as captured before, mentioned experiences that particularly pointed to the confrontation with existential isolation and the fear of dying alone:

> *On the day I came to the hospital, I always said that if they do their job well, I'm convinced that I can't go home anymore. I already had the pyjamas in the car and stuff. And I thought of: 'I have a sister; I have to warn someone in the family. [...] So, I called my sister to come with me so she could inform the family. (P6)*

2. Evaluation of professionals' perceptions

In this second part, the analysis results of the professional interviews are presented, whether they perceive cardiac patients to experience existential anxiety in the period around open-heart surgery and which of the ultimate concerns they consider to be at the forefront in patients.

Overall, all attending professionals gave information that indicated patients' confrontation with the ultimate concerns of (1) *Death,* (2) *Freedom*, (3) *Meaninglessness* and (4) *Isolation*, as described by Yalom (1980) and which, as with the patients, served as overarching themes. In total, 262 fragments were identified and by means of 10 codes assigned to the four themes (see Table 4). The majority of all statements (56%) indicated a confrontation with the ultimate concern of death (n = 147). In descending order, they then gave information regarding the confrontation with the ultimate concern of freedom (n = 88), meaninglessness (n

= 16) and lastly existential isolation (*n* = 11). On an individual level there are mainly differences in the frequency of mentioned perceptions. Professional no. 2 (*n* = 21) made the fewest statements. In comparison, Professional no. 5 made almost three times as many statements (*n* = 61), and thus provided the most information concerning patients' confrontation with the givens of existence.

Table 4
The occurrence of Ultimate Concerns in Interviews with Professionals (N=6)

Theme	**Professionals**						**Total**	
Category • Sub-category	Pro1 (n=49)	Pro2 (n=21)	Pro3 (n=54)	Pro4 (n=33)	Pro5 (n=61)	Pro6 (n=44)	n (N=262)	%[1]
Death	31	13	23	24	39	17	**147**	**56.1**
Confrontation with Severe Illness	15	5	10	12	19	9	**70**	**47.6**
• Confrontation with Physical Complaints	10	4	7	7	14	5	**47**	**67.1**
• Confrontation Need to take Medication	3	1	2	3	3	1	13	18.6
• Denial of Illness	2	-	1	2	2	3	10	14.3
Fear of Unknown due to a Lack of Knowledge	11	5	8	9	11	7	51	34.7
Confrontation with own Death	5	2	2	3	8	0	20	13.6
• Awareness of own Mortality	1	-	1	-	6	-	8	40.0
• Awareness Natural Decay	4	2	1	3	2	-	**12**	**60.0**
Lack of Safety	0	1	3	0	1	1	6	4.0
Freedom	12	8	21	7	14	26	88	33.6
Avoiding taking Responsibility to make Decisions	0	8	15	4	2	11	**40**	**45.5**
• Avoidance of Autonomous Behaviour	-	7	14	4	2	7	**34**	**85.0**
• Displacement of Responsibility	-	1	1	-	-	4	6	15.0
Experiencing Existential Guilt	7	0	6	2	2	7	24	27.3
• Feelings of Guilt against Oneself for the "Unlived Life"	6	-	5	2	1	5	**19**	**79.2**
• Feelings of Guilt towards Others	1	-	1	-	1	2	5	20.8

Note. [1] depending on the code level, it either reflects the percentage distribution of themes (dark blue background), categories within the theme (light blue background) or the distribution of sub-categories within the categories (no background colour).

(table continues)

Table 4 (continued)
The occurrence of Ultimate Concerns in Interviews with Professionals (N=6)

Theme / Category / • Sub-category	Professionals						Total	
	Pro1 (n=49)	Pro2 (n=21)	Pro3 (n=54)	Pro4 (n=33)	Pro5 (n=61)	Pro6 (n=44)	n (N=262)	%[1]
Freedom	12	8	21	7	14	26	88	33.6
Loss of Autonomy	5	0	0	1	10	8	24	27.3
• Loss of Control	3	-	-	1	7	3	**14**	**58.3**
• Being Patronised	1	-	-	-	1	5	7	29.2
• Being Dependent	1	-	-	-	2	-	3	12.5
Meaninglessness	4	0	7	2	2	1	16	6.1
Existential Crisis	2	-	4	1	1	-	**8**	**50.0**
Loss of Meaning	2	-	3	1	1	1	**8**	**50.0**
Isolation	2	0	3	0	6	0	**11**	**4.2**
Need for Social Contacts	2	-	3	-	6	-	11	100.0

Note. [1] depending on the code level, it either reflects the percentage distribution of themes (dark blue background), categories within the theme (light blue background) or the distribution of sub-categories within the categories (no background colour).

2.1. Death

All professionals (n = 6) gave information that patients were confronted with existential anxiety concerning the threat of non-existence. The given information concerning the theme of death were further divided into the four categories: (1*) Confrontation with Severe Illness* (n = 70; 47.6%), (2*) Fear of Unknown due to a Lack of Knowledge* (n = 51, 34.7%), (3) *Confrontation with Own Death* (n = 20, 13.6 %), and (4) *Lack of Safety* (n = 6, 4.0 %).

2.1.1. Confrontation with Severe Illness. Almost 67% (n = 70) of all information associable with death anxiety, could be linked to the category *Confrontation with Severe Illness*. The regarding information was further differentiated in the sub-categories: (*1) Confrontation with Physical Complaints* (n = 47), (2) *Need to take Medication* (n = 13), and (3) *Denial of Illness* (n = 10). The majority of professionals' statements indicated that patients have to deal with severe pain and other complications/side effects as a consequence of open-heart surgery. There was a consensus among all professionals (n = 6) that patients are primarily confronted with *"pain of the sternum because the sternum was completely loose"* (Pro2) Professional no. 2 also stated*: "that [this] is actually the worst pain that people have [and] that's what keeps them most busy."* Professional no. 5 further outlined other pain-related complaints:

> *"Chest pain, feeling of pressure or stabbing in the chest as if an 'elephant is standing on the chest'. The left-arm often hurts. It can also be the right arm*

> *or both. Pain between the shoulder blades, dry mouth, well, those are all symptoms, and one has those symptoms, and the other has other symptoms. (P5)*

Other mentioned symptoms included: sweating, shortness of breath, balance problems, fatigue and sleep problems, problems with fluid and decompensating, sensitive bone, and lung membranes, as well as concentration problems. Professional no. 3 additionally mentioned that some patients also *"get a delirious picture, […] respiratory infection or pneumonia […] atrial fibrillation and arrhythmia […]"* and mentioned that patients experience these complications *"often as setbacks […] that also must be treated again."* Professional no. 1 empathised that these setbacks must be *"frightening experience[s]"*. All six professionals (*n* = 6) further provided insights that patients were confronted with the necessity to take medication after surgery:

> *Actually, there are no restrictions after surgery, they do have to take their pills, and they might have to be a bit more careful about their diet and stuff like that, but physically there are no restrictions. (Pro1)*

Professional no. 2 also stressed the chronic nature of the disease: *"So that basically remains. Well, in that respect, he'll always be a heart patient, he'll always need to take medication."* Beyond that, five out of six professionals (*n* = 5) indicated that there are always patients who try to deny their illness: "*In the group of heart patients, there are often people who just, like, keep going. Having a hard time feeling anything. Always going for maximum."* (Pro3) Professional no. 6 also mentioned that *"there are always very temperamental people who think they will be 25 once they are 85 and show the world after surgery 'look, surgery, and then 'I can do everything again'. They overshoot a bit."* (Pro6)

2.1.2. Fear of Unknown due to a Lack of Knowledge. Regarding the question 'what kind of help/guidance patients need', all attending professionals (*n* = 6) stated that patients mainly seek information concerning medication: *"Patients tend to switch very quickly to questions regarding medication. That seems to be the most important thing for them."* (Pro6) and regarding medical procedures, as professional no 1 explained:

> *Look, people who get a bypass operation would like to know some things like: 'Is something being taking out of my legs?' or 'where do you get the new material from?', 'When they get a new valve, they want to know things like: 'Do I get a pig valve or do I get a metal valve?' and 'how does it go after this time?" (Pro1)*

As a reason for the need for information, professional no. 1 and no. 4 specifically named the *"fear of the unknown."*

2.1.3. Confrontation with own Death. In total, five out of six professionals (*n* = 5) provided information that could be linked to the category *Confrontation with own Death*. The given information regarding this category was further divided into the sub-categories: (1) *Awareness of own Mortality* (*n* = 8) and (2) *Awareness Natural Decay* (*n* = 12). Half of all professionals (*n* = 3) provided information that patients are confronted with the likelihood of dying by thinking about death and resuscitation previous to the open-heart surgery: *"patients imagine that they have to be brought back to life by resuscitation, as in earlier times"* (Pro3). Professional no. 3 also indicated that patients become aware of their mortality due to near-death experiences and the awareness of having survived:

> *If you really have had a reanimation or imagens that those people have been a little further – then they have been really ill, that they really left before death […] and when they come back they are actually already very enthusiastic.(P3)*

Almost all professionals (*n* = 5) additionally provided insight that patients are confronted with the process of ageing and are aware of its ultimately fatal consequences*: "Well, look, an older person who has calcified heart valves, which is purely an issue of ageing, accepts that much easier in the sense of: 'well, that's just wear and tear.'* (Pro1)

2.1.4. Lack of Safety. Four professionals (*n* = 4) gave insight that patients are confronted with the ultimate concern of death by becoming aware of the fact that the world is an unfair place, where the patients have become ill despite their efforts: "*And for a huge group of patients, it is also outrage: 'I have always practised, I have never smoked, and I have always exercised. Now I am 50 years old and still get it [sick].'"*(Pro2) Four professionals (*n* = 4) also pointed out that patients lack the safety that a life-threatening event won't happen again and that they ruminate over the possibility of recurrence: *"Patients [then ask themselves]: 'Can it happen to me again or am I now disabled for the rest of my life?"* (Pro1)

2.2. Freedom

Perceptions that indicated a patients' confrontation with the ultimate concern of freedom were mentioned second most frequently by professionals and accounted for almost 34% (*n* = 88) of all statements. Provided information regarding the patients' confrontation with groundlessness and the 'agony of choice' could be divided into three categories: (1) *Avoiding taking*

Responsibility to make Decisions (*n* = 40), (2) *Experiencing Existential Guilt* (*n* = 24), and (3) *Loss of Autonomy* (*n* = 24).

2.2.1. Avoiding taking Responsibility to make Decisions. Almost 46% (*n* = 40) of all information that could be associated with the ultimate concern of freedom and the threat of groundlessness could be assigned to the category *Avoiding taking Responsibility to make Decisions*. The given information's from professionals could be further divided into the two sub-categories: *(1) Avoidance of Autonomous Behaviour (n* = 34) *and (2) Displacement of Responsibility* (*n* = 6). Five out of six professionals (*n* = 5) indicated that patients avoid making autonomous decisions and even actively refuse to take the necessary steps for recovery due to illness-related insecurities. For instance, five professionals (*n* = 5) mentioned that patients experience a loss of safety and confidence in their body after the occurrence of a cardiac event. Professional no. 4 described it quite vividly: "*They just have to build the trust in their bodies again because they previously ran around with a ticking time bomb."* The professionals indicated that the patients are correspondingly overly cautious and alert on bodily signals: *"They never thought about their pulse before, whether it was 130 or 180 when they did something. Now they are getting too focused on it, and that's not good either."* (Pro 2) Beyond that, they tend to engage in safety behaviour and avoid movement et al as witnessed by half of all attending professionals (*n* = 3). Professional no. 6 explained it like that*:*

> *The thing that remains is, of course: the fear. When I am in pain, I am also more anxious and do not dare to move and probably think 'I can't and shouldn't do anything anymore'. That also promotes the fear component. (Pro6)*

Three attending professionals (*n* = 3) also provided the insight that patients tend to avoid making their own decisions by shifting their responsibility upon others, especially significant others. Additionally, the same three professionals also pointed out that patients frequently trust colleagues and informal caregivers blindly, when it comes to medication management:

> *And that is something I see very often in the cardiac rehabilitation clinic: [When I ask a patient:] 'Have you got your medication now?' [then the patient answers:] 'Well, woman? Do we have medication? – so, the woman manages the medication usage. (Pro6)*

2.2.2. Experiencing Existential Guilt. The majority of attending professionals (*n* = 5) indicated that patients experience existential guilt either against themselves or towards others. Almost 80% of given information regarding this category could be assigned to the sub-category *Feelings of Guilt against Oneself for the 'Unlived Life'* (*n* = 19). Professionals (*n* = 5) indicted

that patients are confronted with illness-related limitations in their daily life, which are considered as *"very obstructing […] especially at a later stage."* (Pro1) Mentioned illness-related limitations in the patients' everyday tasks include difficulties with standing, driving a car, riding a bicycle as well as difficulties with lying down and even with turning in bed at night*: "Especially at night and [regarding]mobilizing. Turning in bed is not an option at first."* (Pro4). Consequently, patients fail to live their life to their used potential, which manifests itself in feelings of regret: *"Yes, there are people who say 'if only I had never done it'"* (Pro6) and also feelings of frustration and shame, while comparing: *"Or you think 'gosh, he is older than me and he can, well I say nothing.' A lot of people do that"* (Pro5). Also, four professionals (*n* = 4) recognized that patients experience feelings of guilt towards their relatives. Due to the confrontation with the illness, patients are unable to perform their usual tasks and worry about their relatives: *"Who will take care of the partner or who will take care of me when I get home, and it won't work out?"* (Pro5)

2.2.3. Loss of Autonomy. Four Professionals (*n* = 4) provided information that indicated a patients' confrontation with the ultimate concern of freedom due to a *Loss of Autonomy* (*n* = 24). This category was further differentiated into the three sub-categories (1) *Loss of Control* (*n* = 14), (2) *Being Patronised* (*n* = 7) and (3) *Being Dependent* (*n* = 3). Most frequently professionals provided insights that patients experience a loss of control regarding the timing of the operation and their hospital stay since they are unable to decide anything by themselves: *"A patient with persistent chest pain is not allowed to go home, of course."*(P5) Three professionals (*n* = 3) emphasised above all that it can be very distressing and overwhelming for a patient when they need to stay in the hospital without suspecting it:

> *But of course, it hits a patient very, very hard when he comes here and thinks something like 'maybe I get some medicine and can go back home' […], and eventually they lie there for more than a week and then they are told that they even have to have surgery all of a sudden. (Pro3)*

Besides, professionals mentioned that patients are then faced with the need to wait for an indeterminate period for surgery, knowing that the disease is advanced enough not to let them go either: *"And then there is still some time between that moment and the actual operation. Not very long. It all goes very quickly, but I think it still takes one or three weeks."* (Pro1) Half of all professionals (*n* = 3) also provided information which indicated a loss of autonomy through the patronage of concerned relatives: "*But the caregivers think: 'I have to do everything', and 'Dad can't do this' and 'my Mom can't do this'."* (Pro6) Professional no. 1 and no. 6 provided the insight, that relatives' patronising behaviour is driven by the fear of losing the loved one.

Accordingly, they tend to "*pamper"* (Pro6) the patient, although they stress that this has a negative impact. Lastly, two professionals (*n* = 2) also provided information that patients are confronted with the loss of autonomy, since they need to rely on the help of others, including strangers, because of the experienced symptoms: *"They often need extra help. Informal care is not always available. Practical things like transport and so […] or to manage the household – shopping for groceries and things like that."* (Pro1)

2.3. Meaninglessness

Information that indicated a patient's confrontation with the ultimate concern of meaninglessness was mentioned a total of 16 times (6.1%) by a total of five professionals (*n* = 5). The information equally distributed over the two sub-categories: (1) *Existential Crisis* (*n* = 8) and (2) *Loss of Meaning* (*n* = 8).

2.3.1. Experiencing an Existential Crisis. Four professionals (*n* = 4) provided information that patients seem to experience an existential crisis due to the fear of the unknown: *"Well, [they experience] a certain fear of the unknown: "What's going to happen?" and "Will I be okay after the operation?" "How will I be after that?" "Will I be back to my old self, or am I losing something?"* (Pro1) Professional no. 5 also indicated that people who have had a reanimation or a near-death experience almost certainly will experience an existential crisis and question what life is about:

> *People who have had a reanimation [...] or have really left before death ... then you always see that no matter if it's cardiac or another clinical picture, but those people often get a sense of 'what is life actually all about' and we [...] often see that they get in contact again with people they hadn´t really contact with anymore. (Pro5)*

2.3.2. Loss of Meaning. To the same extent, professionals indicated that patients experience a loss of meaning and purpose due to the illness. Primarily the loss was hinted at by statements indicating that patients can no longer do anything or have nothing more*: "Well, because at home, you basically have nothing."* (Pro3)

2.4. Isolation

Finally, and most rarely mentioned (*n* = 11), professionals indicated a patient's existential conflict with the fear of becoming isolated. Half of all professionals (*n* = 3) gave insight that patients have a need for social contacts and that they experience separation from others because

of their illness and related complaints. Professional no. 1 stated: *"So that's something that keeps them very busy too, if they [relatives] can visit them."* Moreover, two experts (n = 2) observed that finding meaning often concerns social contacts: *"What can you do then, what you no longer do now? What do you really miss so much? And these are often things that they shared with others."* (P3).

3. Comparison of perspectives

In this last part, the findings are presented that were obtained by comparing the previously evaluated results of patients' experiences and professionals' perceptions on a descriptive level regarding coincidences and differences.

To start globally, with a total of N = 439 coded fragments and an average of M = 81.67 per patient (SD = 30.74), they made almost twice as many statements indicating their confrontation with existential fears than professionals. On average, professionals made M = 43 indicative statements (SD = 14.58), contributing to a total of N = 262 coded fragments. However, the percentage distribution of these fragments into the four existential themes of *death, freedom*, *meaninglessness,* and *isolation* is comparable for both groups, whereby this sequence also reflects their coinciding occurrence in descending order. Beyond that, in terms of content, the experts' perceptions largely coincided with the patients' experiences, which is why the independent qualitative analyses led to almost identical coding schemes. Differences were found primarily at the level of sub-categories, which will be explained in more detail below.

3.1. Death

Both groups named the confrontation with death anxiety most frequently. Fragments related to the tension between the undeniable reality of finiteness and the desire to continue to be were similarly divided into the four categories (1*) Confrontation with Severe Illness,* (2*) Fear of Unknown due to a Lack of Knowledge,* (3) *Confrontation with Own Death* (including the sub-categories *Awareness of own Mortality* and *Awareness of Natural Decay)* and (4) *Lack of Safety.* Although the two groups also equally often associated death anxiety with the confrontation with serious illnesses, the perspectives differed at the level of the associated sub-categories. On the one hand, only patients indicated that their awareness of the inevitability of dying was provoked by experiences with life-threatening disease in their past. On the other hand, it was noticeable that there was a difference in content regarding confrontations with

physical complaints. Professionals explicitly mentioned the word *pain* $n = 144$ times, while patients mentioned it only $n = 54$ times.

3.2. Freedom

Fundamentally, the perception of professionals also overlapped with the experiences of patients regarding the confrontation with the ultimate concern of freedom. The given information of both groups concerning the 'agony of choice' were divided in the three categories: (1) *Experiencing Existential Guilt*, (2) *Loss of Autonomy*, and (3) *Avoiding taking Responsibility to make Decisions*. The two perspectives only differed in the percentage distribution of these categories. While 46% of the patients' experiences in this context could be associated with existential guilt, only roughly 27% of the professionals' statements referred to the same connection. Similarly, 27% of the professionals' statements could be associated with loss of autonomy, and most often professionals gave information (almost 46%) that patients avoid taking responsibility to make decisions. The patient's provided this information scarcest with only 24%. The distributions also differed regarding the subcategories of the latter category. 85% of the assigned statements of the professionals indicated that patients avoid autonomous behaviour and only 15% of the category assigned statements indicated that patients tend to displace their responsibilities upon others. The patients on the other side mainly gave information (58%) that they avoided personal responsibility by shifting it upon others and only 41% of statements assigned to the category indicate that they avoid autonomous behaviour altogether.

3.3. Meaninglessness

Both professionals and patients gave information that a patient's confrontation with the ultimate concern of meaninglessness can be associated with a loss of meaning or the experience of an existential crisis. However, only patients made statements indicating that they were trying to find meaning in life by believing in some form of a higher order. In this respect, the professionals' perceptions did not coincide with the patients' lived experiences.

3.4. Isolation

Professionals and patients most rarely indicated a patients' confrontation with the ultimate concern of isolation. However, while professionals only perceived the patients' need for social contacts, patients gave more differentiated indications regarding the confrontation. They either

indicated to already experience isolation and loneliness, or made statements indicating that they were afraid of becoming isolated and lonely.

Discussion

This study attempted to gain a more comprehensive understanding of cardiac patients' perioperative experiences regarding confrontations with existential anxieties. For this purpose, both the perspective of patients and attending professionals were examined. Additionally, it should be identified which ultimate concern occupied them predominantly and whether the professionals' perceptions coincide with the patients' lived experiences.

Findings and Interpretation

Based on the evaluation of patients' experiences and professionals' perceptions, it can be clearly stated that cardiac patients indeed *are* confronted with existential anxieties perioperatively. In accordance with Yalom's (1980) definition of awareness-catalysing border situations, invasive open-heart surgeries can without any doubt be declared as such. Overall, it can be concluded that despite separate qualitative analysis, participants and attending professionals almost completely mentioned the same issues, albeit the associated codes were represented in a different density. Significant differences will be discussed in more detail below. However, based on both perspectives, the overall picture revealed, that patients most frequently are confronted with the ultimate concern of death. The confrontation with the severe illness (e.g. physical complaints or the need to take medication), the reminiscence of loved ones who succumbed to the shared disease, or near-death experiences all draw the patients' awareness to the inevitability of death. Some patients attempted to avoid the conflict by trying to deny the illness. The second most frequently mentioned ultimate concern was freedom. Patients primarily experienced existential guilt for not being able to live their life authentically. The awareness of it evoked negative feelings such as shame, frustration, and regret for having made the wrong decision. Beyond that, in a non-existential sense, they also experienced feelings of shame towards others, including attending professionals. Furthermore, patients were also confronted with the ultimate concern of freedom when it was taken from them. Especially the loss of control when waiting for surgery was mentioned as extremely distressing and led to feelings of helplessness and despair. Patients also struggled with the loss of autonomy, through illness-related dependence or through the patronage of relatives. The experts emphasised that the patronage is associated with fear components in the partner who himself experiences fear

of death (of a loved one) due to the patients' illness. When patients were confronted with the loss of freedom, this led to feelings of helplessness, frustration, but also to anger, as their self-perception was threatened. On the other hand, patients attempted to avoid the conflict with freedom when displacing their responsibilities upon others. Especially when it came to medical questions, they seemed to trust professionals blindly and not question anything, which was also emphasized critically by the professionals. However, in retrospect, this defence strategy does not necessarily prove to be successful, as it also caused existential guilt and regret in some patients. In addition, some patients were extremely confronted with the groundlessness that comes with freedom. Afraid of making the wrong decisions, they stagnated completely and became even more helpless, insecure, and dependent on the confirmations of others. Due to the surgery, some patients experienced an existential crisis and questioned their life for purpose and meaning. Especially near-death experiences led to the resurgence of suppressed conflicts and the consideration of realigning values. To give life meaning and to ward off existential anxiety, some patients provided insight to believe in some form of higher order. Lastly, both patients and professionals mentioned confrontations with the ultimate concern of existential isolation scarcest. Primarily, patients experienced separation from others, however, some felt true aloneness, provoked by the awareness of the unbridgeable gap between them and others.

Although these results are generally in line with current findings in the literature and clearly indicate patients' confrontation with the givens of existence, based on the overall distribution, no valid statement can be made regarding the question 'which issues occupied them (i.e. the individual) most?' The evaluation of the patients' interviews clearly indicated that four of the six patients were confronted with existential issues in a pathological sense. It also became evident, that each of them had one central theme that occupied them most. Yet not even the identified totals reflected this central theme, since their confrontations with the givens of existence expressed themselves in a unique, interwoven way that cannot be relied on without further interpretation. How intertwined the existential givens are and how distressing the awareness of it can be for an individual, even unconsciously, was also stressed by Yalom (1980, p.9). He also pointed out that an individual, for example, can develop protective, denial-based mechanisms to ward off death anxiety, which "*eventually consists of a highly complex set of mental operations that repress naked death anxiety and bury it under layers of such defensive operations as displacement, sublimination, and conversation"* (Yalom,1980, p.44). That these confrontations are unique for each individual, characterized by subjective thematic connections, was also pointed out by Udo et al. (2012), as well as by Grober et al. (2016) who investigated

the meaning and therapeutic relevance of existential themes in patients undergoing CBT as part of their routine care by means of retrospective interviews with 30 mentally ill patients (diagnosed with anxiety disorders and affective disorders).

What all the four previously mentioned patients had in common were shared feelings of anxiety and depression. According to the *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-V; Appendix 5), symptoms of depression and anxiety disorders include but are not limited to a depressed mood (such as feelings of sadness, hope- and/or helplessness), diminished interest in previously enjoyed activities, fatigue, sleep disturbances, agitation and a noticeable reduction of physical movement. They are also associated with negative thinking and rumination (American Psychiatric Association [APA], 2013a, 2013b). The symptoms the four patients, who experienced confrontations with the existential givens, and also the six professionals named were mostly consistent with these criteria. They described feelings of despair, frustration, helplessness, worthlessness, uncertainties regarding their physical state and finally, they considered themselves as depressed. They also represent almost 67% of the patients examined in this study, which is consistent with current figures regarding the occurrence of depressive comorbidities in cardiac patients (Vögele, 2016; Pogosova et al., 2015), which is an alarmingly high percentage indicating the need for action.

In summary, cardiac patients are confronted with the four givens of existence, which manifests in psychopathological symptoms of anxiety and depression. Although professionals also recognised the distress caused by the confrontations with the ultimate concerns, none of the patients were referred to or advised to participate in a psychological CR programme. A reason for this could be that attending professionals misinterpret indicative symptoms due to their high congruence with typical cardiac symptoms (NVVC, NHS, & projectgroep PAAHR, 2011). For instance, specific cardiac manifestations of anxiety include cardiac arrhythmias such as palpitations or chest pain. In most cases, patients are very concerned about the perceived symptoms. In turn, this can lead to avoidance behaviour, which expresses itself, for example, in the fear of movement, known as kinesiophobia (NVVC, NHS, & projectgroep PAAHR, 2011). In line with research by Simonÿ et al. (2015), concerning existential anxiety in exercise-based cardiac rehabilitation, the fear of movement was also a recurring theme in the current study. Almost all patients and professionals mentioned avoidance behaviour related to movements during the period around open-heart surgery, caused by a lack of knowledge regarding bodily functioning and the associated experienced uncertainties. However, as Leeming, Murray, & Kendall (2014) already noted in a longitudinal study on the impact of

advanced heart failure on existential aspects of personhood, it appears that despite increasing awareness, the lack of physical health still overshadows psychological distress. This is also reflected in the results of the current study and considered as the most crucial and decisive finding. In general, both groups mentioned the confrontation with the ultimate concern of death most frequently and agreed that the awareness of the inevitability of death was primarily provoked by the confrontation with the serious illness. In addition, the two groups coincided with regard to the corresponding contents of the category (e.g. that the confrontation is correlated with physical complaints like pain) but varied considerably regarding the identified density of this code (or category). In total, the experts mentioned the word 'pain' three times as often (144:54) and also stressed that it is *"the worst thing patients can experience"* (Pro2). In contrast to this view and based on the identified lived experiences of the patients, it can be argued that depending on the patient, quite different issues play a much more pivotal role. However, this research result points to the strong biomedical orientation of the professionals and also to the patients' need for person-centred care.

Further Research

Biomedicine has strongly dominated the health care system over the last 30 years and focuses on the human body and its physiological needs while mostly neglecting an individuals' psychological, spiritual, and existential needs (Koslander, Silva, & Roxberg, 2009). It has been identified that mental health care, solely based on biomedicine alone, is prone to be fragmentary and reductionistic. The opposite end of the spectrum is marked by holistic care. It has been proven to be the most beneficial in promoting mental well-being (Koslander, Silva, & Roxberg, 2009). Based on the results of this study, it can be stated that cardiac patients in the period around open-heart surgery are confronted with the givens of existence, which makes it worthwhile to examine the effectiveness of integrating the non-dogmatic existential approach of psychotherapy to optimise cardiac rehabilitation, to adequately respond to the patients' needs and to determine which EP interventions can best be integrated in the cardiac rehabilitation. Therefore, further research could be conducted in the form of a longitudinal study with a group of patients who follow a CR program with integrated approaches of EP and a control group with patients who follow a “classical” CBT-based CR program. The discussion of existential themes, for example, could be integrated into individual and group therapy sessions. Correspondingly, patients' subjective connections could serve as the foundation for discussing therapy-relevant life events or to overcome stagnating therapy phases, which might occur when therapy focuses too early or exclusively on fostering positive and accepting thoughts (Grober,

2010). In group therapy sessions, on the other hand, addressing existential fears could be used to let patients cooperatively establish a value-oriented focus (Grober, 2010). However, according to Yalom (1980), clinicians not only have the task to carefully confront patients with the issues of existence to create awareness, but also to help avoid denial or avoidance when patients have become aware. In his book *Staring at the sun: Overcoming the terror of death,* Yalom (2009), for example, suggests that clinicians should find inspiration in philosophers to help patients with death anxiety to consciously reflect on death in order to overcome their fears. To support atheist patients for example, clinicians could introduce them to Epicurean concept of mortality of the soul, which simply states that death holds no terror because *"where I am, death is not; where death is, I am not. Therefore, death is nothing to me*" (Lucretius; as cited in Yalom, 1980, p. 45; Huguelet, 2014; Yalom, 2009). Likewise, they could introduce them to the Epicurean argument of symmetry, which suggests that the state of nonbeing after death could be identical to the state of nonbeing before birth (Huguelet, 2014; Yalom, 2009). Results of such a study could in the long-term lead to empirical statements regarding the effectiveness of the integration of an EP- approach to CR , which can contribute to the development of cardiac rehabilitation programs that are even closer to the patients' needs. To the same end, further research could also investigate whether the integration of the Existential Problem Questionnaire (ECQ; developed by Van Bruggen et al., 2017) could improve the identification of individual cardiac rehabilitation needs and whether it might even be suitable for inclusion in the decision tree of the Dutch guideline as a recommended screening tool for the detection of psychological symptoms.

Beyond that, further research should also investigate on the professional's knowledge regarding the ultimate concerns. Although all attending professionals described perceptions that pointed to the patient's confrontations with existential conditions, including mental distress as well as avoidance behaviour, none of their mentioned treatment strategies directly addressed these issues. Accordingly, the question arises whether professionals consciously avoid dealing with patients who face existential questions, or if they are not consciously aware of the concerns and the necessity to confront them. This could be qualitatively investigated by conducting in-depth interviews with different attending professionals from the multidisciplinary team.

Strengths & Limitations

This study contributes to the field of psychological cardiac rehabilitation in the Netherlands by providing unique insights into the patients' lived experiences in the period surrounding open-heart surgery and the confrontations with the existential givens. Beyond that, a particular strength of this study lies in its research design and the analysis of previously conducted interviews to answer the research questions. While, the issues surrounding existentialism, existential psychotherapy and the ultimate concerns are rather complicated and confusing, this study was able to assess the patients' confrontation with the ultimate concerns, without addressing them directly, thus avoiding the possibility of causing despair or distortion of the reported experiences. When addressing these issues directly, under the provision of only a brief explanation (e.g. informed consensus or the interviewer's initial statement), it can be assumed that patients may solely focus on the most obvious (or understandable) tension of death. In addition, this study has the decisive strength that its 'non-direct' evaluation approach protects the patient from a possible, unprepared confrontation with the existential givens, that could lead to the development of anxieties and depressive symptoms.

Additionally, this study has its limitations in terms of inter-rater reliability as no second coder has been involved. Therefore, results should be interpreted with caution since this might have caused a subjectivity bias within the coding process. Beyond that, this study has its limitations when it comes to the representativeness of the patients' sample. The participants in this study were predominantly retired and older patients, and although the prevalence of CVDs significantly increases with age, they are not limited to this age group. On the contrary, the onset of atherosclerotic diseases often occurs as early as in adolescence and accordingly, all age groups can be affected by heart disease and consequently can be confronted with the necessity of open-heart surgery (De Boer et al., 2019; WHO, 2017). Additionally, a study by Berman, Weems, & Stickle (2006) also indicated that existential anxiety was even highly prevalent in a sample of adolescents. Thus, it can be assumed that patients, depending on their age, experience the confrontations with the givens of existence in different ways, which is why the findings of the current study are not representative for the experiences of all cardiac patients in the Netherlands. Therefore, future research could contribute to a better understanding of heart patients by investigating the perioperative confrontations with existential questions in a heterogeneous sample of heart patients, including patients of all ages. Based on these results, cardiac rehabilitation programmes could be tailored even better to the needs of the specific target group.

Lastly, this study has another limitation regarding the previous data collection. On behalf of two patients, the interviews were conducted under the presence of the patients' relative (spouse or son). Unfortunately, the relatives were not only silent observers, but actively participated in the conversation. They did not react to questions specifically directed at them but answered for the patients or corrected their experience from their own perspective. As a result, the statements of these two patients must be treated very carefully, as their own experiences may have been biased by the presence of their relatives, hence the interviews not necessarily reflect their true experiences.

Conclusion

Cardiovascular diseases are still one of the biggest threats to humanity. For a large part of the population, the disease is unavoidably associated with open-heart surgery. This study was able to prove that open-heart surgeries represent catalysing border situations, that inevitably draw the patients' attention to the existential givens: *death, freedom, meaninglessnes*s, and *isolation*. With increasing awareness comes increasing existential anxiety, which manifests in psychopathological symptoms of anxiety and depression, when using non-adaptive defence mechanism such as avoidance or denial. Attending professionals generally perceived that patients are confronted with anxieties, such as the fear of the unknown, yet their focus tends to be rather biomedical, with the emphasis on the patient's optimisation. The same observation could also be made regarding cognitive-behavioural therapy in CR. It has some critical limitations regarding CRs overall goal to improve the patients QoL. The integration of an existential approach into existing CR programs could be of added value as it responds to the patient's needs which can ultimately contribute to the implementation of a holistic CR approach. Yet further research is required to examine the effectiveness of integration in practice.

References

American Psychiatric Association. (2013a). Depressive Disorder. In *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington, DC. https://doi.org/10.1176/appi.books.9780890425596.dsm04

American Psychiatric Association. (2013b). Anxiety Disorders. In *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington, DC. https://doi.org/10.1176/appi.books.9780890425596.dsm05

Beck, A. T., Steer, R. A., & Brown, G. (1996). Beck depression inventory–II. *Psychological Assessment*. https://doi.org/10.1037/t00742-000

Beckmann, A., Meyer, R., Lewandowski, J., Markewitz, A., & Harringer, W. (2019). German heart surgery report 2018: the annual updated registry of the German Society for Thoracic and Cardiovascular Surgery. *The Thoracic and cardiovascular surgeon*, *67*(05), 331-344. https://doi.org/10.1055/s-0039-1693022

Berman, S. L., Weems, C. F., & Stickle, T. R. (2006). Existential anxiety in adolescents: Prevalence, structure, association with psychological symptoms and identity development. *Journal of Youth and Adolescence*, *35*(3), 285-292. https://link.springer.com/article/10.1007/s10964-006-9032-y

Berry-Smith, S. F. (2012). *Death, Freedom, Isolation and Meaninglessness, And the Existential Psychotherapy of Irvin D. Yalom.* (Doctoral dissertation). University of Technology, Auckland.

Boos, A. (2014). *Kognitive Verhaltenstherapie nach chronischer Traumatisierung: Ein Therapiemanual* (2nd ed., p.243). Göttingen: Hogrefe.

Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. *Handbook of research methods in health social sciences*, 843-860. https://doi.org/10.1007/978-981-10-5251-4_103

Buser, K. (2003). Kommunikation mit Krebspatienten. *Der Gynäkologe*, *36*(6), 515-521.

Central Bureau for Statistics. (2020) *Statistics Netherlands: Population dynamics; month and year.* Retrieved from https://opendata.cbs.nl/statline/#/CBS/en/dataset/83474ENG/table?ts=1586069565227

Cooper, M. (2003). *Existential therapies*. London: Sage.

De Boer, A. R., Van Dis, I., Visseren, F. L. J., Vaartjes, I., & Bots, M. L. (2018). *Hart- en vaatziekten in Nederland 2018: Cijfers over risicofactoren, hartinterventies, ziekte en sterfte.* (24th ed.) Den Haag: Hartstichting.

De Boer, A. R., Van Dis, I., Visseren, F. L. J., Vaartjes, I., & Bots, M. L. (2019). *Hart- en vaatziekten in Nederland 2019: Cijfers over incidentie, prevalentie, ziekte en sterft*e. (25th ed.) Den Haag: Hartstichting.

Dekker, R. L. (2011). Cognitive therapy for depression in patients with heart failure: a critical review. *Heart failure clinics*, *7*(1), 127-141. https://doi.org/10.1016/j.hfc.2010.10.001

Dela Cruz, C. M. B. (2013). *Existential Concerns of Individuals Living with Chronic Mental Illness in Guam* (Doctoral dissertation). Antioch University, Seattle. Retrieved from: http://rave.ohiolink.edu/etdc/view?acc_num=antioch1372443327

Elliot, M., Salt, H., Dent, J., Stafford, C., & Schiza, A. (2014). Heart2Heart: An integrated approach to cardiac rehabilitation and CBT. *British Journal of Cardiac Nursing*, *9*(10), 501-507. https://doi.org/10.12968/bjca.2014.9.10.501

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, *5*(1), 80-92. https://doi.org/10.1177/160940690600500107

Gebler, F. A. (2010). Integration einer existenziellen Perspektive in die kognitiv-behaviorale Therapie chronischer Schmerzen. *Verhaltenstherapie*, *20*(2), 127-134. https://doi.org/10.1159/000246020

Grober, C., Heidenreich, T., & Rief, W. (2016). Existenzielle Themen in der kognitiven Verhaltenstherapie. *Psychotherapeut*, *61*(3), 229-236. https://doi.org/10.1007/s00278-016-0098-z

Grylka, S., Meyer, T., Lengler, L., Pehlke-Milde, J., van Teijlingen, E., & Gross, M. M. (2017). Postnatal quality of life: domains and changes identified from the Mother-Generated Index. *Normal Labour and Birth Conference, Cumbria, United Kingdom, 2-4 October 2017* (p. 125).

Huguelet, P. (2014). The contribution of existential phenomenology in the recovery-oriented care of patients with severe mental disorders. *Journal of Medicine and Philosophy*, *39*(4), 346-367. https://doi.org/10.1093/jmp/jhu023

Jansen, Y. J., Foets, M. M., & de Bont, A. A. (2010). The contribution of qualitative research to the development of tailor-made community-based interventions in primary care: a review. *European journal of public health*, *20*(2), 220-226. https://doi.org/10.1093/eurpub/ckp085

Kaufmann, W. (2016). *Existentialism from Dostoevsky to Sartre*. Pickle Partners Publishing.

Kemps, H. M. C., van Engen-Verheul, M. M., Kraaijenhagen, R. A., Goud, R., Hellemans, I. M., van Exel, H. J., ... & Peek, N. (2011). Improving guideline adherence for cardiac rehabilitation in the Netherlands. *Netherlands Heart Journal*, *19*(6), 285-289. https://dx.doi.org/10.1007/s12471-011-0104-6

Koole, S. L., Greenberg, J., & Pyszczynski, T. (2006). Introducing science to the psychology of the soul: Experimental existential psychology. *Current Directions in Psychological Science*, *15*(5), 212-216. https://doi.org/10.1111/j.1467-8721.2006.00438.x

Koslander, T., da Silva, A. B., & Roxberg, Å. (2009). Existential and spiritual needs in mental health care: An ethical and holistic perspective. *Journal of Holistic Nursing*, *27*(1), 34-42. https://doi.org/10.1177%2F0898010108323302

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606-613. https://dx.doi.org/10.1046/j.1525-1497.2001.016009606.x

Mako, C., Galek, K., & Poppito, S. R. (2006). Spiritual pain among patients with advanced cancer in palliative care. *Journal of palliative medicine*, *9*(5), 1106-1113. https://doi.org/10.1089/jpm.2006.9.1106

Mendonça, K. M. B., & de Andrade, T. M. (2013). What do patients think about while waiting for myocardial revascularisation? *Critical Pathways in Cardiology*, *12*(4), 188-191. https://dx.doi.org/10.1097/HPC.0b013e3182a2c801

Menzies, R. E., Menzies, R. G., & Iverach, L. (Eds.). (2018). *Curing the Dread of Death: Theory, Research and Practice*. Australian Academic Press. Retrieved from

https://books.google.nl/books?id=8tBmDwAAQBAJ&printsec=frontcover&hl=de#v=onepage&q&f=false

Naderifar, M., Goli, H., & Ghaljaie, F. (2017). Snowball sampling: A purposeful method of sampling in qualitative research. *Strides in Development of Medical Education*, *14*(3). https://doi.org/10.5812/sdme.67670

National Heart, Lung, and Blood Institute. *Heart Surgery*. Retrieved from https://www.nhlbi.nih.gov/health-topics/heart-surgery

Nederlandse Vereniging Voor Cardiologie. (2012). *Beslisboom Poliklinische Indicatiestelling Hartrevalidatie 2012*. Retrieved from: https://www.nvvc.nl/Richtlijnen/Beslisboom%20Hartrevalidatie%202012%20-website-.pdf

Novaes, M. F. P., Knobel, E., Bork, A. M., Pavao, O. F., Nogueira-Martins, L. A., & Ferraz, M. B. (1999). Stressors in ICU: perception of the patient, relatives and health care team. *Intensive care medicine*, *25*(12), 1421-1426. https://doi.org/10.1007/s001340051091

Pogosova, N., Saner, H., Pedersen, S. S., Cupples, M. E., McGee, H., Höfer, S., ... & von Känel, R. (2015). Psychosocial aspects in cardiac rehabilitation: From theory to practice. A position paper from the Cardiac Rehabilitation Section of the European Association of Cardiovascular Prevention and Rehabilitation of the European Society of Cardiology. *European Journal of Preventive Cardiology, 22*(10), 1290-1306. https://doi.org/10.1177/2047487314543075

Prasko, J., Mainerova, B., Jelenova, D., Kamaradova, D., & Sigmundova, Z. (2012). Existential perspectives and cognitive behavioral therapy. *Activitas Nervosa Superior Rediviva, 54*(1), 3-14.

Rao, A., Zecchin, R., Newton, P. J., Phillips, J. L., DiGiacomo, M., Denniss, A. R., & Hickman, L. D. (2019). The prevalence and impact of depression and anxiety in cardiac rehabilitation: A longitudinal cohort study. *European Journal of Preventive Cardiology*, *0*(00), 1-12. https://doi.org/10.1177/2047487319871716

Revalidatiecomissie Nederlandse Vereniging Voor Cardiologie, Nederlandse Hartstichting, & projectgroep PAAHR. (2011). *Multidisciplinaire Richtlijn Hartrevalidatie 2011*.

Retrieved from: https://www.nvvc.nl/Richtlijnen/Multidisciplinaire%20Richtlijn%20Hartrevalidatie%202011%2023052011.pdf

Rijksinstituut voor Volksgezondheid en Milieu. (2019). *Hart- en vaatziekten.* Retrieved from: https://www.volksgezondheidenzorg.info/onderwerp/hart-en-vaatziekten

Schaufel, M., Nordrehaug, J. E., & Malterud, K. (2011). Hope in action—facing cardiac death: a qualitative study of patients with life-threatening disease. *International journal of qualitative studies on health and well-being*, *6*(1), 5917.

Sedaghat, S., Rostami, S., Ebadi, A., & Fereidooni-Moghadam, M. (2019). Stressors in open-heart surgery patients: A qualitative study. *Arya Atherosclerosis*, *15*(4), 192.

Simonÿ, C. P., Pedersen, B. D., Dreyer, P., & Birkelund, R. (2015). Dealing with existential anxiety in exercise-based cardiac rehabilitation: a phenomenological-hermeneutic study of patients' lived experiences. *Journal of Clinical Nursing*, *24*(17-18), 2581-2590. https://dx.doi.org/10.1111/jocn.12867

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, *166*(10), 1092-1097. http://dx.doi.org/10.1001/archinte.166.10.1092

Steer, R. A., & Beck, A. T. (1997). *Beck Anxiety Inventory.* In C. P. Zalaquett & R. J. Wood (Eds.), *Evaluating stress: A book of resources* (p. 23–40). Scarecrow Education.

Tausch, R. (2008). Sinn in unserem Leben. In *Positive Psychologie* (2nd ed.). Weinheim, Beltz: A.E. Auhagen

Udo, C., Danielson, E., & Melin-Johansson, C. (2013). Existential issues among nurses in surgical care–a hermeneutical study of critical incidents. *Journal of advanced nursing*, *69*(3), 569-577. https://doi.org/10.1111/j.1365-2648.2012.06032.x

van Bruggen, V., Vos, J., Bohlmeijer, E. T., & Glas, G. (2013). Over de plaats van existentiele thema's in cognitieve gedragstherapie. *Gedragstherapie, 46*(2), 119-134.

van Bruggen, V., Vos, J., & Glas, G. (2014). Existentiele angst. In B.

Heycop ten Ham, M. Hulsbergen, & E. Bohlmeijer (Eds.), *Transdiagnostische factoren - theorie en praktijk.* (pp. 313-334). Amsterdam: Uitgeverij Boom.

van Bruggen, V., ten Klooster, P., Westerhof, G., Vos, J., de Kleine, E., Bohlmeijer, E., & Glas, G. (2017). The Existential Concerns Questionnaire (ECQ)–development and initial validation of a new existential anxiety scale in a nonclinical and clinical sample. *Journal of clinical psychology*, *73*(12), 1692-1703.https://doi.org/10.1002/jclp.22474

Vos, J. (2015). Meaning and existential givens in the lives of cancer patients: A philosophical perspective on psycho-oncology. *Palliative & supportive care*, *13*(4), 885. https://doi.org/10.1017/S1478951514000790

Vögele, C. (2016). Herz-Kreislauf-Erkrankungen. *Verhaltensmedizin* (pp. 139-152). Springer, Berlin, Heidelberg.

World Health Organisation (2017). *Cardiovascular disease (CVDs)*. Retrieved from: https://www.who.int/en/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds)

Yalom, I. D. (1980). *Existential Psychotherapy*. New York: Basic Books.

Yalom, I. D. (2008). *Staring at the sun: Overcoming the terror of death*. San Francisco: Jossey-Bass.

Ziekenhuisgroep Twente. (2019). *Hartrevalidatie, PEP-module* [Brochure]. Retrieved from: https://www.zgt.nl/media/folders/19476/hartrevalidatie-pep-module.pdf

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, *67*(6), 361-370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

Appendices

Appendix A:

Recommended Screening Tools

Questionnaire Package 1: PHQ-9 & GAD-7

To clarify whether there is an emotional imbalance or increased risk of depressive and anxiety symptoms, the guideline recommends the conduction of the *Patient Health Questionnaire Scale 9* (PHQ-9) and *Generalised Anxiety Disorder Scale 7* (GAD-7) (NVVC, 2012; ZGT, n.d.), based on the self-assessment scales' excellent psychometric and practical properties. The PHQ-9 enables the screening for depressive symptoms, with each of the nine items covering one of the DSM-V criteria for the diagnosis of major depression (Kroenke, Spitzer, & Williams, 2001). The GAD-7, on the other hand, is intended to screen for anxiety symptoms, whereby each item reflects one diagnosis criteria for generalised anxiety disorder (Spitzer, Kroenke, Williams, & Löwe, 2006).

Questionnaire Package 2: BDI-II & BAI

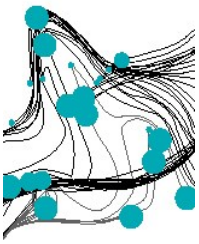
A second recommended questionnaire package to clarify whether there is a disturbance of psychological functioning consists of the Dutch versions of the revised *Beck Depression Inventory* (BDI-II) & the *Beck Anxiety Inventory* (BAI). Both self-report inventories consist of 21 items on a four-point Likert scale, ranging from zero to three points (NVVC, 2012). The patients' total score is obtained by adding up the different item scores and amounts zero to 63 points and provides information about the severity of depressive symptoms (BDI-II) or anxiety symptoms (BAI) in accordance with the diagnostic criteria of the DSM-IV. Thereby, 0-13 stands for minimal, 14-19 stands for mild, 20-28 stands for moderate and 29-63 stands for severe depressive/anxiety symptoms (Steer & Beck, 1997; Beck, Steer, & Brown, 1996). The reliability and validity of the inventories was indicated by numerous studies across different populations and cultural groups (Steer & Beck, 1997; Beck, Steer, & Brown, 1996).

Questionnaire Package 3: HADS-D & HADS-A

The last recommended questionnaire package comprises the two subscales of the *Hospital Anxiety and Depression Scale* (HADS; NVVC, 2012) to detect states of depression (HADS-D) and anxiety (HADS-A) in hospitalised patients (Zigmond & Snaith, 1983). In total, the HADS self-assessment scale consists of 14 items, which alternate between 7 items per subscale. The response options on the four-point Likert scale vary from item to item and measure either the severity or frequency of symptoms or the extent of resulting behavioural changes. Due to its proven reliability and validity, the HADS (with its subscales) is a well-established tool in clinical practice (Zigmond & Snaith, 1983).

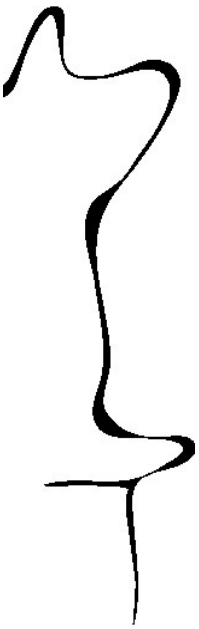
Appendix B:

B.1. Letter of Information Patients (translated)



Promotion of recovery after surgery

Scientific research on recovery after surgery and how an online program can help to promote this.



The University of Twente plans to develop an online aid program for people undergoing surgery in order to optimise their recovery afterwards. In order to properly match the patients' wishes and needs, this research is carried out.

What does participation involve?

The research consists of interviews with patients, nurses and doctors (surgeons). During the interviews, we will ask you questions about your recovery and your wishes, needs and ideas regarding the online aid program.

The interview will be held in November. It takes approximately 60 minutes and can take place at your home or, if desired, at Saxion or at the University of Twente. Of course, all data will be treated strictly confidential.

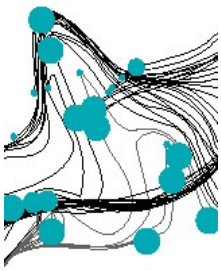
Contact information

This research is carried out by A.H.
She is a researcher at the University of Twente & lecturer in Nursing at Saxion University of Applied Sciences.

If you have any questions about the research, please contact Mrs. H.
(tel. 06-xxx xx xxx; e-mail. A.xxxxxxxxxx-x@utwente.nl)

B.2. Letter of Information Nurses (translated)

Letter of Information Nurses

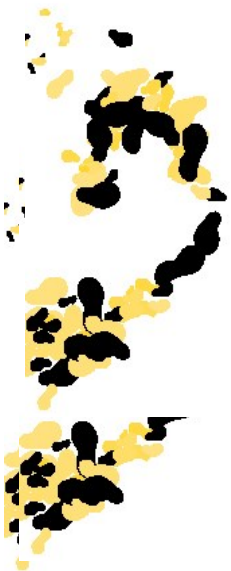


Promotion of recovery after surgery

Scientific research on recovery after surgery and how an online program can help to promote this.

De Universiteit Twente is van plan om een online hulpprogramma te ontwikkelen voor mensen die geopereerd worden met als doel om beter te herstellen na de operatie.

The University of Twente plans to develop an online aid program for people undergoing surgery to promote better recovering after surgery. Through the program, patients learn to cope better with pain, which will help them recover after surgery. The idea is that patients start the online program several weeks ahead of the operation and that this program continues until a few weeks after the surgery. While participating in the program, patients are (lightly) supervised by nurses. This research is being carried out to ensure that the program fits well with the wishes and needs of patients and nurses.



What does participation involve?

The research consists of interviews with patients, physiotherapists and doctors (surgeons). During the interviews, we will ask you questions about your wishes, needs and ideas regarding the online program.

The interview will be held in April. It takes about 45-60 minutes and can take place at ZGT or, if desired, at the University of Twente or your home. All data will, of course, be kept strictly confidential.

If you have any questions about the research, please contact Mrs H. (tel. 06-xxx xx xxx; e-mail. A.xxxxxxxxxx-x@utwente.nl)

Appendix C:

C.1. Informed Consent Patients (translated)

Dear Sir / Madam,

Please read the text below. If you want to participate in the investigation, you must enter your name, address, signature and date at the end of the text.

- I have read the information letter about this study. I was able to ask additional questions. My questions have been answered sufficiently.
- I know that participation is entirely voluntary. I know that I can decide at any time not to participate in the study or to stop participating. I don't have to give a reason for that.
- I permit the use of data for the purposes indicated in the information letter.
- I know that whether or not participating in this study will not have any consequences for my surgery/treatment.
- I know that the recordings of the interview will be deleted after they have been typed out.

Name:
……

Address:
……

Postcode and place of residence:
……

Telefone number:

…….....

Signature: Date: __ / __ / __

……..

C.2. Informed Consent Professionals (translated)

Informed Consent Nurses, Physiotherapist & Cardiologist

Dear Sir / Madam,

Please read the text below. If you want to participate in the investigation, you must enter your name, address, signature and date at the end of the text.

- I have read the information letter about this study. I was able to ask additional questions. My questions have been answered sufficiently.
- I know that participation is entirely voluntary. I know that I can decide at any time not to participate in the study or to stop participating. I don't have to give a reason for that.
- I permit the use of data for the purposes indicated in the information letter.
- I know whether or not participating in this study has no consequences for my work at ZGT.
- I know that the recordings of the interview will be deleted after they have been typed out.

Name:
……

Address:
……

Postcode and place of residence:
……

Telefone number:

…….....

Signature: Date: __ / __ / __

……..

Appendix D

D.1. Interview Scheme Patients (translated)

Name interviwer:	
Number participant:	
Date of interview:	
Place of interview:	
Time of interview start:	
Time of the end of the interview:	

Welcome
Introduction:

- A.H.
- Researcher at the Department of Psychology, Health and Technology, UT & researcher at the Nursing research group of Saxion.
- I am working on this research as part of my PhD.

Thanks, and explanation procedure interview

- Thank you for participating
- Research goal: develop an online intervention for recovery after surgery
    - Consequently, an app for tablet / smartphone / computer
- Purpose of the interview: to identify needs for such a program
- Interview duration: 45-60 minutes
- Privacy:
    - Only UT researchers get access to documents
    - No personal data is used in the final report
    - You can stop the interview at any time
- Consent recording?
    - To be able to work out an interview later,
    - I do not have to write continuously now
    - Recordings are deleted after typing, data further processed anonymously
- Quote permission (anonymous or e.g. first name only)?

If yes;

- Okay, then I will give you a brief explanation on how the interview is structured
    - I would like to ask you some questions about how you experienced the period before and after the operation. For example, whether you had complaints and how you dealt with them.
    - Next, I would like to ask you how an intervention could help to make recovery after surgery even better.
    - Finally, I would like to ask you for some general, personal information.

If no;

- Could you give me a reason for this? (Indicate that it is possible to speak under a fictious name; if the respondent yet does not want to, indicate that you have to type everything and that the interview will therefore take longer.)

Interview Scheme Patients

1. What have you had surgery on? What are you being operated on?

<u>Before surgery</u>

2. How was the pre-surgery period for you? When was that, e.g. what weather, what season was it? What did your life look like (then)?
3. How did you feel before the operation?
4. Can you tell me more about your pre-surgery complaints?
5. How did the complaints affect your life? Could you do everything you used to? Or has something changed in this respect compared to the past (for complaints)?
6. How has the disease affected your daily functioning? *(physical functioning, social functioning, daily activities, emotional functioning, possibly family life, relational).*
7. Are there any other things you run into/ or run into during the illness?
8. What did you do about the complaints before the operation? For example, which care providers have you visited and what have you tried?
9. What worked well for you? What did not work well for you? What was the difference for you?

<u>After surgery</u>

10. How was the operation for you?
11. How long have you been in the hospital after the operation?
12. How did you feel (in the period) after the operation?
13. How did you experience recovery after surgery?
14. Have you had complaints after the operation?
15. If so, what did you do about the complaints after the operation? What have you done to promote recovery? For example, wich care providers have you visited and what have you tried?
16. What worked well for you? What did not work well for you? What was the difference for you?

New intervention

At the moment, I am doing a PhD research at Saxion Hogeschool and the University of Twente. The aim of this research is to develop an online program (e.g. a website or an app) that helps patients to recover better after surgery. The program starts a few weeks before surgery, is also monitored during admission and will be completed several weeks after surgery.

17. What do you think I should think about (not forget) when developing an online program for people who have had surgery?
18. What would have helped you before, during and after the surgery? How could a program respond to this or strengthen it?
19. What conditions / requirements are required for a new program?
20. Do you have an idea of what parts the program should consist of according to you?
21. What would you think of an option, for example, such as a forum, contact with other patients, information about the operating procedure and / or FAQs?
22. Would you use such an online tool for patients undergoing surgery yourself?

- *Why yes?*
- *Why not?*
  - *If respondents are not interested in an online tool at all, then still try to convince them to participate in the survey. "Even if you are not interested in an online tool, would you still like to think about how I can give substance to a program for patients?"*

Boundary conditions online help program

Now I will ask you a few more questions about the boundary conditions of the online tool for patients undergoing surgery.

eHealth

23. Are you willing to work with an online program (e.g. a website or an app), if this could help your recovery after surgery? / Why not?

Time commitment

24. How much time per week would you like / want to spend on an online aid program for patients undergoing surgery?
    …….hours per week

25. Do you see a difference in this before, during or after admission?
    Yes, …….. hours per week. ☐ No

26. How many weeks should an online program last?
    …….weeks

27. How would you divide the weeks, before, during or after admission?
    …….. weeks before surgery
    …….. During admission (1 week?)
    ……..weeks after surgery

Exercises

28. Would you be willing to exercise several times a week / daily, if this can promote recovery after surgery?
29. Would you be willing to do this several weeks before surgery?
30. Would you be willing to continue to exercise until several weeks after the operation?
31. Would you be willing to do exercise to find out what you are doing when you are in pain? And to find out how that feels whether it helps or not?
32. Would you be willing to do exercises that provide insight about yourself? Exercises where you look at yourself?
33. Would you be willing to do exercises, looking at what is important to you in your life? Looking at what you enjoy doing in your life?
34. Would you be willing to do exercises, consciously focusing your attention? For example, where you should focus your attention on (parts of) your body? For example, 10 minutes every day?

Form of guidance

35. Imagine following such a program. How do you want to be guided?
36. Some people, for example, do not have standard weekly contact, but would like the opportunity to ask for help if needed. What do you think of that?
37. Some people, for example, need confirmation from a supervisor that they are doing well. What do you think of that?
38. Some people, for example, need encouragement from an attendant to continue. What do you think of that?
39. Would you like to be supported on the online program by a nurse, for example, to get feedback on exercises you have done?
    ☐ Yes ☐ No

If yes;

- How often would you like to have contact?

If no;

- Why would you rather not be supported?

40. What could the guidance look like?
    ☐ Per email
    ☐ Per chat, video conference (for example Skype)

41. Provisional, the following is envisaged:
    After an introduction, participants start working independently with the program. There is an e-mail exchange between participant and nurse once a week. During hospitalisation, the nurse

stimulates the participant to apply the learned (mindfulness) exercises. The nurse is able to perform the exercise together with the participant if necessary. After the operation, there is another email contact between participant and nurse.
What do you think of this setup? What do you like? What does not appeal to you?

Personal information

We almost arrived at the end of the interview. I would like to ask you to answer a few more questions about your personal data and your internet use.

What is your gender?
☐ Man ☐ Woman

What is your age?
……

Are you religious?
☐ Yes
☐ No
☐ Not known

Do you have any children?
☐ No
☐ Yes, children living at home
☐ Yes, children living away from home

What is your highest completed education?
☐ No training
☐ Primary education only
☐ Vocational education, MAVO, (M)ULO, 3-jarige HBS of VMBO
☐ Secondary vocational education, 5-year HBS, HAVO, MMS, high school or gymnasium
☐ Higher professional education (HBO) or University
☐ Otherwise, namely ……..

What is the best description of your current situation?

☐ I do paid work for 20 hours or more per week
☐ I do paid work for less than 20 hours per week
☐ I am a housewife / houseman
☐ I am still in school or studying
☐ I am looking for a job
☐ I am incapacitated for work (WAO)
☐ I am retired (AOW of early retirement)
☐ Otherwise, namely ……..

Do you have access to a computer, tablet and/or smartphone at home?
☐ Yes ☐ No

Do you have internet access at home?
☐ Yes ☐ No

How many hours a week do you use the internet for personal reasons?
Around…….. hours

Closing/End
Then we have now discussed all topics of the interview.

- Do you have any further questions or comments?

Explanation of next steps and expressing thanks
The interview is typed out and analysed. The report and that of other patients, nurses and doctors will help us develop an online tool for patients undergoing surgery.

Then one last question
- Would you also be interested in taking part in follow-up studies? To develop the online tool, we still need patients, nurses and doctors to help us develop it. This mainly concerns giving feedback on newly developed texts and exercises.

If yes;
- How we are allowed to contact you again (telephone, mail, letter)
  ……..

Then we are now at the end of the interview.

We would like to thank you for your participation.
The interview has ended, and the recording is stopped.

D.2. Interview Scheme Cardiologists (translated)

Name interviwer:	
Number participant:	
Function participant	Doctor (cardiologist)
Date of interview:	
Place of interview:	
Time of interview start:	
Time of the end of the interview:	

Welcome
Introduction:

- A.H.
- Researcher at the Department of Psychology, Health and Technology, UT & researcher at the Nursing research group of Saxion.
- I am working on this research as part of my PhD.

Thanks, and explanation procedure interview

- Thank you for participating
- Research goal: Develop an online intervention for recovery after surgery
    - Consequently, an app for tablet / smartphone / computer
- Purpose of the interview:
    - To identify needs for such a program
    - Share your experience what patients need
    - Share about what you need as a surgeon for the program
- Interview duration: 45-60 minutes
- Privacy:
    - Only UT researchers get access to documents
    - No personal data is used in the final report
    - You can stop the interview at any time
- Consent recording?
    - To be able to work out an interview later,
    - I do not have to write continuously now
    - Recordings are deleted after typing, data further processed anonymously
- Quote permission (anonymous or e.g. first name only)?

If yes;

- Okay, then I will give you a brief explanation on how the interview is structured
    - The first part of the interview is about your experience with patients. What kind of complaints do they have and how could an intervention help?
    - The second part is about how you see an intervention yourself and how an intervention can help you with your work.
    - The last part contains come general questions about personal data.

If no;

- *Could you give me a reason for this? (Indicate that it is possible to speak under a fictious name; if the respondent yet does not want to, indicate that you have to type everything down and that the interview will therefore take longer.)*

Before surgery

1. What kind of help/guidance do you think patients need before surgery?
2. How could a program help you with this?
3. Can you tell me a little bit more about patients' common complaints before surgery?
4. How do you think affects the pain their lives?
5. What have patients already done about the complaints before the operation? Which care providers, for example, visited and tried they themselves?
6. What does work well generally? What does not work well generally? What do you think is the difference?

After surgery

7. What kind of help/guidance do you think patients need after surgery?
8. How could a program help you with this?
9. How do patients generally experience recovery after surgery?
10. Do patients generally have complaints after surgery?
11. If so, what do patients do about these complaints after the operation? What do you advise them?
12. What do patients do to promote recovery? What do you advise patients to do?
13. What works well generally? What did not work well for you? What is the difference for you?

New intervention

Currently, I am doing a PhD research at Saxion Hogeschool and the University of Twente. The aim of this research is to develop an online program (e.g. a website or an app) that helps patients to recover better after surgery. The program starts a few weeks before surgery, is also monitored during admission and will be completed several weeks after surgery.

Now I will ask you a number of questions about the patients, followed by a number of questions about your own work

.

14. What do you think I should think about (not forget) regarding the patients, when developing an online program for people who have had surgery? And regarding the nurses? En regarding the cardiologists?
15. Would it be necessary to recruit a separate subgroup of patients, or would it be better to use it generally for all heart patients?
16. Do you have an idea of which parts the program, according to you, might contain?
17. Would you, as a patient, use an online tool for patients undergoing surgery?

- *Why yes?*
- *Why not?*
  - *If respondents are not interested in an online tool at all, still try to convince them. Answer may influence motivation to supervise such a program*

Now I will ask you some questions about the intervention, related to your work.

18. In what way would a program make your work easier?
19. In what way could a program complement your work?
20. What conditions/ requirements are needed for a new program?
21. What implementation requirements are there? What is needed to properly enter it in the department? How can the program best be implemented in practice? What resources and activities are needed for this?
22. Would such a program complement the usual treatment, or could it be part of the treatment?
23. Who should supervise the program/app?

Preconditions program

Now, a few more questions follow about the preconditions of the online program for patients undergoing surgery. To give you an impression of what an online help program can look like, here I have an example of an online course for people with mild to moderate psychological complaints / people with chronic pain complaints (screenshots of cockpit *"Living with Pain"* or *"Living in Full"*). Please take the time to view the example.

eHealth

24. Are you willing to work with an online program (e.g. a website or an app), if this could help your recovery after surgery? / Why not?

Time commitment

1. How many weeks should an online program maximal last?
   …….weken
2. How would you divide the weeks before, during and after the admission?
   ……. Weeks before surgery
   ……. During admission (1 week?)
   ……. Weeks after surgery

Exercises

25. What do you think about exercises that give the patient insight into themselves?
26. What do you think about exercises in which the patient looks at what is impoertant to them in their life, what they find important to do in their life?
27. What do you think of mindfulness exercises? Exercises in which the patient must consciously focus his/her attention? For example on (parts of) the body?

Form of guidance

28. Provisional, the following is envisaged:
    After an introduction, participants start working independently with the program. Once a week, there is an e-mail exchange between the participant and the nurse. During hospitalisation, the nurse stimulates the participant to apply the learned (mindfulness) exercises. If necessary, the nurse is able to perform the exercises together with the patient. After the operation, there is another email contact between participant and nurse.
    What do you think of this setup? What do you like? What does not appeal to you?

Personal information

We almost arrived at the end of the interview. I would like to ask you to answer a few more questions about your personal data and your internet use.

What is your gender?

☐ Man ☐ Woman

What is your age?

……

What is your highest completed education?

☐ Vocational education, MAVO, (M)ULO, 3-jarige HBS of VMBO
☐ Secondary vocational education, 5-years of HBS, HAVO, MMS, high school or gymnasium
☐ Higher professional education (HBO) or University
☐ Otherwise, namely specialisatie cardiologie na geneeskunde

What is the best description of your current situation?

☐ I do paid work for 20 hours or more per
☐ I do paid work for less than 20 hours per week

How long do you work as a cardiologist? ……..

How long have you been working in your current position? ……..

Do you have access to a computer, tablet and/or smartphone at home?

☐ Yes ☐ No

Do you have internet access at home?

☐ Yes ☐ No

How many hours a week do you use the internet for personal reasons?

Around…….. hours

Closing/End

Then we have now discussed all topics of the interview.

- Do you have any further questions or comments?

Explanation of next steps and expressing thanks
The interview is typed out and analysed. The report and that of other patients, nurses and doctors will help us develop an online tool for patients undergoing surgery.

Then one last question

- Would you also be interested in taking part in follow-up studies? To develop the online tool, we still need patients, nurses and doctors to help us develop it. This mainly concerns giving feedback on newly developed texts and exercises.

If yes;

- How we are allowed to contact you again (telephone, mail, letter)
  ……..

Then we are now at the end of the interview.

We would like to thank you for your participation.
The interview has ended, and the recording is stopped.

Appendix E

E.1. Patients' Extended Coding Scheme

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Death	Confrontation with Severe Illness	Past with Severe Illness	Patients have been confronted with a serious life-threatening illness in the past – either themselves or as relatives. In this context, they also were confronted with the loss of a loved one/ family member due to illness.	Confrontation with severe illness in the past	*"I have had throat cancer [...]" (P3).*
				Confrontation with severe illness in family	*"All my sisters also had it. My one sister died, too; she had a problem with her lungs. It lies within the family." (P1).*
				Loss of loved one/ family member due to illness	*"[...] my son died suddenly - had a cardiac arrest." (P1)*
		Confrontation with Physical Complaints	As consequence of the illness/open-heart surgery, patients are confronted with complications and side effects		*"And the kidneys can't compensate that. And then you get more complications. And that is why I also stayed a night longer on the... [...] And then you slowly recover a little." (P1)*
		Confrontation Need to take Medication	As consequence of the illness/complications, patients are confronted with the need to take medication.		*"Those medicines. Those medicines - every day swallowing. And when you got somewhere, everyone asked: 'Gosh, how are you?'. Oh, god. You know, yes, that's how I experienced it." (P2)*
		Denial of Illness	Although patients are confronted with a chronic condition, they try to deny it by ignoring or trivialising symptoms, neglecting their limitations and by consciously deciding to stop being sick. It also manifests itself in the patients seach for distraction, avoidance of provided information and the avoidance to seek help.	Need for distraction	*"Yes, you have distraction, but if you are alone with it, then you are very occupied with it in your mind." (P1)*
				Avoiding provided information	*"No, the less you know, the happier you are […] I think so." (P1*
				Avoiding seeking help	*"It also always took a while before I went to the doctor […]" (P6)*
				Ignoring symptoms	*"I got respiratory complaints with retrospective effect and I fantasised a little, but I have no sense of fantasy. I have honestly been bothered by that for a few years. I had a feeling for some time that "something might not be right", but the hiding strategies worked fairly decent." (P6)*
				Deciding to stop being sick	*"Yes, I am done with it since January, yes. Since January I've been going back to clubs, bridge and tennis and [silence] I said to myself 'I am just going to do everything normal again." (P2)*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Death	Fear of the Unknown due to a Lack of Knowledge		Due to a lack of knowledge, patients experience fear and uncertainties. The lack of knowledge and the consequent uncertainties relate to the medical procedure in general, medication and bodily functioning.	Need for information regarding medication	*"I think side-effects of the medication. [...] I was suffering from dizziness and you immediately think "the valves are not straight" or something vague. But then you hear from others 'yes, it is because of this and those medicines'. That would then bring up, then you do that and then they no longer defects and then slowly pulls ... something with dipril or something like that. Yes, slowly that is indeed disappearing. And at that moment you think 'if I had not read it, I would have swallowed it'." (P6)*
				• Fear of side effects	*"I've checked the medication list completely because I think 'can this be caused by the medication?' I have checked the package leaflets. I couldn't get wise of it. I brought the urine away and eh if I have a bladder infection. Look, you pay more attention to it, I think." (P6)*
				• Fear of becoming addicted	*"I also did not want to become addicted." (P6)*
				Need for information regarding medical procedure and complications	*"I, I, eh, the only thing I really would have liked to know: 'what does it include?' and nobody can say that, because it is different for everyone." (P2)*
				Need for information regarding bodily functioning:	*"The irregular heartbeat really has plagued me and it is difficult for me to estimate whether that is a consequence of being a heart patient." (P6)*
				• Overly alert on bodily signals	*"I've checked the medication list completely because I think 'can this be caused by the medication?' I have checked the package leaflets. I couldn't get wise of it. I brought the urine away and eh if I have a bladder infection. Look, you pay more attention to it, I think." (P6) I think you are now..." (P2) - "Yes, that you are more alert to physical things?" (Interviewer) - "Yes, unfortunately." (P2)*
	Lack of Safety		Patients become aware of the fact that the world is an unsafe place, where they have no certainty, that a life-threatening/traumatic event will not happen again.		*"If I went for a walk and I think 'here it comes again'. And I wasn't sure either, then you will become very uncertain of yourself." (P2)*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Death	Confrontation with Own Mortality	Awareness of own Mortality	Due to the severe illness and the open-heart operation, patients are confronted with the possibility of dying and become aware of their own mortality.	Thinking about death, the possibility of dying and afterlife.	*"You know that the chance of your death is present and that was estimated at 5% for me. I saw something like that, about 100 people who cross a highway with a blindfold and 5 of them don't make it. I think 'yes, that will be me'. [...] So you know that's a real thought and then you start thinking about it." (P6).*
				Awareness survival	*"But we made it, in the nick of time." (P1)*
				Near-death experience	*"No, I lay relaxed in the sun and suddenly I was a bit too far away." (P5)*
				Reanimation	*"But I am also catheterised before the operation. That did not go entirely as desired. I ... they had to help me back in the world with the defibrillator. I felt that it went wrong and then also shout outs of 'goes wrong', but I'm sure I'm going away. [...] When I recovered ... I only remembered what I can remember, nothing before. From the moment I ... the transition was coming close, what they describe, a ... that was light somewhere, was light. I found it slightly irritating that I was being sent into reality, which I thought was unreal at that moment ... when I was there and could think a little, I thought 'gosh, if that is dying, then it seems annoying to those left behind then for yourself '. That has been a more unpleasant situation for me than comparative, say, the operation itself." (P6)*
				Confrontation "remaining time"	*"I had to do it, otherwise, I wouldn't have had two years to live. Within two years it would have been over." (P1)*
		Awareness of Natural Decay	Patients are confronted with (and become aware of) the process of ageing and its (ultimately fatal) consequences	Patients are aware of getting old	*"That you are the old one. No, that disappoints me. "(P3).*
				Consequences of getting old	*"[...] but what will he do in a year?! You don't know that in advance either. You just don't know that ... as long as it is now ... I think it's good. I mean, he isn't the youngest anymore either." (significant other of P5)*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Freedom	Experiencing Existential Guilt	Feelings of Guilt against Oneself for the "Unused Life."	Patients are confronted with illness-related limitations in their daily life and consequently fail to live their life to their full/used potential. The awareness about it leads to feelings of guilt on account of an " unused life". It also manifests in patients' feelings of shame and frustration about their condition. They tend to compare themselves with their former self and regret the decision to have had surgery. Moreover, as a result they perceive an increased emotionality.	Limitations everyday life	*"A bit, a bit almost convulsive. I felt that when I was admitted that weekend. I felt that when I was sweeping that kitchen. And eh, because, well that is very simple work, such a broom is not a challenge." (P2)*
				Shame & frustration	*"[…] And my mother-in-law takes the walker and walks to the road, 91 and she is still walking, and I am 64 years old and I cannot walk to the road. That really is a shame." (P1)*
				Regret	*"Yes, if I would have known that, I wouldn't have done it. No, really, I wouldn't." (P1) - "What would you choose for instead?" (Interviewer) - "I don't know, but I am even more tired now than usual. […] Now I have lost that and then I have lost that. I have lost a lot of tension there." (P1) - "Do you regret it?" (Interviewer) - "No, I wouldn't have done it. If they say 'and now you have to go again' then I really wouldn't do it." (P1)*
				Increased emotionality	*"They are shorter. They change faster. That started first after surgery." (P1)*
		Feelings of Guilt towards Others	Patients feel guilty that their illness (-related limitations) affect loved ones. Their feelings of guilt towards others become apparent by statements that emphasise that they do not want to be a burden to others, or that others experience distressing, negative emotions (such as fear or worry) because of them.	Avoiding being a burden to others	*"Yes Yes. But I want to do my own thing. I don't want to be so dependent on the children. I think that's terrible. I think "they are all busy, they all work and I don't want that." (P3)*
				Wanting to protect loved ones from negative emotions	*That depends on how the children are. How caring the children are or how anxious the children are. You can also scare them. I have a very caring daughter who lives here in [name city] and yes, I don't say much to her, because then she will be worried. So, that is also possible, that danger is there, too." (P2)*
	Avoiding taking Responsibility to make Decisions	Displacement of Responsibility	Although patients are able to take responsibility and to choose their own path in life, they avoid making decisions by shifting them upon others. They shift their responsibility not only to partners and family members but also trust experts and informal caregivers blindly, even when it comes to medication management.	Blind trust in professionals and informal care givers	*"And those medicines that I received ... I had no idea, but maybe that is something I missed when my brain was still not working properly again. Or that I just don't ... Very briefly: I was given medication and I did not understand it at all. I never took medication, so. At first, I didn't delve into that either, luckily I had a sister-in-law who prepared everything for me. I also said '[name], do whatever you need.' I have eaten an entire package, but I got a lot at first." (P6)*
				Displacement of responsibility to partner	*"Well, I also say every time that my wife has done that, she did it nicely." (P5)*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Freedom	Avoiding taking Responsibility to make Decisions	Displacement of Responsibility		Displacement of responsibility to relatives	*"If there is anything, I have my children, they will do it. [...] At least I, I don't need anything to do. Everything is done automatically. So as long as you have your bills, yes, ah, so my daughter does that entirely on the computers. [...] Yes, yes, yes. She does my business there and also what needs to be done for it [...]. Well, my other daughter, who has... she takes care of the rest and yes..they both do something. So that is so easy." (P3)*
		Avoidance of Autonomous Behaviuor	Although patients are able to take responsibility for their lives and to make the right decision for their recovery, *they actively refuse to take the necessary steps* due to insecurities. Those insecurities are closely related to the fear of unknown, respectively the lack of knowledge, and inhibit the patients' decision-making process. The insecurities express themselves, for example, in the patients' fear of movement, the fear to take medication or the need for confirmation.	Need for confirmation	*"Yes, because I have asked everyone who [unclear] to my brother, my oldest brother, who was also operated on to the heart and who also received a valve, and he says 'no, he does not hear that.' He has an artificial valve." (P1)*
				Overly cautious	*"And then I sleep in the room, I still have the bed in the room. [...] Yes. The first night I slept upstairs. And then I slept upstairs again and I said 'I won't go there anymore' because I didn't trust the stairs." (P1)*
				Lack of self-security	*"Because then you have to do something, and you didn't know how much. And you became uncertain." (P2)*
				Fear of movement	*"I slept here in the chair for a few days. I don't exactly know the time span between things, but the period ahead of the water-pills I got ... well, first to my feeling - I couldn't lie anymore either - then I thought 'you imagine something' [...] 'it gets worse'. And then, when I was lying down, then at once I became oppressed, I shot away and then it was over again. After a while, I didn't even dare to lie down, when I also went to sleep in the chair for a few days. So that has been in the period when I was waiting."(P6)*
				Aversion to take medication	*"[...] I don't want to sit there constantly like: 'I don't want those tablets [...]." (Relative of P1)*
				Non-adherence to medication	*No, that was necessary for so long and I understood that I ... that it can become a very big thing if you keep using them for a long time. Well, I think 'I will stop right away'. Back then I took a sleeping pill and then oxazepam, but when I got here, it was all gone." (P6)*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Freedom	Loss of Autonomy	Being Dependent	Because of the illness/surgery, patients are dependent on others, whereby they experience a loss of autonomy and accordingly their freedom to make choices. The dependency also becomes clear through the emphasised need for self-determination.	Being dependent on family members	*"Otherwise my daughter must bring me. Because you can't ride a car for six weeks, do you? So that's difficult because you can't. I mean, also with grocery shopping, I was not allowed to carry more than one kilo per arm." (P2)*
				Being dependent on strangers	*"Yes, I receive home care every morning. With showering, but that is because there is water back pressure. That is all sensitive. " (P5)*
				Need for self-determination	*"I want to get rid of the dependency. I must, eh, I always had. I just need to do something and don't want to ask every time. If you always do something, like making groceries, then you want that thing. I can't stand that. [...] That is also difficult in the sense of 'well, I will do everything myself again' and then I have called, and I almost never use the car, though. Only the idea that I can leave - that I can use it." (P3)*
		Being Patronised	Patients experience a loss of autonomy through the patronage of concerned relatives.		*"And eh, I didn't feel free at all. When I turn around or what, she said: 'Can I do something for you, a glass of water?' You know. I think "oh god, child. You must have that night's rest'. Or 'do you need this or do you need that?' After two nights I say 'ooooh [daughter's name] you know what, go home'." (P1)*
		Lack of Control	Patients experiences a lack of control regarding the timing of the operation and their hospital stay. The lack of control also causes feelings of powerlessness and helplessness.	Need to wait for operation	*"No, you observe a lot. You have time to think. I think 'oh all those ...'. Well, I said 'you can't remember your despair'. I'm still in the period before the operation. You cannot remember the desperation that you feel - luckily - when you are waiting." (P6)*
				Feeling powerless/helpless	*"I think, at that moment, I already (before the operation) - that applies to me, I already had the feeling so bad that 'I have nothing under control' [...]" (P6).*
				Patients are unable to decide things by themselves	*"I told my son-in-law 'we will be back in half an hour', but they would like to see me. But they kept me. [...] Well, that is, I was ashamed." (P1)*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Meaninglessness	Experiencing an Existential Crisis		Due to the open-heart surgery (traumatic event) patients experience an existential crisis and consequently question their lives, whether it has meaning, purpose or value.	Thinking about own life, values, purpose	*"And what did you think?" (Interviewer) - "Yes, everything." (P1).*
				Realignment of values	*"I had a good relationship with my daughter, but then a few terrible things happened to her and eh, very traumatic and since then she doesn't like me anymore. And so that is something now, which I thought of 'well, I am over it', but that came up again at a certain point in the whole process at night when I thought 'oh dear'. "(P4) - "And you mean that came after the operation?" (Interviewer) - "Yes." (P4) - "That you have to start thinking about that again?" (Interviewer) - "Yes, yes, yes, yes. [...] Yes that was a bit covered up and that came up again [...] with a restless feeling of 'hey, I thought it was a bit parked'." (P4)*
	Loss of Meaning		Due to the illness and the associated consequences, the patients experience a loss of meaning in life, e.g. the patient is unable to do things that previously gave meaning to his life or feels unimportant/worthless. The loss of meaning is also associated with a loss of structure or content in life and causes feelings of emptiness and boredom.	Feeling unimportant/worthless	*I've thought about it for a very long time, like: 'what will I do with this?' [...] Because I've always cleaned by myself. I say 'yes, you must listen. I find it difficult now. I still worked until November. Once a week. I cancelled it last week." (P3)*
					"I also went into the city to realise that life just went on and such as this is part of it. But of course, you are not worth so much at first." (P6)
				'Can't do anything anymore'	*"Yes, I can actually do anything, I imagined. And then I ruled out that I was no longer able to do everything, you know. "(P2)*
				Death wish	*"Yes, if that continues, I call a doctor. I don't want to sit there constantly about "I don't want those tablets" or "I'm going to hang myself in the shed." (Relative of P1)*
				Boredom	*"And then you sit in the chair, and then you put that on and then you put that on. TV is nothing on. No, and then you still have Ziggo."(P1).*
				Emptiness	*"Yes, because I always had the grandchildren on the weekend. Little boys, the baby boys. From my son then. They came every Friday evening and returned on Sunday evening. Nice distraction, and now that is gone. "(P1)*
	Cosmic Meaning		The patient's attempt to give meaning to life by believing in some form of a higher order.	Being religious	*"Yes, yes. It certainly gives you support. [...] It is a very nice one "upstairs", but no one has ever returned, has he? [...] I am quite convinced [that it's very nice in "heaven"]."(P3)*
				Believing in fate	*"[...] because I'm not here next year. You never know, do you?"(P3)*
				Being spiritual	*"I've always had faith, and I have hardly been aware that my heart failed. Very strange actually." (P4).*

(table continues)

E.1. Patients' Extended Coding Scheme (continued)

Extended coding scheme for occurrence of ultimate concerns in patients (N=6), including code definition, variation within code and exemplary quotation.

Ultimate concern	Code	Sub-code	Definition code	Variation within Code	Example
Meaninglessness	Cosmic Meaning			Being fatalistic	*"I wanted to prove something to myself in the sense of 'OK, I'll go and then I drop dead, then that's how it is, but then I know it in any case' - something like that." (P6)*
Isolation	Experienced Loneliness/Isolation		Patients face (increasingly more) isolation from others and already experience loneliness. The separation occurs, for example, due to the illness, the loss of the partner, or interpersonal conflicts. Moreover, due to the experienced loneliness (and also lack of attention), patients are disappointed in existing social contacts.	Being lonely due to the loss of the partner	*"And now, now that my husband has died, before the operation [silence] [...]." (P1)*
				Increasing isolation	*"[...] see, you come home, and you have lost everything. Nobody comes to look after you anymore." (P3)*
				Being lonely	*"Yes, I am always alone. Night and day you are alone." (P1)*
				Conflicts with family members	*"And my eldest son, he does not come all week - busy with music. Yes, that's how it is! [empathically emphasised towards the other person (the person in question) in the room] My daughter-in-law does not come at all. I have a little argument with her [...]." (P1)*
				Lack of attention	*"Yes, so in particular being alone and the lack of attention and lack of people around you makes it much harder now?" (Interviewer) - "Yes, and I never get a visit, no. I have six brothers, four brothers, and I have one sister who died then. They never come either. So, the family is not coming." (P1).*
				Being disappointed in existing social contacts	*"My son? I don't get any support from him. Otherwise, I have no one else. And I think that's a shame." (P1)*
	Fear of Loneliness/Isolation		Patients have a need for social contacts and fear isolation/loneliness. They are not facing loneliness yet and try to prevent becoming lonely.	Fear of being isolated	*"Then I am in [name of city], my children in [name of another city] and, and I don't like that at all." (P3)*
				Need for social contacts	*"[...] but when I went well there was no one there and then I shouted, 'I am awake' [...]" (P4)*
				Fear loss of contacts	*"I spoke to my surroundings that I can behave oddly for a year and that includes things like that and it doesn't have to be made a big deal out of it. [...] At first, I only got half a year. I said 'that's not enough'." (P6)*
				Fear of stigmatisation	*"And when you got somewhere, everyone asked: 'Gosh, how are you?' Oh god, you know, yes. I experienced it like that."(P2) - "So the fact for yourself that you were taking medication and the fact that other people also saw you as a heart patient, a kind of stamp, that you thought 'oh, it's different'?"(Interviewer) - "Yes, that made me a little depressed." (P2)*
				Patients are aware of the possibility of dying and are afraid of facing death alone.	*"I have a sister; I have to warn someone in the family." (P6)*

E.2. Professionals' Extended Coding Scheme

Extended coding scheme for the occurrence of ultimate concerns in interviews with professionals (N=6), including code definition, variation within code and exemplary quotation.

Theme	Code	Sub-code	Definition code	Variation within code	Example
Death	Confrontation with Severe Illness	Confrontation with Physical omplaints	Professionals indicate that patients have to deal with severe pain and possible other complications/side effects as a consequence of the open-heart surgery	Pain	*"Pain from the sternum, because the sternum was completely loose [...] that is actually the worst pain that people have" (Hart 2)*
				Other complaints	*"You see other patients that they do get a delirious picture and that they get a respiratory infection or pneumonia. You often still see AF (Atrial fibrillation), and arrhythmias are also common postoperatively. (Hart2)*
				Experience symptoms	*"Well, I think it's a frightening experience" (Hart 1)* *That must then also be treated again, so these are often setbacks for people" (Heart 2)*
		Need to take Medication	Professionals provide insights that patients are confronted with the need to take medication due to illness/surgery or complaints.		*"They have to take their pills." (Cardio 1)*
	Confrontation with own Death	Awareness of own Mortality	Professionals provide information that patients are concerned/confronted with the likelihood of death.	Thinking about death	*"Because the open-heart surgery sound and is also a severe operation with a long recovery, and it is sometimes very unknown to people, and then they imagine that people have to be brought back to life by resuscitation, as in earlier times." (Heart 2)*
				Awareness of survival	*"and when they come back they are actually already very enthusiastic about 'hey you here, too?!' and ... yes, kind of - do I recognise him like 'you see, I'm here again' or 'I made it'." (Heart 2)*
				Near-death experience through resuscitation	*"If you really have a resuscitation or images that those people have been a little further - that they have been really ill, that they really left before death [...]" (Hart 2)*
		Awareness of natural decay	Professionals provide insights that patients are confronted with (and aware of) the process of ageing and its (ultimately fatal) consequences.	Patients are aware of getting old	*"Yes, look, an older person who has calcified heart valves, which is purely an issue of aging, accepts that much easier in the sense of: "yes... that's just wear and tear"." (Cardio 1)*
				Consequences of getting old	*"[The group here] is just a bit older and therefore needs a little longer to recover." (Heart 1)*
	Lack of Safety		Professionals provide information that patients are confronted with the fact that the world is an unfair and unsafe place, where they have become ill despite their efforts and also have no certainty that a life-threatening event will not happen again.	Outrage at the onset of the disease	*"And for a very large group of patients, it is also outrage: 'I have always practiced; I have never smoked, and I have always exercised. Now I am 50 years old and still get it.'" (Fysio1)*
				Uncertainty whether life-threatening event occurs again	*Patient: "Can it happen to me again or have am I now disabled for the rest of my life? (Cardio 1)*

(table continues)

E.2. Professionals' Extended Coding Scheme (continued)

Extended coding scheme for the occurrence of ultimate concerns in interviews with professionals (N=6), including code definition, variation within code and exemplary quotation.

Theme	Code	Sub-code	Definition code	Variation within code	Example
Death	Fear of unknown due to a lack of knowledge		Professionals indicate that patients are afraid of the unknown and consequently experience uncertainty due to a lack of knowledge. This uncertainty is also demonstrated by the patients' need for information. The lack of knowledge relates to medical procedure in general and more specifically regarding the medication.	Fear of unknown	*"Yes, a certain fear of the unknown. What is going to happen? And do I get out of the operation well?"*
				Need for information regarding medical procedure	*"Look, people who get a by-pass operation would like to know some things like, "is something being taken out of my legs? or "where do you get the new material from?" When they get a new valve, they want to know things like: "Do I get a pig valve, or do I get a metal valve?" and "how does it go after this time?" And more complicated procedures are often difficult to explain because they can be better explained with images. So, they really have a great need, therefore. (Cardio 1)*
				Need for information regarding medication	*Patients tend to switch very quickly to questions regarding medication. That seems to be the most important thing for them. (VPK specialist)*
				Being afraid of drug usage	*Patient: "Yes, yes, let's stop there." (VPK specialist)*
Freedom	Experiencing Existential Guilt	Feelings of Guilt against Oneself for the "Unlived Life"	Professionals indicate that patients are confronted with illness-related limitations in their daily life and consequently fail to live their life to their full/used potential. The awareness about it, even achieved by comparing with others, leads to feelings of guilt on account of an "unlived/unused life". It also manifests in patients' feelings of shame, frustration/disappointment in own abilities or regret for the decision to have had surgery.	Limitations everyday life	*"Well, of course, after that time there are limitations regarding the strain on the sternum and some things that people unwittingly do, although that's not beneficial."*
				Experience limitations	*"Is it very obstructing for those people in their lives? These complaints?" "Yes at a later stage that is very restrictive." (Cardio 1)*
				Comparison with others	*Or you think "gosh, he's older than me and he can, well I say nothing." A lot of people do that. (Heart 2)*
				Regret	*"Yes, there are people who say, "if only I had never done it." (Heart2)*
		Feelings of Guilt towards Others	Patients experience feelings of guilt towards others, especially towards their partners, as they are (negatively) affected by their illness, too.	Worry about relatives	*"Who will take care of the partner or who will take care of me when I get home, and it won't work out yet?" (Cardio 1)*
	Avoiding taking Responsibility to make Decisions	Displacement of Responsibilities	Professionals provide insights that patients avoid making their own decisions by shifting their responsibilities upon others. Not only do they shift their responsibility to the significant others, but also trust experts and informal caregivers blindly, even when it comes to medication management.	Blind trust in professionals and informal caregivers	*"An example is a patient who comes to the clinic, and the doctor says: "Everything is fine". (Patient:) "Look, I didn't say I had chest pain because the doctor said everything was fine" (VPK specialist)*
				Displacement of responsibility to partner	*And that is something I see very often in the cardiac rehabilitation clinic. An example: "Have you got your medication now?" – (Patient:) "Yes, woman? Do we have medication?" - So, the woman manages the medication usage. (VPK Specialist)*

(table continues)

E.2. Professionals' Extended Coding Scheme (continued)

Extended coding scheme for the occurrence of ultimate concerns in interviews with professionals (N=6), including code definition, variation within code and exemplary quotation.

Theme	Code	Sub-code	Definition code	Variety within code	Example
		Avoidance of Autonomous Behaviour	Although patient's physical are able to take responsibility for their lives and to make the right decision for their recovery, *they actively refuse to take the necessary steps* due to insecurities. Those insecurities are closely related to the fear of unknown, respectively the lack of knowledge, and inhibit the patients' decision-making process. The insecurities express themselves, for example, in the patients' fear of movement, the fear to take medication or the need for confirmation.	Lack of self-security	*"They just have to build trust in their bodies again, because they previously ran around with a ticking time bomb." (Heart 1)*
				Need for confirmation	*"It is often about confirming what people want to heart" [...] So people often find it difficult to say "what can and what can`t"?" (Heart 2)*
				Overly cautious	*"And I think sometimes people have something like "yes, but I have it with my heart, so I have to be careful" (heart 2)*
				Overly alert on bodily signals	*"Some people focus very much on their heartbeat: "Oh god, I wasn't allowed to go beyond 100." They never thought about their heartbeat before, whether it was 130 or 180 when they did something. Now they are getting too focused on it and that's not good either. You shouldn't think: "Oh, what is my this, oh what is my that..". (Fysio1)*
				Safety behaviour (avoiding moving at all)	*"[...] then they often choose the safe way. Then they don't do anything anymore. Then nothing goes wrong." (Heart 2).*
				Fear of movement postoperative	*"You can say: 'I have to have an operation in two weeks and until then I will sit two weeks" (Heart 2)*
				Avoidance to take medication	*Patient: "Yes, yes, let's stop there." (VPK specialist)*
	Loss of Autonomy	Being Dependent	Professionals indicate that patients feeling helplessness/powerless are dependent on others, whereby they experience a loss of autonomy and also their freedom to make independent choices.	Being dependent on family members /strangers	*"Um, that they often need extra help. Informal care is not always available. Practical things like transport and so [...] or just to manage the household - shopping for groceries and things like that." (Cardio 1)*
				Being helpless/powerless	*"Who will take care of the partner or who will take care of me when I get home, and it won't work out yet?" (Cardio 1)*
		Being Patronised	Professionals provide insight that patients experience a loss of autonomy through the patronage of concerned relatives.		*But the caregivers think: "I have to do everything," and "dad can't do this," and "my mom can't do this". (VPK specialist)*
		Lack of Control	Professionals indicate that patients experience a lack of control regarding the timing of the operation and their hospital stay.	Need to wait for operation	*"And then there is still sometime between that moment and the actual operation. Not very long; it all goes very quickly, but I think it still takes one or three weeks." (Cardio 1)*
				Patients are unable to decide things by themselves	*"A patient with persistent chest pain is not allowed to go home, of course." (hart 2)*

(table continues)

E.2. Professionals' Extended Coding Scheme (continued)

Extended coding scheme for the occurrence of ultimate concerns in interviews with professionals (N=6), including code definition, variation within code and exemplary quotation.

Theme	Code	Sub-code	Definition code	Variation within code	Example
Meaninglessness	Experiencing an Existential Crisis		Due to the open-heart surgery, patients question their lives, whether it has meaning, purpose, or value. (In this case also under the guidance of professionals as preparation for the possible shock).		*And then comes a moment when you have had the operation, the post-operative recovery, you have had your rehabilitation, and then?* *What should your life look like then? What do you want to be able to do again? And should it stay as it was? Or can it be a little less?* *What decisions do you want to make? What will you do with your lifestyle? How is your lifestyle at the moment? Are there any factors that can affect you? Maybe hm, to make people think about it once again - we often do this in the clinical phase: This has happened now, you are now a heart patient, you have to take medication but how do you want to ensure that you have as few risks as possible? You cannot prevent risks, but how can you organise your life? How do you deal with stress? How healthy do you want to eat? Are you a smoker? How controlled are your values? Can you do anything with it? And what is your effort? (Heart 2)*
	Loss of Meaning		Professionals indicate that patients experience a loss of meaning and purpose.		*Yes, because at home you basically have nothing [...]" (Heart 1)*
Isolation	Need for Social Contacts		Professionals give insights that patients have a need for social contacts and that they experience a separation from others because of their illness and the consequences of it.		*"What can you do then, what you no longer do now? What do you really miss so much? And these are often things that are shared with others, and that is what they should have." (Heart 2)*

Appendix F: Diagnostic Criteria DSM-5

DSM-5 Criteria for Major Depressive Disorder (F32)
A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure. 1. Depressed mood 2. Diminished interest or pleasure 3. Weight loss or weight gain 4. Insomnia or hypersomnia 5. Psychomotor agitation or retardation 6. Fatigue or loss of energy 7. Feelings of worthlessness or guilt 8. Diminished ability to think or concentrate 9. Recurrent thoughts of death, suicidal ideation, or suicide attempt **B.** The symptoms cause clinically significant distress or impairment (e.g. social, occupational) **C.** The episode is not attributable to the psychological effects of a substance or to another medical condition. **D.** The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified and unspecified schizophrenia spectrum and other psychotic disorders **E.** There has never been a manic episode or a hypomanic episode.
Data obtained from the diagnostic and statistical manual of mental disorders, 5th ed., (APA, 2013a)

DSM5 Criteria for Unspecified Depressive Disorder (F32.9)
With *anxious distress* as specifiers for Depressive Disorder Anxious distress is defined as the presence of at least two of the following symptoms during the majority of a major depressive episode or persistent depressive disorder (dysthymia): 1. Feeling keyed up or tense. 2. Feeling restless. 3. Difficulty concentrating because of worry. 4. Fear that something awful may happen. 5. Feeling that the individual might lose control of himself or herself. Specify current severity: **Mild**: Two symptoms. **Moderate**: Three symptoms. **Moderate-severe**: Four symptoms. **Severe**: Four of five symptoms and with motor agitation.
Data obtained from the diagnostic and statistical manual of mental disorders, 5th ed., (APA, 2013a)

DSM-5 Criteria for Generalised Anxiety Disorder (F41.1)
A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance). **B.** The individual finds it difficult to control the worry C. The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms have been present for more day than not for the past 6 months): 1. Restlessness or feeling keyed up or on edge. 2. Being easily fatigued. 3. Difficulty concentrating or mind going blank 4. Irritability 5. Muscle tension 6. Sleep disturbance (difficult falling or stay asleep, or restless, unsatisfying sleep) **D.** The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. **E.** The disturbance is not attributable to the physiological effects of a substance or another medical condition. The disturbance is not better explained by another mental disorder, contamination or other obsessions in obsessive-compulsive disorder, separation from attachment figures in separation anxiety disorder, reminders of traumatic events in posttraumatic stress disorder, gaining weight in anorexia nervosa, physical complaints in somatic symptom disorder, perceived appearance flaws in body dysmorphic disorder, having a serious illness in illness anxiety disorder, or the content of delusional beliefs in schizophrenia or delusional disorder).
Data obtained from the Diagnostic and Statistical Manual of Mental Disorders, 5th ed., (APA, 2013b)