# Readiness for the end of Life:
# Importance of Death Anxiety, Assessment and Interventions in Cancer Care

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**Content**

List of Figures VIII

1 Summaries 1

1.1 English Summary 1

1.2 Zusammenfassung 2

2 Introduction 5

2.1 Epidemiology 5

2.2 Psychological challenges in cancer care 5

2.2.1 Fear of cancer recurrence or progression 6

2.2.2 Death anxiety 8

2.2.3 Impact on health behavior 9

2.2.4 Terror management health model for behavior health promotion 10

2.3 End-of-life conversations 12

2.3.1 Challenges 14

2.3.2 Possibilities 15

3 Dissertation proposal 17

3.1 Relevance and background 17

3.2 Objective and research question 18

4 Summary of Studies 20

4.1 Study I: Death anxiety and fear of cancer recurrence 20

4.2 Study II: Need for advance care planning in a hospital setting 22

4.3 Study III: The Readiness for End-of-Life Conversations Scale 24

4.4 Study IV: Validation of the Readiness for End-of-Life Conversations Scale 26

4.5 Study V: Online intervention to change readiness for end-of-life conversations 28

5 General discussions and implications 30

5.1 Limitations 31

5.2 Strengths 34

5.2.1 General strengths 34

5.2.2 Study-specific strengths 35

5.3 Implications for future research 37

5.4 Implications for people affected by cancer 39

5.5 Conclusion 40

6 References 41

7 Appendix A: Studies 56

7.1 Study I 56

7.2 Study II 67

7.3 Study III 114

7.4 Study IV 129

7.5 Study V 139

8 Appendix B: Curriculum Vitae 177

9 Appendix C: Contribution to science 179

10 Appendix E: Declaration of honesty 181

11 Appendix F: Percentage distribution 182

## List of Figures

Figure 1. Conceptual model for FCR (Simonelli et al., 2017) 7
Figure 2. Terror management process model (Goldenberg & Arndt, 2008) 9
Figure 3. Terror management health model (Goldenberg & Arndt, 2008) 11
Figure 4. Inclusion of dissertation project in terror management health model. 19

# 1 Summaries

## 1.1 English Summary

In psychological research, death anxiety is discussed as a potential restrictive factor on psychological well-being often experienced by cancer patients. One important consequence of death anxiety is engagement in maladaptive health behavior to avoid thoughts and emotional distress regarding the end of life. This dissertation project focused on the relevance of death anxiety in addition to the development of assessments and interventions to overcome personal and organizational barriers and facilitate engagement in adaptive health behavior.

At first, the structural relationship between death anxiety and fear of cancer recurrence or progression was psychometrically analyzed to interpret relevance of death anxiety for cancer patients (Study I). For a predominantly female sample (*N* = 121), death anxiety explained the majority of shared variance to fear of cancer recurrence or progression and could therefore be interpreted as the general factor.

The general impact of death anxiety emphasizes the need to address maladaptive health behavior due to death distress. As such, avoidance of end-of-life (EOL) conversations due to death anxiety can result in overtreatment and superfluous intensive care in addition to psychological distress for patients as well as family members. Identification of patients in need of EOL conversations (e.g., advance care planning) can be facilitated by screening for distressed patients and patients who wish to engage. Therefore, a feasible screening tool for uncomplicated assessment in a hospital setting was developed (*N* = 92) and cut-off criteria evaluated (*N* = 201) in a mixed sample of cancer patients (Study II). External interpretation of need was based on death anxiety distress and combined with subjective expression of need. The screening instrument represents the first tool with excellent sensitivity and good specificity in a hospital setting.

When assessing need for advance care planning, subjective expression was unrelated to external assessment and highlighted the need to acknowledge personal readiness for EOL conversations. In two successive studies (Study III), we designed and validated a questionnaire that could further be used to assess readiness for EOL conversations, not only in a community setting (*N* = 349) but also in a sample of cancer patients (*N* = 84). Factor structure and psychometric properties for cancer patients (*N* = 295) were also supported in a hospital setting (Study IV).

After successful development of a measurement tool for EOL conversations, the effect of two interventions on readiness for EOL conversations was explored in a randomized controlled trial (Study V). The first achievement was successful adaptation of both interventions to an online setting to facilitate future application and accessibility. Also, both interventions ($N = 118$) succeeded in increasing readiness for EOL conversations. Secondary analyses also provided first insights into intervention effects on death anxiety, fear of cancer recurrence or progression, and gratitude. Long-term benefits are indicated and discussed in terms of practical applications as well as potential avenues for future research.

Overall, the study results emphasize a) the general role of death anxiety for cancer patients; b) the possibility to assess need for advance care planning in hospital settings, if death-related distress and subjective desire or readiness for conversations are combined; c) the possibility to assess readiness for EOL conversations in a community setting and for cancer patients; and d) the modifiability of readiness in cancer patients with two online interventions that also impact the experiences of death anxiety, fear of cancer recurrence or progression, and gratitude. This dissertation project not only emphasizes the importance of death anxiety in cancer care; it also highlights the need to address readiness for health behavior and provides first solutions to facilitate engagement.

## 1.2 Zusammenfassung

In bisherigen Studien wird der zugrunde liegende Einfluss von Angst vor Tod und Sterben (engl. death anxiety, DA) auf psychologisches Wohlbefinden diskutiert. In der onkologischen Praxis berichten auch Krebspatient:innen zu verschiedenen Zeitpunkten im Verlaufe der Erkrankung von entsprechenden Beeinträchtigungen. Zusätzlich wurde in verschiedenen Bereichen der Einfluss von DA auf gesundheitsbezogenes Verhalten festgestellt. Neben Motivation kann DA dementsprechend auch zu Vermeidung von Verhalten führen, welches das Erleben von DA in den Vordergrund rücken und in emotionaler Belastung resultieren könnte. So zählen auch Gespräche über das Lebensende zu langfristig vorteilhaftem Gesundheitsverhalten, welches durch Vermeidung betroffen ist. Die vorliegende Dissertation untersucht die Relevanz von DA für Krebspatient:innen, entwickelt Instrumente zur Erfassung von Bedarf und Bereitschaft für Gespräche über das Lebensende und berichtet erste Ergebnisse zweier Interventionen auf die Bereitschaft, über das Lebensende ins Gespräch zu kommen. Außerdem werden erstmals Erkenntnisse zu Veränderungen von DA, Angst, dass der Krebs wiederkommen oder sich die Prognose verschlechtern könnte (engl. fear of cancer recurrence or progression, FCR) und Dankbarkeit durch die Teilnahme an den Interventionen erfasst.

Die strukturelle Beziehung zwischen DA und FCR wurde in einer ersten Studie (Study I) für eine Stichprobe von mehrheitlich an Krebs erkrankten Frauen ($N = 121$) untersucht. Die

überwiegende Varianzaufklärung durch einen allgemeinen Faktor DA bestätigt die Relevanz für Krebspatient:innen.

Durch die Ergebnisse der ersten Studie verdeutlicht sich der Einfluss von DA auf Krebspatient:innen und legt einen starken Einfluss auf gesundheitsbezogenes Verhalten nahe. Die Vermeidung von Gesprächen über das Lebensende kann langfristig zu längerer und intensiverer medizinischer Versorgung führen als sich das Patient:innen gewünscht hätten. Neben dem psychologischen Wohlbefinden der Patient:innen kann dies auch die Angehörigen nachhaltig beeinträchtigen. Aus diesem Grund erscheint es notwendig, entsprechend belastete Patient:innen frühzeitig zu identifizieren und Gesprächsangebote zu bereiten. Eine bewährte Möglichkeit, belastete und bedürftige Patient:innen zu erkennen, findet sich in Screening Instrumenten. Diese erleichtern es, krankenhausinterne, sowie persönliche Barrieren zu umgehen und Gespräche zu initiieren. Dementsprechend wurde das erste Screening Instrument zur Erfassung von Bedarf an Gesprächen über das Lebensende mit der Möglichkeit, eine Patient:innenverfügung im Gespräch (engl. advance care planning) zu erstellen, entwickelt (Study II). Die Evaluierung resultierte in ersten Vorschlägen für Initiierungs-Kriterien. Zusätzlich wurde deutlich, dass eine Kombination von Bedarf und Bereitschaft in der Erfassung notwendig ist, da diese zeitweise unabhängig voneinander bestehen können.

Während ein Screening Instrument ausschließlich der Erfassung und Vermittlung dient, können Fragebögen sowohl für die Erfassung des Status-Quo, als auch für die Messung von Veränderungen genutzt werden. Folglich wurde ein Fragebogen entwickelt (Studie III), der die Bereitschaft für Gespräche über das Lebensende in der Allgemeinbevölkerung ($N = 349$) erfassen sollte. Erste Überträge in einer Stichprobe von Krebspatient:innen ($N = 84$) konnten in einer weiteren Studie ($N = 295$) psychometrisch bestätigt werden (Study IV).

Der entwickelte Fragebogen konnte daraufhin in einer vergleichenden Interventionsstudie (Study V) eingesetzt werden. Zwei Interventionen wurden für ein online-Setting adaptiert und die Effekte in einem randomisiert-kontrolliertem Design untersucht ($N = 118$). Beide Interventionen waren erfolgreich in der Steigerung der Bereitschaft, an Gesprächen über das Lebensende teilzunehmen. Des Weiteren zeigten sich in Sekundäranalysen erste Befunde zu Langzeit-Auswirkungen beider Interventionen auf das Erleben von DA, FCR und Dankbarkeit bei Krebspatient:innen.

Insgesamt lässt sich durch die Ergebnisse dieser Dissertation a) die Relevanz von DA für Krebspatient:innen bestätigen, b) ein erstes Screening-Instrument zur Erfassung von Bedarf und subjektiver Bereitschaft für Gespräche über das Lebensende mit Erstellen einer Patient:innenverfügung im Krankenhaus bereitstellen, c) ein Fragebogen zur Erfassung der

Bereitschaft für Gespräche am Lebensende zuverlässig in der Allgemeinbevölkerung und für Krebspatient:innen einsetzen und d) zwei online Interventionen zur Steigerung der Bereitschaft, über das Lebensende zu reden nutzen, welche ebenfalls DA, FCR und Dankbarkeitserleben beeinflussen. Diese Doktorarbeit verdeutlicht nicht nur den Einfluss von DA auf verschiedene Aspekte in der Gesundheitsversorgung Krebsbetroffener. Zusätzlich wird die Bereitschaft für Gesundheitsverhalten hervorgehoben und entsprechende Methoden sowie Interventionen zur Veränderung und Motivation von langfristig hilfreichem Verhalten bereitgestellt.

# 2 Introduction

## 2.1 Epidemiology

Epidemiological assessment of changes in national and international cancer diagnoses, survivorship and mortality is essential for primary and secondary prevention of cancer (Robert Koch-Institut, 2021). Variables of assessment include incidences, comparison of cancer types, effects of socio-demographic variables (e.g., age and gender), and mortality risk. The International Agency for Research on Cancer (IARC) provides international comparisons of data and offers an overview of changes in epidemiology, including predictions for the following years. Additionally, the German Center for Cancer Registry evaluates national epidemiological data and presents results for interpretation of health care needs in cancer care (Robert Koch-Institut, 2021).

When focusing on incidences of cancer, Germany was ranked fifth-highest worldwide in 2020 (International Agency for Research on Cancer, 2020). Incidences in 2070 are expected to double, with more than 30 million new cancer cases every year (Soerjomataram & Bray, 2021). This trend is partially attributable to the aging population, but it is also explained by continuously decreasing mortality rates resulting from improvements in treatment (Robert Koch-Institut, 2021). For Germany (Statistisches Bundesamt, 2020), it is evident that cancer remains the second-biggest cause of death (23.5%), closely following cardiovascular disease (34.3%). A German’s likelihood of one cancer diagnosis in life is 49.3%, whereas the risk of dying from cancer is 24.5%. For 2022 (Robert Koch-Institut, 2021), more than 500,000 cases of cancer were prognosed, and more than 200,000 cases of cancer-related deaths at age 77 were projected for females, and 75 for males. This discrepancy between incidence and mortality results in higher survival rates after the first cancer diagnosis and elevates the necessity to cope with chronic illness. It further increases chances of second cancer diagnoses over the trajectory of cancer survivorship (Bischoff, 2013). Cancer survivors are confronted with constant adaptation processes and are challenged to cope with physical changes as well as psychological side effects.

## 2.2 Psychological challenges in cancer care

When people are diagnosed with cancer, they are directly confronted with the worrisome and stressful possibility of their own death (Abdollahi et al., 2021; Emanuel et al., 2004; Soleimani et al., 2017; Solomon et al., 2000). Negative psychological consequences of diagnosis, treatment and even survivorship include stress, anxiety (Roth & Massie, 2007), feelings of social isolation (Tan & Karabulutlu, 2005) and depression (Linden et al., 2012). More than 80% of German patients specifically report fear of recurrence or progression of cancer (Koch et al., 2014). The development of a second cancer site or metastases often signals a severe diagnosis and triggers fear of potential pain, necessary treatment and death (Koch-Gallenkamp et al., 2016). Consequently, fear of cancer recurrence, intensifies experience of death anxiety (Tang et al., 2011)

### 2.2.1 Fear of cancer recurrence or progression

For many years, researchers struggled to define a concept of fear of cancer recurrence and progression (Sharpe et al., 2018). In 2016, an expert panel decided upon a definition of "[f]ear, worry or concern relating to the possibility that cancer will come back or progress" (Lebel et al., 2016); this constellation of emotions is generally (and hereinafter) referred to as FCR. Although patients with anxiety disorders tend to fear situations that are highly unlikely, cancer patients are at the disadvantage that the threat of recurrence is not only real but often realistic as well (Curran et al., 2017). The experience of FCR is of persistent psychological impact for cancer patients (Simonelli et al., 2017). It can promote adaptive coping strategies, motivate treatment adherence and compliance with health behavior if FCR levels are low. High levels of FCR, however, have been found to impact quality of life and even increase risk for the development of psychological disorders (Simonelli et al., 2017). Key aspects include preoccupation with the possibility of cancer recurrence or progression, engagement in maladaptive coping strategies, clinically significant distress experience, limitation of daily functioning, and inability to plan ahead (Lebel et al., 2016). It can occur at any time and is often triggered by interactions or exposures to situations that are related to cancer. For example, conversations about cancer, media coverage, health care appointments and procedures, physical memories such as pain or fatigue, and anniversaries of diagnosis can all trigger FCR (Crist & Grunfeld, 2013; Gill et al., 2004; Koch et al., 2013; Simard & Savard, 2009). Also, the development of a second cancer site or metastases is often a signal of a severe diagnosis, possible pain and death (Koch-Gallenkamp et al., 2016). Researchers are undecided as to whether FCR experience is stable over survivorship trajectory, but they generally agree that it impacts all areas of quality of life and well-being, independent of cancer type (Simonelli et al., 2017).

In a conceptual model of key factors influencing FCR (Simonelli et al., 2017), moderating aspects such as social context, socio-demographical components or engagement in maladaptive defense mechanisms are connected to individual appraisal and processing of emotions and cognitions (Figure 1). Overall, individual representation of cues as threat are expected to trigger coping styles that may have already been established prior to cancer diagnosis (Lee-Jones et al., 1997). Maladaptive information processing (Butow et al., 2015), can result in behaviors such as hypervigilance and misinterpretation of symptoms, overutilization or avoidance of medical care, or related health behavior. Additionally, social context can facilitate adaptive cognitive processing or may also present a barrier that increases avoidance and experience of negative effects when patients are confronted with cues (Lepore, 2001). In contrast, if uncertainty or trigger cues are interpreted as natural and related to opportunities, this appraisal poses as protective factor facilitates meaning making or adaptive coping styles (Mishel, 1990).

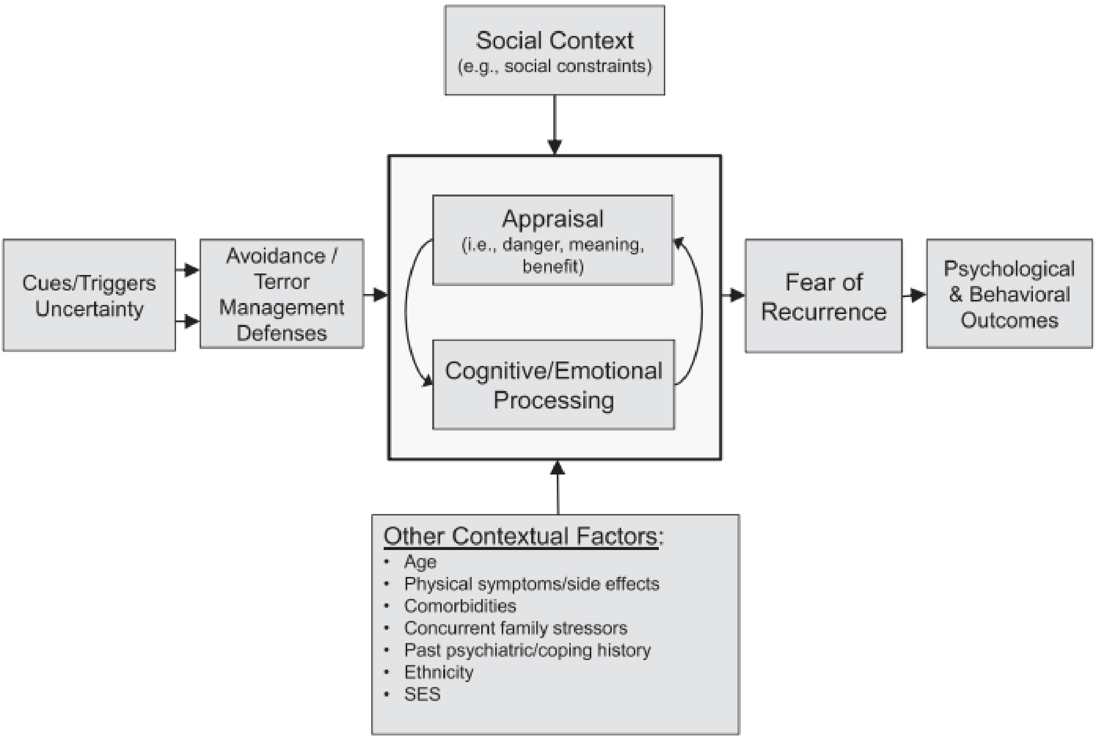

*Figure 1.* Conceptual model for FCR (Simonelli et al., 2017)

Engagement in, or avoidance of, psychological or health behavior outcomes is explicable by terror management theory (TMT, Pyszczynski et al., 1999). TMT proposes that humans engage in psychological defense mechanisms that prevent the experience of constant terror because they desire prolonged life but are subconsciously aware of their limited lifespan. These defenses can either promote health behavior or facilitate avoidance behavior to reduce the experience of death anxiety. When applying TMT to cancer, cancer cues can easily be interpreted as activators and reminders of death that increase salience of mortality and thus trigger defensive coping behavior. The inclusion of TMT defenses in FCR conceptualization emphasizes the overlap of both constructs and the importance of closer inspection. When assessing qualitative findings, FCR is described (and often explicitly identified) as death-related fear (Sharpe et al., 2018). Notably, intense FCR has been found to increase worries about death and dying among breast cancer patients in particular (Thewes et al., 2016), while cancer in general is associated with death, trauma or fear (Robb et al., 2014). It is hypothesized that the concepts of FCR and death anxiety are strongly connected and that a correlation does not fully represent the impact of death anxiety on FCR (Cesario et al., 2010). Understanding the occurrence of death anxiety and defense mechanisms may improve understanding of FCR. Ultimately, interventions to reduce one or both stressors (i.e., death anxiety and FCR) for cancer patients can be improved and adapted accordingly. The first objective of this dissertation is a psychometric assessment of the relationship between FCR and death anxiety.

### 2.2.2 Death anxiety

The term “death anxiety” refers to excessive existential fear of death, the dying process and dying without leaving a lasting impression. It derives from humans’ biological drive for self-preservation and it can also affect thoughts, emotional reactions and behaviors that may appear unrelated to death (Greenberg et al., 1997). As introduced above, TMT proposes a dual defense mechanism (Figure 2) for coping with death anxiety (Pyszczynski et al., 1999): Situations or social interactions that trigger thoughts of death in individuals are addressed either consciously (*proximal defenses*) or unconsciously (*distal defenses*).

The purpose of proximal defenses lies within immediate removal of conscious thoughts of death from focal attention by suppressing such thoughts from working memory, avoiding exposure to death-related themes, engaging in cognitive bias, or through simple distraction and denial. Anticipation of exposure to, and experience of, negative affective responses triggers an automatic reaction of avoidance that is based on rational, threat-focused skills. Rationalization includes denial of risk factors, validity or importance of assessment, whereas cognitive biases maintain an illusion of objectivity in the appraisal and interpretation of given information. Proximal defenses are activated only if death-related themes enter consciousness, for example, directly after mortality is made salient (e.g., cancer diagnosis) and may be mediated by negative affect. They reduce the accessibility of thoughts related to one’s own death and dying in order to reduce anxiety (Goldenberg & Arndt, 2008).

Interestingly, if proximal defenses are successful and attention is a) focused elsewhere, b) cognitive load is high, or c) the topic of death is introduced indirectly, death thought accessibility increases on a subliminal level. Death anxiety then is represented through specific alternative fears and affects attitudes, stereotypes or self-esteem. Activation of distal defenses supports coping with death threat by focusing on pursuit of self-esteem, cultivating worldview and maintaining physical attributes aligned with personal values (creatureliness). Cultivating worldview creates buffers against anxiety by providing structure, stability and security. It creates a sense of personal value in hope of transcendence. The interaction of both mechanisms suggests a flexible reaction to death threat that is dependent on context and individual factors (Goldenberg & Arndt, 2008).

People in general are interested in protecting their health and living longer (Goldenberg & Arndt, 2008). When applying TMT defenses as filter processes in the experience of FCR (Simonelli et al., 2017) or death anxiety and consequent health behavior, self-regulatory processes are used to reduce physical and psychological distress. Paradoxically, the chosen behaviors may even emphasize mortality salience (e.g., overuse of health care) or activate defensive responses that decrease the likelihood of preferred health care (e.g., avoidance of advance care planning).

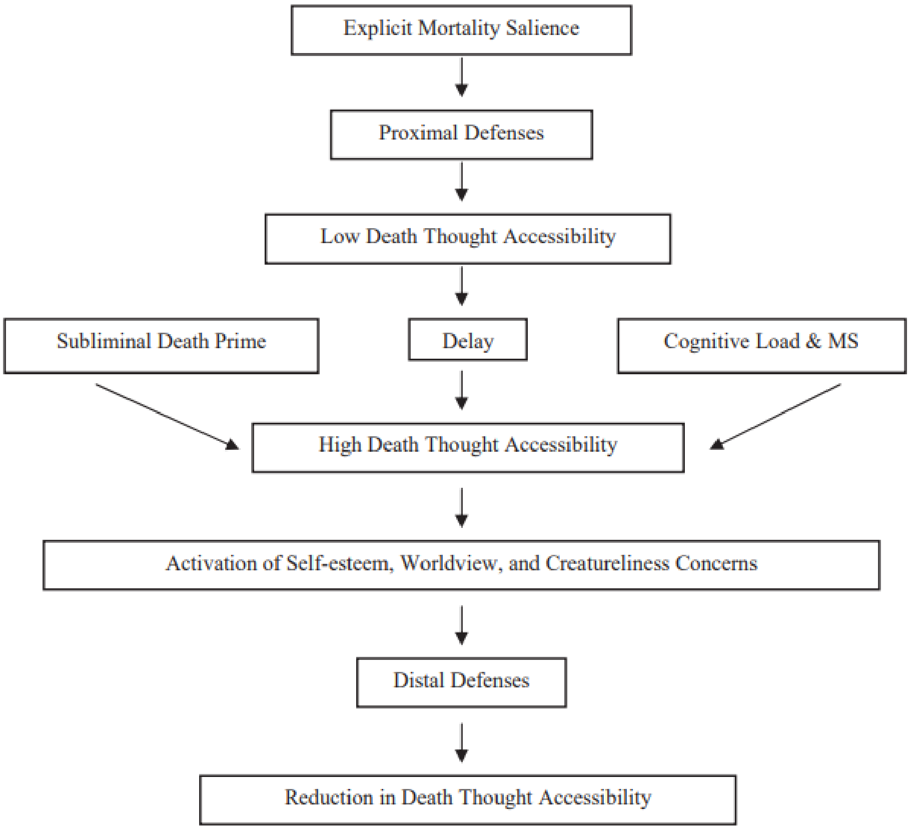

*Figure 2.* Terror management process model (Goldenberg & Arndt, 2008)

### 2.2.3 Impact on health behavior

In addition to negative psychological outcomes, death anxiety and FCR may also impact health behavior that is related to medical care and that results in avoidance of doctor’s appointments or neglect of beneficial health behavior. Although Kasl and Cobb (1966) originally distinguished three types of behavior related to illness. They described the intent for prevention or detection of illness as *health behavior*. The definition of health (e.g., diagnosis) or remedy (e.g., corrective action) was described as *illness behavior*. However, actions in purpose of getting well (e.g., resting) were simply described as *sick-role behavior*. All three types are of importance to cancer patients. After the first year of successful cancer treatment, patients may focus on prevention or detection, remedy previously harmful behavior (e.g., smoking), or getting well after extensive side effects. They could further adapt new behavior for prevention of recurrence. Head and neck or lung cancer patients, for example, are specifically coached to reduce previous smoking habits (if applicable), whereas all patients are encouraged to increase physical activity and improve nutrition intake for symptom management and general risk reduction (Pinto & Trunzo, 2005). For the purpose of this dissertation, health behavior therefore combines all three definitions and generally refers to behavior that is related to physical or mental health.

When inspecting the impact of FCR and death anxiety on health behavior engagement or avoidance, higher FCR (for example) was related to both. Frequency of unscheduled control visits and breast self-examination increased, whereas utilization of mammograms or other cancer screening procedures was equally avoided and resulted in higher FCR experience (Thewes et al., 2012). This discrepancy in clear prediction of health-behavior avoidance or engagement is emphasized in a recent review by Reed et al. (2021) addressing FCR impact on health behaviors. Whereas some studies report improvements in nutrition intake, doctor’s appointments and screening procedures, others report increases in smoking, reduction of physical activity, avoidance of check-ups, or overly frequent use of primary care.

Regarding death anxiety experiences in community settings, health behavior intention is also negatively impacted: Higher levels of death anxiety have been associated with reduced active engagement in health care (Knight & Elfenbein, 1996). If mortality becomes salient and people view physicians as responsible to promote health care behavior, physicians may be required to initiate conversations about health care. Otherwise, engagement is likely to be avoided. Also, death anxiety experience increased dominant coping behaviors, which diverged along gender lines. Men avoided and reduced communication of emotional responses, whereas women expressed fear and sought assurance in information (Knight & Elfenbein, 1996).

### 2.2.4 Terror management health model for behavior health promotion

When applying TMT to health behavior intention, several basic assumptions for the terror management health model (TMHM) are proposed by Goldenberg and Arndt (2008). First, people’s assessment of health is motivated by individual health-oriented concerns. Specifically, self- and response efficacy predict motivation for exposure- or fear-avoidance health behaviors. If efficacy is high, people are motivated to engage in health behaviors that result in positive health outcomes. If efficacy is low, defenses are used to control fear. Second, motivation for behavior should be aligned with social norms, interpretation of integrity and cultural values. Third, consciousness of mortality salience moderates motivation and intention for health behavior.

If mortality becomes salient, people should be motivated to eliminate thoughts of death from their consciousness and engage in proximal defenses (Figure 3). The relationship of behavior and threat thereby moderates the response: If vulnerability to threat is perceived as high, threat avoidance and suppression of thoughts of death are effective in elimination. Moderators of engagement include appraisal of behavior as effective, active coping personalities and optimistic health beliefs. Focus on positive emotions, attributions and interpretations buffer against death anxiety and facilitate engagement in health behavior even though it is associated with risk. If an individual has previously been confronted with cancer, a reminder of skin cancer risk prior to sun exposure can facilitate adaptive health care behavior (e.g., applying sunscreen) and eliminate thoughts of death from their consciousness.

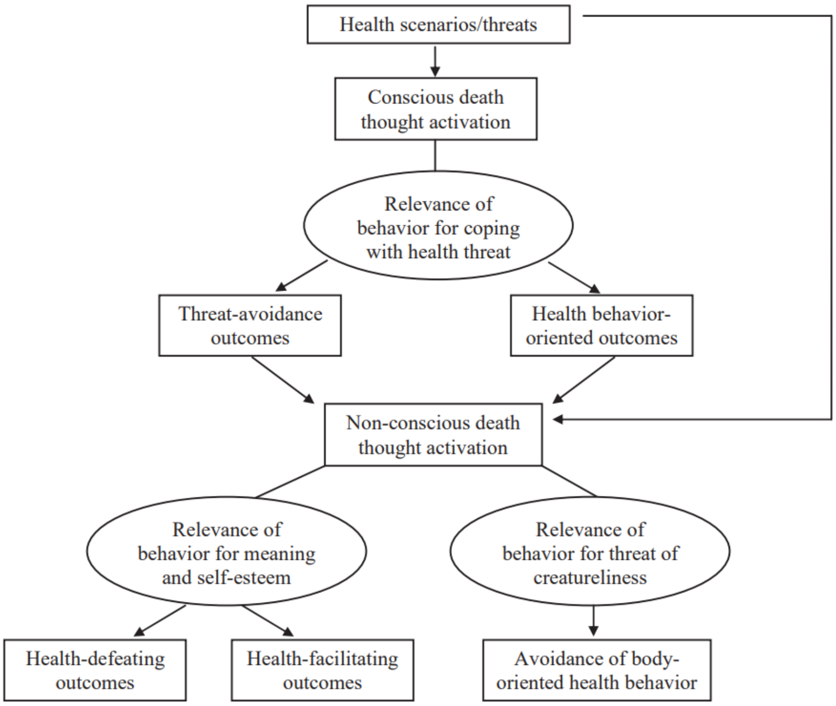

*Figure 3.* Terror management health model (Goldenberg & Arndt, 2008)

Reasons for, and examples of, mortality salience at a distal level include: first, impaired cognitive functioning after chemotherapy and radiation (Pendergrass et al., 2018), which reduces avoidance and suppression capacity. Second, termination of successful cancer treatment can result in decrease of death threat over time. Third, unconscious reminders of death threat may manifest as innocuous advertisements. For example, a shampoo commercial for strong hair growth may activate thoughts about loss of hair through chemotherapy in women. A relevant and efficient behavior might include purchase of said product and care of appearance. Although unaware of mortality salience, TMHM argues that cancer a patient's intention can focus on defense of personal values, perception and integrity to reduce the activation of thoughts of death (Goldenberg & Arndt, 2008). The motivation to maintain meaning and self-esteem can facilitate or inhibit health behavior. Therefore, it is not always necessary to directly target specific health implications, but rather to provide reasons for engagement that align with values — such as by appealing to the benefits of physical fitness in the case of people who value a healthy lifestyle. For breast cancer patients, death-thought accessibility increased when check-ups were framed as empowering, but patients' intent to attend check-ups regularly increased as well. Contrarily, avoidance was increased if only educational reasons for check-ups were provided under mortality salience (Goldenberg & Arndt, 2008). This example emphasizes the abstract pathway of subliminal activation of death threat, distal defenses and health behavior engagement. To offer an example of health-defeating outcomes, campaigns that label smoking as a deadly habit tend to activate — rather than prevent — smoking behavior among individuals who identify as smokers and who live in a culture where smoking behavior is accepted. Aside from meaning and self-esteem, Goldenberg and Arndt (2008) further discuss the possibility that confrontation with mortality salience prevents health-oriented behavior if physicality (creatureliness) is activated: Worry and discomfort during breast screening exam then may either prevent cancer patients from uptake or reduce duration of examination. Their study highlighted that avoidance intention stems not only from thoughts of death, but also from physical interaction while mortality salience is activated.

Overall, TMHM explains moderators to short-term agreement of health behavior and long-term avoidance when mortality salience is no longer a conscious threat. For cancer treatment and interventions that aim to increase the likelihood of adaptive health behavior, TMHM emphasizes awareness of individual interpretation, regulation processes, delay, and importance of personal values for engagement. For clinical practice, TMHM highlights the necessity of communication processes between patients and medical staff in order to address relevant moderators and facilitate long-term health behavior.

### 2.3 End-of-life conversations

Every health behavior that includes medical decisions initiates a shared decision-making process: Physicians provide necessary information and patients must consent treatment (Barry

& Edgman-Levitan, 2012). Because life expectancy is increased, society is focused on life-prolonging measures, even though every person must die eventually. Focusing on end-of-life (EOL) care during these conversations in shared decision-making is often interpreted as failure and is therefore avoided or postponed (Nogler, 2014; Wright et al., 2008). Based on the TMHM, avoidance of such conversations can be interpreted as a proximal defense that eliminates thoughts of death from a patient's consciousness. If EOL and death are appraised as taboo topics, continued avoidance of EOL conversations and focus on survival is in alignment with cultural worldview and therefore a logical health behavior outcome. Unsurprisingly, high levels of death avoidance are found to be related to less EOL planning. However, death avoidance loses relevance when informal discussions within families are practiced: People who engaged in informal EOL conversations within families were seven times more likely to also engage in EOL planning (Carr & Khodyakov, 2007).

Unfortunately, long-term avoidance can have negative consequences not only for the patient, but also for the family system. An obvious consequence is the avoidance of preparation for times of incapacity—for example, by conducting advance care directives (formal EOL planning). When the incidence of advance care directives was assessed, fewer than 50% of respondents reported having a living will (Hahn, 2003). Also, even when living wills exist, their effectiveness are questionable because often they are unclearly worded, irrelevant or inaccessible (Fagerlin & Schneider, 2004). Additionally, health care decisions are often delegated to family members or caretakers (Breen et al., 2001) who are seldom aware of documented wishes and are thus unable to provide details as to patients' specific medical preferences (Ditto et al., 2001); as a result, they often favor decisions that result in overtreatment (Coppola et al., 2001). Unexpected responsibility can then result in insecurity, isolation and emotional distress on the part of decision-makers, who may be pressured to make time-sensitive decisions when unprepared to do so, unaware of preferences, exposed to family conflict, and experiencing feelings of guilt (Dempsey, 2014). In the end, family members are more likely to suffer from psychological disorders if EOL conversations are postponed until it is too late (Bachner et al., 2021; Detering et al., 2010).

In contrast, if EOL conversations are engaged in early, they can produce feelings of empowerment, result in respecting of medical choices and wishes, and improve quality of life and satisfaction with treatment for patients. For advanced care patients, acceptance and adaptation of illness is strengthened, and hospice care is asked for more frequently and received earlier—whereas aggressive treatment choices decline in favor of palliative choices (Bischoff et al., 2013; Detering et al., 2010; Mack et al., 2010; Mack et al., 2012; Wright et al., 2008). Furthermore, if EOL conversations are introduced or encouraged early, the remaining time for family members is experienced as precious and helpful in preparation for farewell and loss. Also, EOL conversations facilitate double awareness and flexibility in emotional processes (Brighton & Bristowe, 2016): Cancer patients manage to address aspects of death and dying without losing hope or sight of the benefits of life.

### 2.3.1 Challenges

Even though the benefits of early EOL conversations are known (Banner et al., 2019), cancer patients seldom experience EOL conversations with treating physicians. Systematic interdependent barriers preserve a circle of avoidance for patients, family members and physicians alike (Brighton & Bristowe, 2016).

Patient-related barriers include lack of mental capacity (e.g., communication of choice and reasoning, cognitive capacity for understanding choices and consequences) for EOL conversations resulting from the advanced nature of their illness. Although many patients were mentally capable when admitted to a hospital, reduction in capacity of 50% was often the main barrier to initiation of EOL conversations. If people had not engaged in EOL conversations prior to admission, likelihood for initiation decreased dramatically. As a result, conversations about medical preferences are never engaged in, while decision fall upon caretakers and family members (Zaros et al., 2013).

Also, barriers of patients and family members varied in readiness for EOL conversations: some patients and family members are ready to engage in EOL conversations, whereas others strive to avoid them (Brighton & Bristowe, 2016). Emotional discomfort with broaching the subject, paired with personal belief of "not being there yet" (Banner et al., 2019), can then result in delay. Mortality is not interpreted as salient and conversations are not believed to be of relevance. Also, cultural understanding of importance and normality of EOL conversations, potential gaps in education, misunderstanding of the process and lack of skills in preparation can hinder engagement (Brighton & Bristowe, 2016).

For physicians, prognostic uncertainty and identification of the "perfect time" to initiate EOL conversations are often reported as important barriers. Further, anticipated negative psychological impact on patients and family members as well as the possible destruction of hope—or even causing harm—are additional reasons for avoidance (Banner et al., 2019; Brighton & Bristowe, 2016). Ultimately, physicians feel unprepared for EOL conversations and for coping with the emotional reactions of patients and family members (Brighton & Bristowe, 2016; Trankle et al., 2020).

Structural barriers include organizational pressure and difficulty of operationalization of EOL conversations in a clinical setting. Combined with prognostic uncertainty, time of initiation and the daunting prospect of conducting emotionally challenging negotiations hinder routine implementation (Lund et al., 2015). In Study II, we provide a possible solution that combines routine assessment, identification and initiation of EOL conversations.

### 2.3.2 Possibilities

Engaging in conversations about EOL preferences has certain advantages. The reality of EOL is clearly acknowledged during conversations, while personal preferences and limitations on medical treatment are heard and negotiated within families and medical care systems. They offer room for questions and specification of preferences prior to emotional distress or mental incapacity. Delegation of responsibilities is discussed openly and possibly divided between different people so that no one person carries the full weight of voicing decisions (Lund et al., 2015; Seymour et al., 2004). Finally, repeated EOL conversations can help to normalize the patient's responsibility in EOL care decisions; reduce uncertainty experience; and facilitate empowerment, emotional expression and personal growth (Zwakman et al., 2018). Although they can be very specific in focusing on treatment choices and limitations to medicine, and may result in advance care directives for the case of incapacity, EOL conversations can also be interpreted as shared contemplation of the future (Lund et al., 2015).

In health care, implementation of formal EOL conversations such as advance care planning could change the framework towards routinized practice of initiation, documentation and, consequently, normalization of such conversations (Lund et al., 2015). Furthermore, trainings for medical staff can ease communication processes (Brighton & Bristowe, 2016) and reduce fear of initiation caused by lack of confidence. Then, repeated confrontation with EOL conversations could reduce avoidance behavior (proximal defense) while simultaneously changing cultural evaluation (distal defense). Furthermore, addressing the readiness of patients may be helpful (Zwakman et al., 2018). Patients themselves advocate for continued promotion of EOL conversations to facilitate readiness (Brighton & Bristowe, 2016). The transtheoretical model (TTM) of health behavior change (Prochaska et al., 2008) in EOL conversations (Fried et al., 2010) emphasizes the importance and dynamic flow of individual barriers and facilitators to health behavior and is incorporated into TMHM (Goldenberg & Arndt, 2008). The five stages of TTM are precontemplation, consultation, contemplation, preparation, and action. In precontemplation, people have no intention to engage in health behavior in the near future. In consultation, this may be represented by patients refusing to engage in EOL conversations (proximal defenses) and to excessively engage in avoidance after consultation (distal defenses). Contemplation allows first assessment of behavior change, potentially refusing consultation on EOL care but also contemplating the possibility after leaving the hospital (distal defenses). Preparation already includes commitment while also possibly avoiding consultation but planning informal discussion with family members at dinner. In action, first EOL conversations during consultation are not refused and follow-up appointments for advance care planning are specified. Ultimately, changes in health or passing of time would result in continued discussion of preferences if people were motivated to maintain EOL conversations.

Studies III and IV describe development and validation of a questionnaire for readiness assessment and provide possible benefits of implementation. It is important to note that people may vary in their readiness for health behavior engagement. Whereas some may be ready for informal discussions within families, others may prefer formal discussions that result in official documents (Fried et al., 2010). Readiness may also depend on prior coping strategies and gender stereotypes: Women, for example, were more likely to engage in informal discussion, whereas men tended to document their preferences in a living will (Carr & Khodyakov, 2007). However, engagement in informal discussions was the key mechanism in EOL care planning and may be a necessary step prior to shared decision-making (Carr & Khodyakov, 2007). Therefore, Study V assesses the impact of two online interventions on readiness for EOL conversations.

# 3 Dissertation proposal

## 3.1 Relevance and background

Continuously increasing incidences of cancer diagnoses coincide with persistent psychological distress over the trajectory of treatment and survivorship. These sources of distress highlight the importance of treatment and interventions that address key concerns for cancer patients. Two of these psychological stressors are termed “FCR” and “death anxiety”. Initial inclusive conceptualizations have focused on the strong relation between both concepts as well as possible overlap in content, assessment and psychological defenses that patients engage in (Simonelli et al., 2017). Regarding psychological treatment, the current literature recognizes a need to differentiate between specific worries of cancer patients and to identify perpetuating factors in psychological distress experience to improve the efficacy of existing interventions. Therefore, the first study of this thesis addresses the possible overlap among conceptualizations.

Excessive FCR and death anxiety impact quality of life, the ability to cope with cancer and can even impact health behavior engagement (Simonelli et al., 2017). The TMHM (Goldenberg & Arndt, 2008) suggests a complex interaction of relevance of triggers, conscious or subliminal activation of thoughts of death, and interpretation of coping strategies as being relevant to reduction of death anxiety experience as well as health behavior avoidance or engagement. TMHM also explains readiness to engage in health behavior and can be used to understand existing barriers to—and facilitators of—EOL conversations in cancer patients.

Advance care planning combines both formal and informal aspects of EOL conversations: In a shared communication process among family members, patients and physicians, personal values, preferences and limits on medical treatment are discussed and negotiated. If desired, the decisions reached in such discussions can also be documented in an advance care directive. Although cancer diagnosis and treatment can increase relevance of death for patients and family members, cultural focus on survival often results in the interpretation of EOL conversations as a failure in medicine and “giving up” for patients (Trankle et al., 2020). In a hospital setting, this worldview—combined with organizational and personal barriers for both physicians and patients—initiation and conduction of EOL conversations becomes complex and difficult to routinize (Lund et al., 2015). One approach to normalize and assist with identification and initiation of health behavior in health care may be the implementation of screening instruments that are comprehensible, fast and easily interpretable for practitioners, and—if routinely distributed—sensitive to changes. At present, no such screening instruments or objective routine procedures for oncological care exist in Germany. The second study addresses this deficiency.

When further focusing on patient-related barriers to engagement in EOL conversations, not only physicians but also patients interpret uncertainty about readiness for EOL conversations as barrier to initiation  (Brighton & Bristowe, 2016). For physicians, often the interpretation of readiness does not coincide with experiences reported by patients (Coulourides Kogan & Taguchi, 2019), ultimately resulting in undesired engagement in or disregard of desired EOL conversations. Aside from routine screening to identify patients in need of advance care planning, specific assessment of readiness prior to consultation may also support medical staff in communication processes and prompt patients to engage. For research, the assessment of readiness enables interventions to increase readiness for EOL conversations to be evaluated for efficacy. Development and validation of a possible assessment tool is described in Studies III and IV.

Finally, this thesis focused on the gap in interventions that are designed to improve readiness for EOL conversations in an informal manner. First interventions exist that use face-to-face interviews (von Blanckenburg et al., 2021) or card games (van Scoy et al., 2017) in a community setting. However, not one is focused solely on cancer patients in daily surroundings who can interact online. Study V adapts existing interventions in an online setting available to cancer patients in Germany, thereby contributing to a better understanding of applicability to a population affected by cancer. Consequently, we provide a solution to avoidance of adaptive health behavior for a group with heightened mortality risk.

### 3.2 Objective and research question

Based on previous research, this thesis focuses on the conceptual relationship between FCR and death anxiety. It further addresses the lack of tools for assessing the need for advance care planning in oncological departments in German clinics as well as readiness for EOL conversations of cancer patients. Finally, it provides a realistic approach to increasing readiness for EOL conversations in cancer patients.

Study I:

a) Is the relationship between death anxiety and FCR best explained in a bifactor solution?

b) Can death anxiety be interpreted as general factor to a specific factor of FCR?

Study II:

a) Can objective and subjective needs for advance care planning be assessed via a feasible screening instrument for cancer patients in a hospital setting that

b) provides cut-off criteria for identification and recommendation of routine implementation?

Study III:

a) How can we assess readiness for EOL conversations reliably in a community sample?

b) Are the results transferrable to a sample of cancer patients?

Study IV:

a) Can the psychometric properties of an assessment tool for readiness for EOL conversations in cancer patients be validated in an independent sample?

b) Can limitations of original development be addressed and reduced.

Study V: How can we increase:

a) accessibility of an already existing intervention targeting readiness for EOL conversations; and

b) readiness for EOL conversations for cancer patients in an informal matter?

c) Do interventions affect psychological factors of impact (death anxiety, FCR, gratitude) for adaptive health behavior?

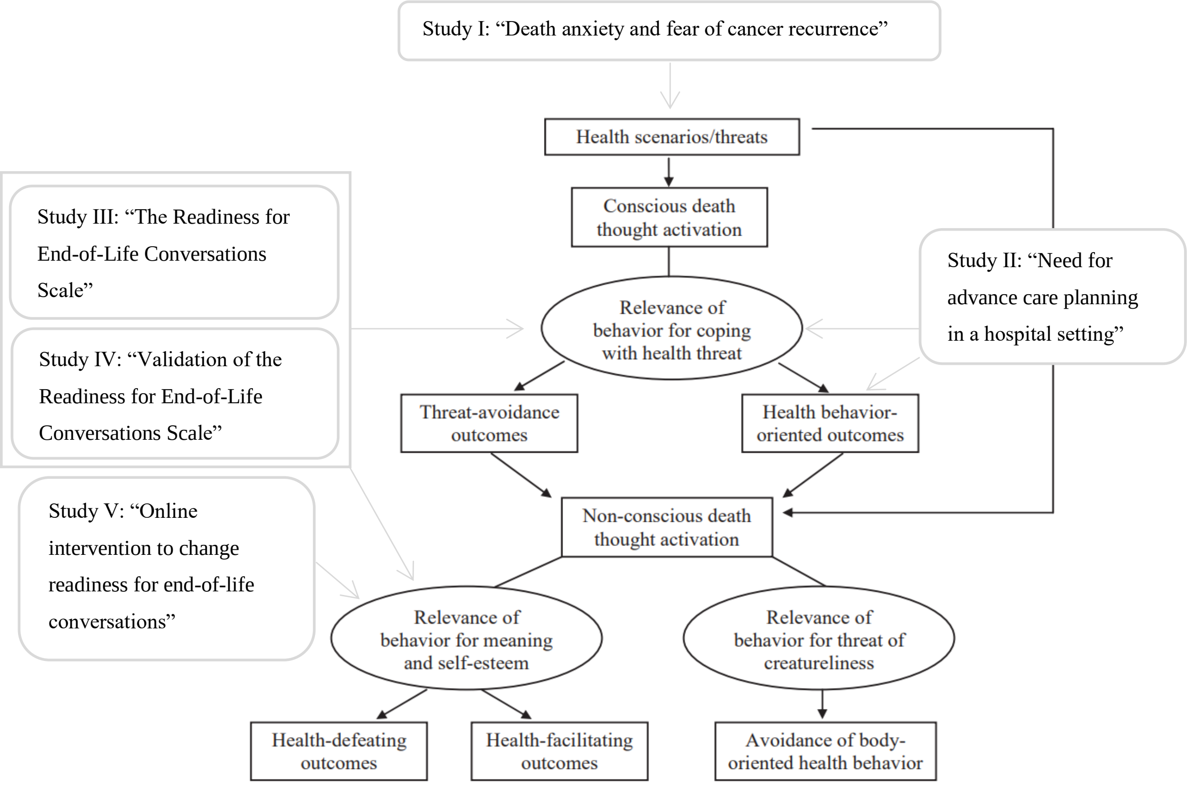

*Figure 4.* Inclusion of dissertation project in terror management health model

# 4 Summary of Studies

## 4.1 Study I: Death anxiety and fear of cancer recurrence

Berlin P. and von Blanckenburg P. (2022). Death anxiety as general factor to fear of cancer recurrence. *Psychooncology*. 1-9. https://doi.org/10.1002/pon.5974

**Background:** Cancer survivors often report FCR (Simard et al., 2013). High levels of FCR can have an impact on psychological well-being and medical decisions—for example, FCR can result in overuse or avoidance of check-ups, experience of isolation and constant worry regarding life. When assessing specific worries, death anxiety is—worldwide—the most ubiquitous topic of relevance (Sharpe et al., 2018). “Death anxiety” describes a state of consuming fear when mortality becomes salient; coping strategies combine proximal and distal defense mechanisms. Proximal defenses divert attention from the threat of death and are often witnessed in avoidance and over-rationalization. Distal defenses, in contrast, improve self-esteem as well as feelings of connectedness and immortality (Greenberg et al., 1997). Whereas the general population is seldom confronted with death and attention shift is easily accomplished, cancer patients are repeatedly confronted with reminders of their (perhaps imminent) mortality and consequently experience FRC (Simonelli et al., 2017). Previously, separation of both constructs was methodologically challenging and researchers’ personal barriers to confrontation with death and dying in oncology limited the focus of studies. Recently, however, the overlap in FCR and death anxiety was challenged by Sharpe et al. (2018) and the possibility of a hierarchical—compared to correlational—structure between the concepts has gained currency. Because some psychologists argue that death anxiety is a general concept within a variety of psychological disorders (Iverach et al., 2014), the primary objective of the present study was to support interpretation of death anxiety as general factor in oncology. Therefore, a bifactor approach was used to interpret shared common variances between both concepts with FCR as a group factor explaining additional variance and death anxiety as a general factor.

**Methods:** Data on cancer patients participating in an online intervention study was used. Analyses were based on data collected prior to intervention start ($N$ = 121). Death anxiety was assessed using the German version of the Death and Dying Distress Scale (DADDS-G, Engelmann et al., 2016); FCR was assessed with the Fear of Progression Questionnaire as Short Form (FoP-Q-SF, Mehnert et al., 2006b). In two consecutive steps (Herting & Costner, 2000), first, correlational factor structure was confirmed with CFA; modifications of the measurement model were permitted only when theoretically applicable. Second, a bifactor structure was estimated using structural equation modeling. Models were estimated with maximum-likelihood and Satorra–Bentler correction; item inter-correlations were allowed and goodness-of-fit indices included SB $\chi^2$, relative $\chi^2$, rRMSEA, SRMR and CFI.

**Results:** Three additional correlations to original factor solutions were allowed in CFA and bifactor models that included attachment avoidance, relevance of working ability, and life goals. The majority of common variance was explained by death anxiety (75.14%) but unique variance of FCR was high. More than 60% of variance in FCR was independent of death anxiety and explicable by alternative constructs. A multidimensional structure is recommended with emphasis on death anxiety's impact on FCR.

**Conclusion:** Death anxiety strongly impacted item responses of cancer patients. As a psychological construct of importance for well-being and health behavior, death anxiety among cancer patients warrants greater attention in cancer care. Inclusion of specific interventions in treatment may improve existing therapies and provide additional coping strategies for cancer patients. Possible adaptations include strengthening of double awareness, tailored interventions focusing on individual worries, as well as acceptance—and increased use of—emotional support. Additionally, independent impact factors for the experience of FCR must be addressed and included in care.

## 4.2 Study II: Need for advance care planning in a hospital setting

Berlin, P., Göggelmann, L., Herzog, S., Pedrosa Carrasco, A. J., Hauk, J., Timmesfeld, N., Kruse, J., Rief, W., Riera-Knorrenschild, J., von Blanckenburg, P., and Seifart, C. (in revision). Need for advance care planning – Development of a screening tool for cancer patients. Manuscript submitted in *PLOS ONE*.

**Background:** Every medical decision is based on consent by medical staff (predicated on necessity and ethical justifiability) and consent by the patient. If the patient is incapacitated, advanced care directives, health care proxies or the court are responsible for representing the patient as best they can. In Germany, intensive care physicians recently highlighted the need to promote early engagement in discussions about advance care because of overtreatment and inadequate understanding of patient preferences (Michalsen et al., 2021). They further support implementation of advance care plans (ACPs) because they include definitions of personal values and fears, clear medical limitations and conversations about decisions within a family system, determination of health care proxies and inclusion of medical staff (if necessary). In a hospital setting—and specifically for cancer patients—barriers to initiation of ACP often arise from prognostic uncertainty; fear of reducing hope or inducing emotional distress; dubious timing or context; and responsibility for initiating or misinterpreting readiness in patients. However, applications such as screening instruments allow medical staff to identify patients in need of a certain intervention in a timely, economical and subconscious manner. They circumvent barriers of initiation by providing rules of engagement after screening. The objective of the present study, therefore, was to develop the first screening tool for ACP need among cancer patients in a hospital setting.

**Methods:** In two phases, screening items were developed, analyzed for feasibility, and reduced based on difficulty, discriminatory and predictive values, sensitivity, and specificity. For utilization, an optimal cut-off was defined and construct validity was assessed based on correlations with communication avoidance in families of cancer patients, relationship with medical staff, and experience of death anxiety. Additionally, an item of interest in—and desire for—ACP information and conduction was included to strengthen patient engagement and to identify patients with low levels of anxiety but who nevertheless desired to make health care preparations.

**Results:** Item reduction in phase one ($N = 92$, $M_{age} = 61.0$, $SD_{age} = 13.4$, 55.4% palliative diagnosis) resulted in four items of good feasibility, difficulty ($P_i = .23–.49$) and discriminatory value ($r_{itc}$ = .60–.75). In phase two ($N$ = 201, $M_{age}$ = 61.2, $SD_{age}$ = 11.9, 61.2% palliative diagnosis), predictive value was compared for mild, moderate and great death anxiety levels and resulted in a screening item combination of *"I am burdened by the feeling of being ill prepared for the end of life"* and *"I am burdened by thoughts of an unfavorable course of the disease."* Cut-off was set at sum-scores ≥ 6 because of high sensitivity (95%) and specificity (81%). Critical ACP need was supported for patients with clinical distress, depression or anxiety, as well as patients who believed themselves to have a palliative prognosis. Participants who expressed a desire for ACP were likely to have used alternative support services and tended to be in the stages of *contemplation* or even *preparation*.

**Conclusion:** In a hospital setting, screening of ACP need and desire for ACP initiation among cancer patients is feasible with a newly designed instrument of two objective items and one subjective item. Cut-off for the objective assessment is recommended at sum-scores greater than five as indicator of death anxiety. Regarding the subjective desire for ACP, inclusion of uncertainty option to select for patients is recommended to reduce hesitation and pressure.

## 4.3 Study III: The Readiness for End-of-Life Conversations Scale

Berlin, P., Leppin, N., Nagelschmidt, K., Seifart, C., Rief, W., & von Blanckenburg, P. (2021). Development and validation of the readiness for end-of-life conversations (REOLC) scale. *Frontiers in Psychology*, 12, e795, DOI: 10.3389/fpsyg.2021.662654.

**Background**: Although end-of-life (EOL) preparations are widely recognized to be of importance (Banner et al., 2019), external and internal barriers often prevent people from engaging in early health care behavior. Specific health care behaviors (e.g., financial, medical and psychological preparations) can include boundaries to medical treatment, voicing preferences and minimizing conflicts within family structures. If EOL conversations are initiated at an early stage, people may feel empowered and assured in decision-making. Advance care planning (ACP) is a guided process that provides information, respects personal values and preferences, identifies fears and worries, and focuses on quality of life (Pearlman et al., 1995). After participation in ACP, knowledge of medical wishes and limitations of life-prolonging measures increased satisfaction with treatment and experience of quality of life (Detering et al., 2010). Also, family members suffered less after bereavement (Bachner et al., 2021).

A potential barrier to patients' engagement in EOL conversations is expected to be found in motivation and readiness for engagement (Fried et al., 2010). Based on health behavior change stages proposed by the transtheoretical model (TTM, Prochaska et al., 2008), readiness for behavior is flexible and changes between precontemplation and contemplation until increasing commitment and motivation eventually facilitate preparation, action or maintenance. In health care, common barriers to initiation include definition of responsibility, time, context and successful interpretation of readiness (Brighton & Bristowe, 2016). The objective of this study was to a) develop a method to assess peoples' readiness to engage in EOL conversations and b) validate the assessment tool for a population affected by cancer.

**Methods:** Exploratory factor analysis was conducted for a 13-item questionnaire. Data was collected from a community sample ($N = 349$) in precontemplation for completion (44.41%) but currently without a living will (70%) or conversations within family about EOL wishes (42.94%). Structural equation modelling was based on data from an online-intervention study for cancer patients ($N = 84$) to confirm factor structure of exploratory analyses. Restrictions included fixed parameters, Maximum-Likelihood estimation and Satorra-Bentler-correction with robust standard errors. As goodness-of-fit indices, RMSEA, SRMR and relative $\chi^2$ ($\chi^2$/df

< 2) were chosen. Correlations with depression, fear of progression, death anxiety and general anxiety or distress indicated convergent and discriminant validity.

**Results:** Exploratory factor analysis of 13 items suggested a three-factor solution of values ($\alpha = 0.56$), communication ($\alpha = 0.76$) and readiness ($\alpha = 0.84$) for assessment within a community sample. Additionally, the possibility of one common factor was considered ($\alpha = 0.84$). Convergent validity for all three factors was supported by correlations with living will and talking about EOL. Discriminant validity was supported by the absence of correlations with depression or distress. Readiness was positively correlated with gratitude ($r = 0.14$, $p < .01$). Structural equation modeling to support a possible one-factor solution in a sample of cancer patients resulted in item reduction and assessment of 12 items. The proposed one-factor structure ($\alpha = 0.86$) was confirmed and supported by convergent and divergent validity: Readiness for EOL conversations was unrelated to distress, depression, anxiety, death anxiety or fear of cancer recurrence and progression in cancer patients. Gratitude was positively and strongly related to readiness ($r = 0.44$, $p < .01$).

**Conclusion:** Although conversations about end-of-life have proven to be beneficial, people may vary in readiness for engagement. Interventions and initiation of conversations, therefore, need to consider differences and may initially assess readiness. The readiness for end-of-life conversations scale (REOLC) is found to be a reliable instrument for assessment within varying populations. For utilization within a community sample, at present a 13-item version with three factors is suggested.

For application within a community affected by cancer, a 12-item version is recommended: One item clearly separating life and death may not be of relevance for cancer patients, because cancer diagnosis, treatment and survivorship are often connected to death and dying. The one-factor solution covers avoidance tendencies for end-of-life conversations and openness to engagement. Psychometric evaluation supported usage, but future studies are encouraged to further validate factor solutions in larger samples and varying settings.

## 4.4 Study IV: Validation of the Readiness for End-of-Life Conversations Scale

Berlin, P., Seifart, C., & von Blanckenburg, P. (2022). Validation of the Readiness for End-of-Life Conversations (REOLC) scale in a German hospital setting. *PEC Innovation*, e100045, DOI: 10.1016/j.pecinn.2022.100045.

**Background:** Prior to initiation of behavior, people contemplate engagement and develop motivation and readiness for action despite potential negative consequences (Prochaska et al., 2008). In health care, behavior includes engagement in conversations about medical decisions, preferences and consideration of challenges and prospects. For cancer patients, conversations further include the possibility of recurrence or progression and, ultimately, end-of-life. However, end-of-life conversations are often feared and therefore postponed to avoid emotional burden (Banner et al., 2019). Delaying end-of-life conversations until the last moment often prolongs medical treatment and reduces opportunities for palliative care. If patients and family members engage in early end-of-life conversations, preferences are communicated, invasive treatment choices are less likely, satisfaction with treatment increases, and bereaved family members are less adversely affected (Bachner et al., 2021; Detering et al., 2010).

In order to provide interventions and programs that ease engagement with cancer patients according to their state of readiness, there is a need for reliable assessment tools. The Readiness for End-of-Life Conversations (REOLC) scale was developed primarily for a community sample and adapted to cancer patients (Berlin et al., 2021). For the purpose of reliable usage, newly developed assessment tools need to be verified in independent comparable samples. Therefore, the objective of this study was to validate the factor structure found for the REOLC scale in cancer patients, within a hospital setting.

**Methods:** The REOLC scale was presented to cancer patients ($N = 295$, $M_{age} = 61.2$, $SD_{age} = 12.3$, 59.7% male) as part of a screening development study. Structural equation modeling with goodness-of-fit indices ($\chi^2$-test, SRMR, RMSEA, relative $\chi^2$/df) was replicated from development. Convergent validity was assessed with the Advance Care Planning Engagement Survey (ACP-E, Sudore et al., 2017), discriminant validity with the Death and Dying Distress Scale (DADDS-G, Engelmann et al., 2016), the Patient-Health Questionnaire with screening for depression and general anxiety (PHQ-4, Kroenke et al., 2009) and the visual scale of Distress Thermometer (Mehnert et al., 2006a).

**Results:** Structural equation modeling supported the second-order structure with one general factor (readiness for end-of-life conversations) to three latent constructs: *communication*, *values* and *readiness* ($N$ = 261, rRMSEA = 0.064 [0.044;0.083], SRMR = 0.065). Assessment of convergent validity supported readiness assessment: Cancer patients were less ready to name a health care proxy, sign an advance directive or discuss medical preferences with their physician if they scored lower on the REOLC scale. Readiness for end-of-life conversations was marginally related to distress experience but unrelated to depression and anxiety symptoms. Contrary to previous findings, death anxiety correlated significantly—albeit weakly—with REOLC scores ($r = .13$, $p < .05$).

**Conclusion:** Psychometric evaluation of the Readiness for End-of-Life Conversations (REOLC) scale supports reliability, interpretation of a general readiness score and importance of avoidance factors for end-of-life conversations. Analysis of moderating or mediating effects may include socio-demographic factors of interest (e.g., age or gender), medical factors (e.g., treatment, prognosis or disease severity) and psychological factors (e.g., interaction of avoidance tendencies and death anxiety). In clinical practice, practitioners and cancer patients could further profit from interventions or workshops that facilitate engagement in end-of-life conversations tailored to participants' readiness.

### 4.5 Study V: Online intervention to change readiness for end-of-life conversations

Berlin, P., Kloos, T., & von Blanckenburg, P. (submitted). Addressing readiness for end-of-life conversations, death anxiety and fear of cancer recurrence in people affected by cancer: A randomized controlled online study. Manuscript submitted in *Psychotherapy and Psychosomatics*.

**Background:** When diagnosed with cancer, people face many challenges that include medical decisions, physical and psychological side effects to diagnosis, treatment and survivorship. Although medical improvements over the years have increased patients' odds of recovery, risk of recurrence, progression and death are still realistic outcomes. Therefore, conversations about medical preferences and personal limits on life-prolonging treatments are necessary and beneficial in cancer care. Although patients, physicians and families believe end-of-life (EOL) conversations to be relevant (Waller et al., 2019), uptake and engagement is often affected by aversive emotions, namely death anxiety, fear of cancer recurrence (FCR) or general distress. These impact well-being, treatment compliance, check-ups and engagement in health behavior (Deimling et al., 2006; Gao et al., 2010; Mehnert et al., 2018; Riba et al., 2019). For all three, threat monitoring may impair capacity for EOL care decisions and favor emotional defense mechanisms such as avoidance or denial. However, two possible interventions strengthen coping mechanisms and reduce usage of maladaptive defenses.

First, the Motivational and Value Based Intervention (MoVa) was successful in increasing readiness for EOL conversations in a community sample, strengthening ability of double awareness, flexibility in engaging in EOL-related thoughts, and shifting intentionally to thoughts that focus on present life (von Blanckenburg et al., 2021). Second, focusing on gratitude during Loving-and-Kindness Meditation (LKM) practice reduces death-related FCR and distress, broadens attention, and strengthens coping ability as well as engagement in health behavior (Fredrickson et al., 2008; Otto et al., 2016). The present study aimed primarily to adapt MoVa as online intervention (eMoVa) for cancer patients and compare effects of eMoVa and LKM on readiness for EOL conversations. Secondary analysis included effects on death anxiety, FCR and gratitude.

**Methods:** Cancer patients ($N = 118$) were recruited online and randomly allocated to either LKM ($M_{age} = 41.8$, $SD_{age} = 13.5$) or eMoVa ($M_{age} = 44.3$, $SD_{age} = 13.3$). Pre-intervention as well as six weeks, three months and six months post-intervention participants were asked to answer a variety of questionnaires assessing readiness for EOL conversations (REOLC, Berlin et al., 2021), FCR (FOP-Q-SF, Mehnert et al., 2006b), death anxiety (DADDS-G, Engelmann et al., 2016), and gratitude (GQ-5-G, Hudecek et al., 2020). During intervention, respondents received weekly reminders for participation and assessment of experienced distress (DT, Mehnert et al., 2006a).

Statistical analysis was based on intention to treat and used Bayesian Linear Mixed Models for simultaneous imputation and estimation. Likelihood for effects within the given sample was expressed using Bayesian Factor (BF): values smaller than one showed negligible effects and values between 1 and 3 were of only anecdotal effect. Values between 3 and 10 were of moderate, values between 10 and 30 indicated strong evidence, 30–100 showed very strong, and > 100 indicated extremely strong evidence for effects within the sample. Effect size was estimated with Cohen's *d* based on ten multiple imputed data sets.

**Results:** Readiness for EOL conversations successfully increased after participation in LKM and eMoVa, respectively. Effect sizes were small ($d = 0.13$-$0.40$) but showed moderately to extremely strong evidence (BF > 100). Comparisons of both interventions revealed stronger increase in readiness for eMoVa (BF > 100) at all time-points ($d = 0.17$-$0.34$). Secondary analyses provided first insights into possible short-term reduction effects of LKM on death anxiety and FCR for three months, with constant increases of gratitude. If participants in LKM reported clinical distress prior to intervention, FCR did not remain stable but was reduced for the time of participation. Six months after intervention, levels of FCR increased strongly over baseline levels. In eMoVa, independent of clinical distress prior to intervention, for the time of intervention, death anxiety and FCR slightly increased but returned to baseline levels by the six-month follow-up assessment. If pre-intervention clinical distress was reported, participants' FCR experience decreased constantly in eMoVa.

**Conclusion:** The increase in readiness for eMova supports application for cancer patients in an online setting. Bringing attention to milestones, values and loved ones prior to challenges and advantages of EOL conversations could have improved double awareness. Additionally, LKM practice increases gratitude and broadens perspective for EOL conversations. Future studies may focus on moderating influences of medical and socio-demographical data and combination of both interventions. Engagement in online interventions about EOL did activate fears for a short time but was not persistent. For clinically distressed cancer patients prior to intervention, participation in LKM may be of only short-term value.

# 5 General discussions and implications

This dissertation focused on the construct relationship between death anxiety and FCR as an important trigger for health behavior in cancer patients (Study I: “Death anxiety and fear of cancer recurrence”). Furthermore, two measurement tools for assessing readiness for, and need of, EOL conversations were developed and validated. First, a screening instrument for identification of the need for advance care planning in cancer patients (Study II: “Need for advance care planning in a hospital setting”) was evaluated in a German hospital setting. Second, a questionnaire to assess readiness for EOL conversations was developed for a community sample and cancer patients (Study III: “The Readiness for End-of-Life Conversations Scale”). Psychometric properties were additionally validated for cancer patients currently in treatment at a German hospital (Study IV: “Validation of the Readiness for End-of-Life Conversations Scale”). Finally, the effects of two online interventions on readiness, death anxiety, FCR and gratitude were evaluated and compared (Study V: “Online intervention to change readiness for end-of-life conversations”).

This dissertation provides first insights that death anxiety can be interpreted as a general factor and explains the majority of shared variance between death anxiety and FCR in cancer patients. The multidimensionality of the proposed bifactor structure further supports the importance of additional factors specifically impacting FCR (Study I: “Death anxiety and fear of cancer recurrence”). It is likely that previously interpreted triggers of FCR are caused mainly by death anxiety and are currently not treated adequately. Consequently, future psycho-oncological interventions should provide new support systems and interventions to address the impact of death anxiety for cancer patients. This includes possible fears of progression and impact on medical decisions at the end of life and, more specifically, decisions in regard to medical treatment when incapable of giving consent. For cancer patients, death anxiety was experienced if cognitive functioning was perceived to be impaired (Eggen et al., 2020). Although every person is faced with the possibility of inability to consent, for cancer patients, mortality salience may increase the likelihood and necessity of conversations about advance care for the end of life.

This dissertation also contributes the first screening tool (ACP Screening) to assist physicians and patients in a hospital setting with initiation of EOL conversations. It objectively assesses need for advance care planning in combination with personal desire, independent of burden by worries or fears (Study II: “Need for advance care planning in a hospital setting”). Cut-off criteria allow identification and activation of engagement procedures for medical staff. However, independent of burden because of advance care need, people may not feel ready for engagement and may avoid conversations even when approached. Furthermore, perception of changes in readiness between screenings then may go undetected by medical staff. In order to assess readiness without triggering death anxiety defenses that activate health-avoidance behavior, practitioners may rely upon a questionnaire prior to consultations to use patients' answers as guidance through the conversation.

As part of this dissertation, a questionnaire was developed for a community setting and validated for cancer patients (Study III: "The Readiness for End-of-Life Conversations Scale"). Results suggested a different factor structure for cancer patients. Avoidance of mortality was not as simple, and was therefore only partially integrated. In order to provide a reliable assessment tool, the questionnaire for cancer patients was validated and supported within a hospital setting (Study IV: "Validation of the Readiness for End-of-Life Conversations Scale"). It was further included in the final study of this dissertation project, evaluating increase in readiness for EOL conversations in two interventions (Study V: "Online intervention to change readiness for end-of-life conversations"). Both interventions successfully increased readiness over the course of participation with a stable effect for the following six months. The intervention that specifically addressed informal aspects of EOL conversations showed stronger changes compared to a meditation intervention focusing on gratitude. Secondary analyses revealed heterogeneous but promising effects of both interventions on death anxiety, FCR and gratitude. Gratitude slightly increased during and after meditation practice, whereas death anxiety and FCR experience were unaffected or returned to baseline levels for both interventions. Only for clinically distressed participants did meditation practice result in increases of FCR after six months.

## 5.1 Limitations

It is important to critically discuss limitations to this dissertation and conducted studies. First, all studies could have been impacted by participation bias because they were openly advertised as EOL-related. The main reason for this disclosure was transparency: For online settings specifically (Studies I, III, V), emotional reaction to unexpected content is impossible to control. If participants were negatively surprised by questions and interventions focusing on aspects of EOL, it would not be possible to provide emotional support, especially for participants who dropped out, due to physical distance. Consequently, negative experiences with EOL aspects could increase avoidance and reluctance to engage in related interventions in the future. Still, transparency could have resulted in participation of cancer patients who were already in (pre)contemplation for confrontation with EOL aspects and possible emotional responses. For the general impact of death anxiety on FCR (Study I), we do not expect participation bias to have impacted overall study results. For cancer patients who avoid EOL-related topics, death anxiety may be an even stronger influence on FCR: Focus on cancer-related distress may function as an emotional regulation strategy of avoidance. Increased levels of FCR would be the consequence of increased death anxiety experience when confronted with death-related questions. However, we acknowledge the possibility of bias and encourage future studies to replicate bifactor results for studies with alternative advertisement methods. For screening development (Study II), for example, participation bias could have impacted cut-off criteria that were based on death anxiety experience. If patients with intense death anxiety avoided participation, the recommended cut-off may be too sensitive. Criteria for the present sample were related to moderate death anxiety. However, for screening purposes, sensitivity is a key quality factor. Bias cut-off due to open-minded participants would only result in early confrontation with the possibility to engage in EOL conversations for a variety of patients.

In health care, including more patients than needed is generally preferred to excluding patients in need. For development and validation of the REOLC scale, different advertisement strategies were relied upon that did not necessarily include mention of EOL-related assessments. The replicability of factor solutions contradicts impact of advertisement in Study III and Study IV. For participation in interventions (Study V), openness to EOL may have mainly impacted prior readiness. Participants may have already (pre)contemplated EOL so that intervention effects were only small. However, changes in readiness supported success of both interventions, even for people already interested in, and open to, the topic of EOL.

Considering all effects that participation bias may have had on this dissertation, future studies may profit from cover stories in order to include a more diverse sample and solidify present results. However, we caution researchers to design studies that also provide dropped-out participants with a positive experience in order to increase the likelihood of their future engagement in EOL-related health behavior (van Cappellen et al., 2018). For online interventions, for example, the possibility of dropping out could be introduced prior to participation and repeatedly offered as check-box throughout the intervention. In order to debrief participants who wish to drop out and activate the check-box, specific information, positive framing and contact details could be provided. Also, automatically generated emails could contact dropped-out participants to offer emotional support.

It is also worth noting that participants in three studies were predominantly females who had been diagnosed for the first time and who reported curative prognoses. It is not surprising that mainly women consented to participation in online EOL related studies, given that research has found women to prefer informal over formal conversations (Carr & Khodyakov, 2007; Seifart et al., 2020). Furthermore, recruitment was strongly supported by advertisers focusing on breast cancer patients. However, the primary impact of socio-demographic characteristics would likely have been on generalizability; because oncology is a heterogenous research field, replication of results in varying samples could counteract this limitation. To address gender effects specifically, it may be favorable to approach men directly, focus on various cancer types (e.g., prostate, urology, lung cancer) and assess preference for formal versus informal EOL conversations.

Second, sample sizes were small, except in Study II and Study IV. Small samples can result in model misspecification and misinterpretation of results. For Study I and Study III, this may have resulted in flawed interpretation of structural equation models. Nevertheless, statistical analyses were conducted with corrections and precautions, including fit indices that differed in sensitivity to bias. While the results of Study I are discussed to need further validation, the scale development of Study III was already validated using a sufficient sample (Study IV), supporting goodness-of-fit indices used in this dissertation. Also, specifically for the intervention study (Study V) we chose a Bayesian approach in analysis to interpret sample specific results and minimize bias.

Third, measurements chosen may have impacted our results. In Study I, for example, we relied upon two questionnaires previously validated in palliative samples in Germany and substantively focusing on progression of disease. Interpretation of FCR as a combination of fear of progression and recurrence may also be questioned. Additionally, alternative assessments of death anxiety include aspects of death avoidance or acceptance and may merit future interpretation of death anxiety as a general factor. We believe our results to be very specific and in need of further validation. Also, data from online studies was based on self-reporting. In the future, medical information in particular should be assessed through medical records comparable to Study II and Study IV. Comparisons between physical oncological characteristics will then likely be more reliable, and studies may even include specific characteristics as inclusion criteria.

Finally, changes in readiness in Study V were assessed with, and compared between, two active interventions. Active interventions were chosen mainly in order to provide an incentive for participation despite a potentially dissuasive research topic. Unfortunately, this decision prevented assessment of individuals' natural flow of readiness change when regularly confronted with questionnaires regarding EOL. Continued exposure might have kept thoughts of death activated and reduced suppression tendencies, despite increasing readiness. Future studies may vary the frequency of assessment and sequence of questionnaires and items to assess exposure impact.

## 5.2 Strengths

### 5.2.1 General strengths

This dissertation is also characterized by several general strengths and assets from which future research may profit. Most importantly, it constitutes an integrative research project that connects several factors of influence for EOL care in oncology from bench to bedside. In addition to research on principal relations between key factors in cancer care, this dissertation is also distinguished by high methodological quality in statistical analysis and progress in psychological interventions.

For three studies, structural equation models were conducted as exploratory analysis, confirmatory analysis and structural relation of latent variables in bifactor analysis. Also, item development and selection with consequent probability and sensitivity estimation extended variation in statistical analysis and psychometric quality of this dissertation. Finally, novel application of Bayesian linear mixed models for analysis of psychological interventions constitutes an extraordinary effort to achieve creativity and diversification. Including Bayesian statistics to interpret intervention effects supports the belief of continuously including new evidence for the prediction of intervention efficacy. We therefore support the general potential for improvement of interventions when applied to a field of high heterogeneity, such as psycho-oncology. Bayesian statistics enables future studies to base efficacy estimations on previous findings and therefore supports constant adaptation and flexibility in research. Future studies may base estimations on effects found in this dissertation and produce more accurate estimations of intervention success. Furthermore, in response to difficulties in replicating previous findings, validation of the developed questionnaire (Study III) was conducted using the exact same code for statistical analysis. This exact replication made it possible to identify alternative factors of influence on the measured outcome variable. Differences in study outcome, therefore, were unrelated to differences in psychometric analyses or methodological application. Consequently, interpretation of differences may demonstrate alternative moderating factors of interest for future research considerations.

Another strength is the inclusion of curative and palliative cancer patients. Whereas other studies have mainly included advance care patients (Engelmann et al., 2016; Sudore et al., 2017; Tang et al., 2016), we followed suggestions to include patients independent of diagnosis (Larson & Tobin, 2000). We thereby support the belief that participation in EOL conversations improves self-efficacy experience for all patients coping with chronic illness (Beckham et al., 1997) and, ultimately, death anxiety is a universal construct that concerns us all (Iverach et al., 2014).

Furthermore, all but one study were impacted by COVID-19 and the accompanying lock-downs, restrictions and psychological challenges. Recruitment was delayed because cancer patients belonged to one of the main risk groups. Additionally, participation may have been impacted because of the study's focus on mortality salience, which may have repelled some potential participants. However, innovative recruitment methods were implemented to compensate. Aside from usual in-person recruitment in a hospital setting, daily screenings and provision of advance care planning sessions for interested cancer patients, online recruitment was pushed forward. In order to reach as many patients as possible, an Instagram account for recruitment and research communication was created. Advertisement entailed general information on study participation as well as regular interaction with patient support groups to improve accessibility and answer questions. Furthermore, articles about the study were printed by national papers of interest to cancer patients, blog posts were published, and questions were answered in support group meetings. These invitations for participation made it possible to include participants from all over Germany and may have counteracted avoidance of EOL topics and longitudinal studies.

### 5.2.2 Study-specific strengths

Focusing on study-specific strengths, we present first insights into the conceptual relationship between death anxiety and FCR on a psychometric level (Study I). Previous studies have addressed correlational relations (Tang et al., 2016), death-specific fears of FCR (Otto et al., 2016), conceptual overlap (Simonelli et al., 2017) and reasons for closer examination of structural relations (Sharpe et al., 2018). However, none have supported theoretical interpretations by focusing on bifactor structures. This dissertation further widens the discussion focusing on the relevance of death anxiety in cancer care and provides new research as well as clinical incentives.

Additionally, prior to our research, there existed no screening method for need of advance care planning that has been tested within a hospital setting worldwide (Study II). We therefore covered a gap in support services during a time for cancer patients when mortality salience is likely to be activated. Furthermore, we provided the possibility to engage in health behavior (advance care planning) that is tailored to emotional and medical needs of patients. Based on the TMHM (Goldenberg & Arndt, 2008), we therefore enable cancer patients to adapt long-term positive health behavior with high self- and response efficacy while mortality salience is activated. With globally increasing life expectancy and cancer diagnoses, our instrument has the potential to address difficult initiation processes and can therefore be viewed as a milestone in research and clinical practice. Specifically, we are the first group to acknowledge the importance and influence of death anxiety on health behavior.

Furthermore, whereas alternative research groups have focused solely on formal aspects of readiness (Sudore et al., 2017), we pair emotional distress as an indicator for help services with personal interpretation of readiness. Acknowledging the personal interpretation of readiness for EOL conversations, independent of specific medical decisions in assessment and interventions (Studies III–V), facilitates the interaction between cancer patients and practitioners. It also allows new interventions to be developed, evaluated, adapted and helps bridge the gap between informal discussions and engagement in formal EOL conversations.

The transferal of face-to-face interventions to an easily accessible online setting (Study V) provides new opportunities and change for support services. For cancer patients, interaction is not always a possibility due to weakened immune systems, inaccessibility of interventions, or physical exhaustion. Online interventions are an effective way to overcome these barriers. Additionally, we did not control for the process of engagement and intensity of participation. For meditation, specifically, many people do not begin meditation practice with engaging in a face-to-face weekly group session. However, studies normally test meditation efficacy after participation in high-intensity interventions (Fredrickson et al., 2008; Kearney et al., 2021). Meditation requirements for our study, in contrast, were comparable to all existing online applications for meditation. These applications offer meditation services and, if requested, weekly or daily reminders without negative consequences for non-engagement. We copied this practice by sending weekly reminders and providing access to guided meditation on personal accounts. We believe this to be a realistic assessment of meditation efficacy. Therefore, the effects of meditation from our study are believed to be related to general health behavior.

Furthermore, this dissertation was able to address a common fear (and consequent barrier) to initiation of EOL conversations in cancer care: Practitioners fear increasing emotional distress in cancer patients by initiating conversations about EOL (Almack et al., 2012; Hancock et al., 2007; Vleminck et al., 2014). For one, none of the conducted studies of this dissertation indicates systematic drop out in participation due to increased distress when confronted with EOL questions. Also, whereas participation in eMoVa (Study V) leads to short-term increase of FCR and death anxiety, the long-term reduction of both support harmlessness of exposure to EOL-related aspects. Notably, in case of heightened FCR, confrontation with EOL questions is likely to continuously diminish FCR experience. It is hoped that these results will encourage practitioners to engage more and adapt their expectations and fears of causing unmanageable distress for patients when initiating EOL conversations (Brighton & Bristowe, 2016). Also, these results represent a general incentive for patients and practitioners to improve their ability to cope with emotional distress compared to avoidance of emotional experience.

### 5.3 Implications for future research

Because study-specific research ideas are displayed in each article, the following section focuses on four selected ideas that stem from the combined results of this dissertation project.

First, heterogeneity in medical characteristics is a barrier to the generalizability of research findings in oncology. Cancer types, treatment choices, prognosis or prior experience with chronic illness can vary greatly. When focusing on the most commonly diagnosed cancer types in Germany (Robert Koch-Institut, 2021), aside from breast cancer for women and prostate cancer for men, both are most likely to suffer from colon and lung cancers. Comparison of EOL health behavior between these diagnoses would provide insights for 50% of expected cancer diagnoses in Germany. Lung cancer, specifically, could be of interest for future studies because it is one of the top three diagnoses for both genders and is also the diagnosis with the highest mortality rates among men. Because Study I identified death anxiety as a general factor—especially for female breast cancer patients—replication with lung cancer patients could strengthen generalizability for a population that accounts for 20% of cancer cases in Germany (Robert Koch-Institut, 2021).

A second important factor in oncology is related to gender differences. Assessment of EOL health behavior engagement among healthy participants (Carr & Khodyakov, 2007) suggested a tendency toward formal behavior (advance directives) among men and toward informal behavior (EOL conversations) among women. Furthermore, engagement in informal EOL conversations was the strongest predictor for EOL planning, indicating ascendance in readiness stages. Interestingly, we also found gender differences in the relationship between death anxiety and readiness for EOL conversations (Study IV). Because the need for advance care planning (Study II) was related to death anxiety, future studies may assess whether gender stereotypes moderate the relationship between need for advance care planning and readiness for EOL conversations. Based on our previous findings, we hypothesize that men are motivated toward engagement in formal health behavior if they associate themselves with male stereotypes and experience higher levels of need for advance care planning. For women, however, the association of social connectedness with EOL conversations may motivate health behavior. Results from meditation practices (Study V) focusing on social relations suggest that the activation of personal relations may decrease death anxiety experience and increase readiness for EOL conversations.

A third area of research focuses on the emotional experiences involved in EOL conversations. Secondary analyses of our intervention study (Study V) showed short-term increases in FCR and death anxiety but long-term returns to baseline or even reductions in FCR and death anxiety following EOL conversation. Additionally, contrary to worries among practitioners, participation in EOL conversation was found to be related to increased hope (Cohen et al., 2022). For future research, it would be of interest to assess positive and negative emotions during (in)formal EOL conversations. The broaden-and-build theory (Fredrickson, 2004) suggests that mindful experience of positive emotions can broaden perspectives and increase resources as well as the likelihood for future engagement in health behavior (van Cappellen et al., 2018). For EOL conversations, specifically, researchers could assess whether the experience of positive emotions (e.g., gratitude, satisfaction, hope) during and after engagement result in long-term reductions of death anxiety and FCR. Consequently, implementation of regular EOL conversations could reduce two major psychological impactors for cancer patients (i.e., death anxiety and FCR), improve understanding of personal preferences and values, and result in reduced uncertainty in medical decisions for physicians, patients and family members.

The fourth and final research area targets distal defenses of terror management. Acting in accordance with cultural norms and engaging in behavior that contributes to self-worth both influence motivation and maintenance of long-term behavior (Goldenberg & Arndt, 2008). However, when focusing on implementation processes in Australia, it becomes apparent that even though advance care planning is incorporated into health care structure, EOL conversations appear relatively late and barriers persist. When practitioners were asked to describe difficulties, it is clear that a key factor in EOL conversations is practitioners' worldview of a patient's death as a failure or bad health care outcome (Trankle et al., 2020). This dissertation has focused on barriers such as conceptual interpretation of cues as related to death anxiety, initiation and contemplation of EOL conversations, or lack of interventions to improve readiness. However, the general cultural view of death impacts successful implementation of EOL conversations. Comparison of worldviews related to the initiation—and avoidance—of early EOL conversations may identify moderating factors of change. Additionally, the development of educational training programs for medical students with the assistance of cancer patients and physicians who interpret death as a natural occurrence may dramatically improve EOL communication within the health care system in Germany.

## 5.4 Implications for people affected by cancer

Although practitioners support the importance of EOL conversations, barriers to such conversations persist (Trankle et al., 2020). When EOL conversations are interpreted by practitioners as indicative of personal failure, avoidance is strengthened and stabilized. In order to change such a mentality, practitioners need to understand general aspects of EOL conversations as well as the importance of death anxiety among cancer patients. Facilitators of cultural change may include the implementation of multi-professional teams, early trainings in communication, emotional expression and regulation for prospective practitioners, and understanding of the relevance of death anxiety and EOL conversations among patients and families. Ultimately, positive experiences can change perception, self-esteem and adaptive coping strategies for practitioners (Goldenberg & Arndt, 2008).

Specific changes in clinical practice include true understanding, normalization, and expectation management. For true understanding, practitioners must encourage patients to articulate their specific fears and worries—for example, whether their concerns are related to changes in lifestyle or finances, or if they are directly related to death and dying (and thus could perhaps be resolved in EOL conversations). In order to normalize the process of engagement in EOL conversations, practitioners must be transparent about their reasons for initiating such conversations with the patients in their care. If physicians feel unprepared for such a confrontation, the inclusion of psycho-oncologists in consultations may ease that process. Finally, if patients expect to be presented with a questionnaire regarding EOL conversations or if they are asked to participate in advance care programs when treatment is not successful or when prognosis worsens, EOL health behavior is consistently linked to increases in death anxiety. As a result, expectations are formed that EOL conversations are only initiated as last resort and therefore likely to be feared and avoided. Routine assessment or consultation with psycho-oncologists can help to minimize maladaptive expectations and interpretations while also supporting normalization (Brighton & Bristowe, 2016); although thoughts of death may be activated, patients expect to be asked about EOL care preferences and can prepare accordingly.

Finally, gender differences in readiness for EOL conversations may depend on death anxiety experience and existing offers of (in)formal conversations. It is possible that the advertising and framing of the benefits of EOL conversations must be adapted to gender-specific tendencies in death anxiety experience. When in consultation with male patients, practitioners might emphasize the benefits of updated advance care directives (formal) as form of participation in health care and self-control. For women, practitioners might emphasize the benefits of focusing on personal preferences, clearing uncertainties within families, and reducing potential emotional burden (informal).

It is hoped that this dissertation project will raise awareness about the relevance of EOL-related fears and actions for psychological and physical well-being and care among cancer patients. Additionally, we provide first assessment tools to facilitate assessment of need and readiness for EOL conversations. Also, we acknowledge dual responsibility of engagement in EOL conversations by not only asking practitioners to assess and initiate conversations, but also offer an easy was of stating interest in advance care planning for patients. It becomes clear that readiness for EOL conversations is adaptable, that cancer patients are resilient to negative affect during EOL conversations, and that focus on social connections may buffer against experiences of negative affect. If cultural worldview includes positive effects of EOL conversations, positive experiences strengthen health optimism and response efficacy so that attempts at initiating EOL-related conversations are no longer ignored, nor are fears negated or dismissed. Furthermore, patients can support normalization processes by opening up in support groups, becoming experts in health behavior, and sharing positive experiences.

## 5.5 Conclusion

This dissertation project acknowledges the importance of death anxiety for cancer patients and engagement in EOL conversations. Our results indicate that death anxiety is not only a component of psychological well-being, but is also often expressed through alternative worries and barriers to EOL conversations, such as FCR. We addressed these barriers to engagement in EOL conversations among practitioners as well as patients by developing the first instrument to screen for advance care planning need. Aside from the intrinsic toll of emotional distress, we also acknowledged the practical importance of readiness for health behavior and necessity of acknowledging readiness for EOL in health care. Therefore, we developed and validated the first reliable assessment of readiness for EOL conversations—not only for a community sample, but also for cancer patients. Finally, we adapted two interventions to increase cancer patients' readiness for EOL conversations in an online setting. Our results support the use of both interventions and suggest an overall positive impact on FCR as well as death anxiety. Future research should expand our findings to various cancer types and strengthen the possibility of implementing EOL conversations in routine care.

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# 7 Appendix A: Studies

## 7.1 Study I

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ORIGINAL ARTICLE

# Death anxiety as general factor to fear of cancer recurrence

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## Abstract

**Objective:** Fear of cancer recurrence or progress is strongly related to Death anxiety (DA) in cancer patients, but due to lack of conceptualization and measurement methods, the relationship was not analyzed quantitatively before. The aim of the present study was to investigate the conceptual relationship of both constructs, with DA expected to be the general construct.

**Methods:** Cancer patients ($N = 121$) participated in an online study. They provided information on socio-demographical, medical and psychological measures including death anxiety and fear of cancer recurrence or progression (FoP-Q-SF). Relation of constructs was assessed using a two-step process: Confirming individual construct structure with confirmatory factor analysis, including correlation of constructs and modification of measurement model, followed by structural equation modeling and comparison of structure models for best model fit.

**Results:** The measurement model was modified to include three residual correlations within and between constructs. Comparison of structure models supported a bifactor structure with DA as general factor and fear of recurrence or progression as group factor: $SB\chi^2$ (173) = 207.74 ($p < 0.05$), SB = 1.538, relative $\chi^2 = 1.2$, rRMSEA = 0.05 [0.01, 0.07] ($p > 0.05$), SRMR = 0.07, CFI = 0.94, AIC = 7543.60.

**Conclusions:** DA can be interpreted as general factor to fear of cancer recurrence or progression. Psychological interventions to reduce emotional burden of cancer patients need to focus additionally on existential threat and individual fears regarding DA.

KEYWORDS

bifactor-model, cancer, death anxiety, fear of cancer recurrence, psycho-oncology, structural equation modeling

## 1 | Background

In the 21st century the promise of life includes a possible life span of up to 100 years. While modern medicine and innovation focus on delaying dying and to reduce impact of existential threats, cancer is persistently the second biggest killer and often associated with death, fear and trauma.[1] Life limiting diseases have been reported to be related to anxiety symptoms that affect experienced quality of life, social relations and daily functioning of patients.[2,3] Untreated they reduce trust in physicians, overall treatment compliance, coping ability of patients and overall health behavior.[2–5] High quality care in oncology therefore also includes recognition and treatment of

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psychological symptoms and support of coping and adaptation processes.[6]

For cancer patients, anxiety symptoms are often related to fear, worry or concern that cancer may progress or recur and defined as *fear of cancer recurrence* (FCR[7]). At severe levels, FCR may lead to avoidance or excessive use of medical appointments, feelings of isolation, insecurity, anxiety and feelings of being left alone.[8] Independent of FCR intensity, the most reported theme of importance was related to persistent intrusive thoughts about death and dying.[9]

*Death anxiety (DA)*, defined as paralyzing state of fear developed from natural survival-instinct and mortality awareness,[10] is discussed to be a transtheoretical concept that is strongly related to all variations of anxiety disorders.[11] Terror Management Theory (TMT[12]) proposes that two defense mechanisms prevent humans from experiencing a constant state of DA: First, proximal coping prevents conscious thoughts about death and dying and relies on diversion, suppression of thought and rationalization. Second, distal coping as long-term mechanism mobilizes a worldview and view of self that has meaning and provides an illusion of immortality. For cancer patients, DA becomes salient at various time points in life, possibly at first when diagnosed, with every check-up, in case of cancer recurrence or progression[13] and is found to be more elaborated when levels of FCR are high.[9]

Previous studies have focused on FCR rather than DA because of several barriers to research: Death attitudes and avoidance strategies of clinicians and researchers, lack of validated and reliable measurement tools for DA and FCR, overlap in concepts of fear of recurrence and fear of progression and uncertainty about the relationship of DA and FCR.[13] Whereas FCR includes specific dimensions, such as relationships, social functioning and ability to work, all contribute to the central fear and distress experience.[14,15] The concept of DA, however, is broader but both include regret, worries about the future and inability to successfully reach personal goals or feelings of senselessness.[16] Previous qualitative studies support the strong connection of both concepts: Cancer patients experience fear of recurrence in relation to worries about death, worries about the dying process and the impact on family members.[1,17,18] In the past years, measures to assess DA have been developed and validated[19] and researches are acknowledging the possibility of DA as transdiagnostic construct.[11] Few studies have focused on the relationship using quantitative methods and findings are controversial. Whereas FCR and sense in purpose where found strongest predictors for DA,[20] DA was coincidently found to be the second strongest predictor for FCR.[21] Sharpe and colleagues emphasized the need to address this gap in knowledge about the psychometric relationship and take the possibility of hierarchical structures into account.[13] The present study therefore aimed to provide new insights whether DA and FCR in oncology patients shared common variance that would be reflected in a bifactor structure. In bifactor structures[22] the general factor reflects shared common variance whereas the grouping factor reflects additional specific variance of traits. Based on previous research, we hypothesize that DA explains common variance as general and FCR explains additional variance as group factor.

## 2 | METHODS

### 2.1 | Ethics statement

Ethical approval was granted by the ethics committee of the psychology department of the Philipps-University of Marburg (Identification Number: 187-19). The main study was pre-registered at Open Science Framework (Registration DOI: 10.17605/OSF.IO/2VTFY).

### 2.2 | Participants

Participants were eligible if 18 years or older, were diagnosed with cancer, sufficiently understood German and had Internet access.

### 2.3 | Procedure

Participants were recruited via support group mailing lists, online platforms and social media accounts. After provision of study information and consent, participants were then contacted by an automatic email system and standardized email that contained a personalized study link. All participants were asked to answer several questionnaires, were randomly assigned to one of two micro interventions for the following 6 weeks and contacted weekly, at three and 6 months for follow up questions. The present study only presents information and questionnaires relevant to research questions and solely uses data before interventions started and participants were randomized.

### 2.4 | Measures

Self-reported socio-demographical data included age, gender, family status, living situation, religion and working status. Medical information focused on year of first diagnosis, current diagnosis and cancer site, prognosis (curative or palliative), currently in active treatment (yes/no) and psychological support (psycho-oncology or psychotherapy).

Death anxiety was measured with the *Death and Dying Distress Scale* (DADDS-G[19]). Nine items were rated from zero ("does not apply") to four ("very much so") on a five-point Likert scale, with sum scores from zero to 36.

Fear of cancer progression was measured with the *Fear of Progression Questionnaire Short Form* (FoP-Q-SF[14]). 12 items were rated on a five-point Likert scale from one ("never") to five ("very often"), with sum scores from 12 to 60. Clinical cut-off is recommended at ≥ 34.[23]

### 2.5 | Statistical analysis

Statistical analysis with R was based on completed data set for DA and FCR, missing data were controlled for missing at random before exclusion from analyses to address possible dependencies in missing values. For demographical data, homogeneity of variance was controlled for using Levene's test and differences analyzed using Students *t*-test, Welch-test or Fisher's Exact $\chi^2$-test for count data ($\alpha = 0.05$, if not noted otherwise). Bartlett's Test of Sphericity and Kaiser-Meyer-Olkin (KMO) criterion were used to control for factor sample adequacy. Violations of multivariate normality in skewness or kurtosis were tested and maximum likelihood estimations adjusted accordingly with robust standard errors and Satorra-Bentler scaled test statistic. Model fit was based on $\chi^2$-test ($p \geq 0.05$), Standardized Residuals (SRMR≤0.11), Comparative Fit Index (CFI ≥ 0.90), Root-Mean-Square-Error of Approximation (RMSEA≤0.08), relative $\chi^2$-test statistic ($\chi^2/df < 2$[24,25]) and Akaike's An Information Criterion.

In a first step,[26] we used confirmatory factor analysis (CFA) for factor specification and identification of modifications in measurement model. Based on previous studies, the original model hypothesized correlation of latent factors and allowed correlations of residuals. Modifications were conducted if theoretically explicable. In a second step, a bifactor model was defined and evaluated. All items were restricted to load on one general factor and one specific factor only. Whereas latent factors need to be uncorrelated, inter-item correlations were allowed to acknowledge item variance explicable by other factors. Models were compared with Satorra-Bentler Scaled Chi-Squared Difference Test ($\alpha = 0.05$). Additional indices for bifactor evaluation included omega coefficient (ω) and omega subscale (ωs) as estimates of the reliability of general and group factor. Omega hierarchical (ω) represents the proportion in common variance explained by the general factor. Values of $\omega_H > 0.80$ indicate unidimensional measures. Variance explained by the group factor after controlling for the impact of the general factor is represented as $\omega_{HS.}$ Construct replicability and representation of latent variables was interpreted as well-defined, stable and replicable for $H > 0.80$. Further, the percentage of uncontaminated correlations (PUC) and explained common variance (ECV) support either unidimensional or multidimensional/bifactor specification of models. The proportion of total variance explicable by the general factor is represented as ECV, whereas item-intercorrelations that reflect the general factor are indicated by PUC. Higher values on both indices (> 0.70) support unidimensional structure of common variance and strong general factor. Independent variance for the group factor was calculated comparing original ω and $\omega_s$.[27]

Sample size estimation[28] for a bifactor model was calculated for power of 80% on an alpha error of 0.05 and compared for RMSEA = 0.08 and RMSEA = 0.05, respectively. Minimum sample size varied between $N_{RMSEA.08} = 48$ and $N_{RMSEA.05} = 120$.

## 3 | RESULTS

### 3.1 | Participant characteristics

Participants ($N = 121$, Table 1) were 42.7 years old ($SD = 13.3$, *range* = 18–72), female, of high educational level and married. The majority of participants reported to have received a curative prognosis, were diagnosed in the past 5 years, reported to be diagnosed for the first time and currently in treatment. Participants reported average scores of DA ($M = 19.3$, $SD = 9.1$, *range* = 0–45) and clinical fear of progression ($M = 35.9$, $SD = 10.0$, *range* = 18–72).

### 3.2 | Two-step approach

Bartlett's test of sphericity ($\chi^2$ (210) = 1341.17, $p < 0.001$) and Kaiser-Meyer-Olkin criterion (KMO = 0.88, *range* = 0.73–0.93) supported adequacy for factor analysis. Mardia-test for multivariate normality was significant ($p < 0.001$) so that all analyses were conducted with Satorra-Bentler correction and robust standard errors. In CFA, the original model showed poor model fit (Table 2) with modification indices suggesting correlations of residuals: DA1 and DA3 described unfulfilled goals and ambitions. Fear of cancer recurrence 4 (FCR4) and fear of cancer recurrence 12 (FCR12) described reductions in performance at work place. Death anxiety 8 (DA8) and fear of cancer recurrence 11 (FCR11) broached the issue of worries about family members left behind (Supplementary Material, Table S3 and S4). Correlation of these residuals improved fit significantly ($\Delta_{\text{SB-scaled}} = 89.15$, $\Delta_{df} = 3$, $p < 0.001$). All residual correlations were significant but varied in strength: DA and FOR ($r = 0.74$) and FOR4 and FOR12 ($r = 0.70$) correlated strongly, for DA8 and FOR11 ($r = 0.53$) and DA1 and DA3 ($r = 0.45$) correlation was medium, and small for DA3 and DA6 ($r = 0.27$). For the structural model, bifactor structure (Figure 1) with DA as general factor, FCR as group factor, and inter-correlations of residuals improved goodness of fit indices considerably, power was good (β = 82.60%, Table 2).

### 3.3 | Bifactor model of death anxiety with correlations

Factor loadings for the general factor and group factor of fear of progression are presented in Table 3. Factor loadings of all items were significant ($p < 0.05$) for the general factor DA except item FOR4 (*Being afraid of becoming less productive at work*), whereas three FCR-items showed no significant loadings on FCR (*Being nervous prior to doctor's appointment or periodic examinations*, *Being afraid of the possibility that the children could contract cancer*, *Worrying about what will become of the family*). The majority of all items had strong factor loadings ($\lambda \geq 0.40$) on the general factor, whereas FCR-items ranged from $\lambda = 0.15$ to $\lambda = 0.58$ on the group factor and 50% had higher factor loadings on the general factor.

The observed $\omega_h$ indicated that 78.01% of variance of the composite DA score was attributable to the general factor, with more than 50% of item-intercorrelations (PUC = 68.57%) and 75.14% of common variance accounted for by DA. When controlled for variance attributable to DA, the observed $\omega_h$ for FCR ($\omega_s = 48.82\%$) still indicated importance of unique variance: Comparison of the model implied ω and $\omega_s$ suggests that 62.58% of reliable variance in FCR is

**TABLE 1** Patient characteristics

| Socio-demographical data | n (%) | Psychological and medical data | n (%) |
|---|---|---|---|
| Age (M,SD,range) | 42.7 (13.3,18–72) | Psycho-oncology | |
| Gender | | Yes | 62 (51.2) |
| Male | 13 (10.7) | No | 59 (48.8) |
| Female | 108 (89.3) | Psychotherapy | |
| Family | | Yes | 32 (26.4) |
| Single | 19 (15.7) | No | 89 (73.6) |
| Partnership | 40 (33.1) | Diagnosis | |
| Married | 59 (48.8) | First | 72 (59.5) |
| Divorced | 1 (0.8) | Second | 6 (5.0) |
| Widowed | 2 (1.7) | Third | 2 (1.7) |
| Education | | Recurrent | 13 (10.7) |
| Middle school | 3 (2.6) | Cancer free | 25 (20.7) |
| Secondary school | 9 (7.4) | Other | 3 (2.5) |
| A-level | 22 (18.2) | Treatment | |
| Training | 22 (18.2) | Yes | 91 (76.9) |
| Master | 1 (0.8) | No | 30 (24.8) |
| University | 64 (52.9) | Prognosis | |
| Work | | Curative | 93 (76.9) |
| Unemployed | 8 (6.6) | Palliative | 28 (23.1) |
| Part-time | 30 (24.8) | | |
| Full-time | 36 (29.8) | | |
| Housewife/-husband | 4 (3.3) | | |
| Retirement | 18 (14.9) | | |
| Other | 25 (20.7) | | |
| Living | | | |
| Alone | 18 (14.9) | | |
| Shared flat | 7 (5.8) | | |
| Family | 96 (79.4) | | |

*Note*: Average (*M*), standard deviation (*SD*), percentage (%) and number of participants (valid *n*).

**TABLE 2** Fit indices for structural models of Death anxiety (DA) and fear of cancer recurrence or progression

| Model | SB $\chi^2_{(df)}$ | SB | $\chi^2$/df | rRMSEA (90%-CI) | SRMR | rCFI | AIC |
|---|---|---|---|---|---|---|---|
| Confirmatory factor analysis | | | | | | | |
| Two-factor oblique model (original) | $419.23_{(187)}$*** | 1.150 | 2.24 | 0.11 [0.10;0 .11]*** | 0.09 | 0.77 | 7677.95 |
| Two-factor oblique model (modified correlated residuals) | $298.93_{(184)}$*** | 1.143 | 1.62 | 0.08 [0.06;0 .09]* | 0.08 | 0.90 | 7543.60 |
| Structural equation modeling | | | | | | | |
| Bifactor model (modified correlated residuals) | $207.75_{(173)}$* | 1.538 | 1.20 | 0.05 [0.01;0 .07] | 0.07 | 0.94 | 7543.60 |

*Note*: $N = 121$, $p < 0.001$***$p < 0.01$**$p < 0.05$*.

Abbreviations: AIC, Akaike's An Information Criterion; df, degrees of freedom; rCFI, robust Comparative Fit Index; rRMSEA, relative χ2, robust Root Mean Square Error of Approximation; SB χ2, Satorra-Bentler χ2; SB, Satorra-Bentler scaling correction factor; SRMR, Standardized Root Mean Square Residuals.

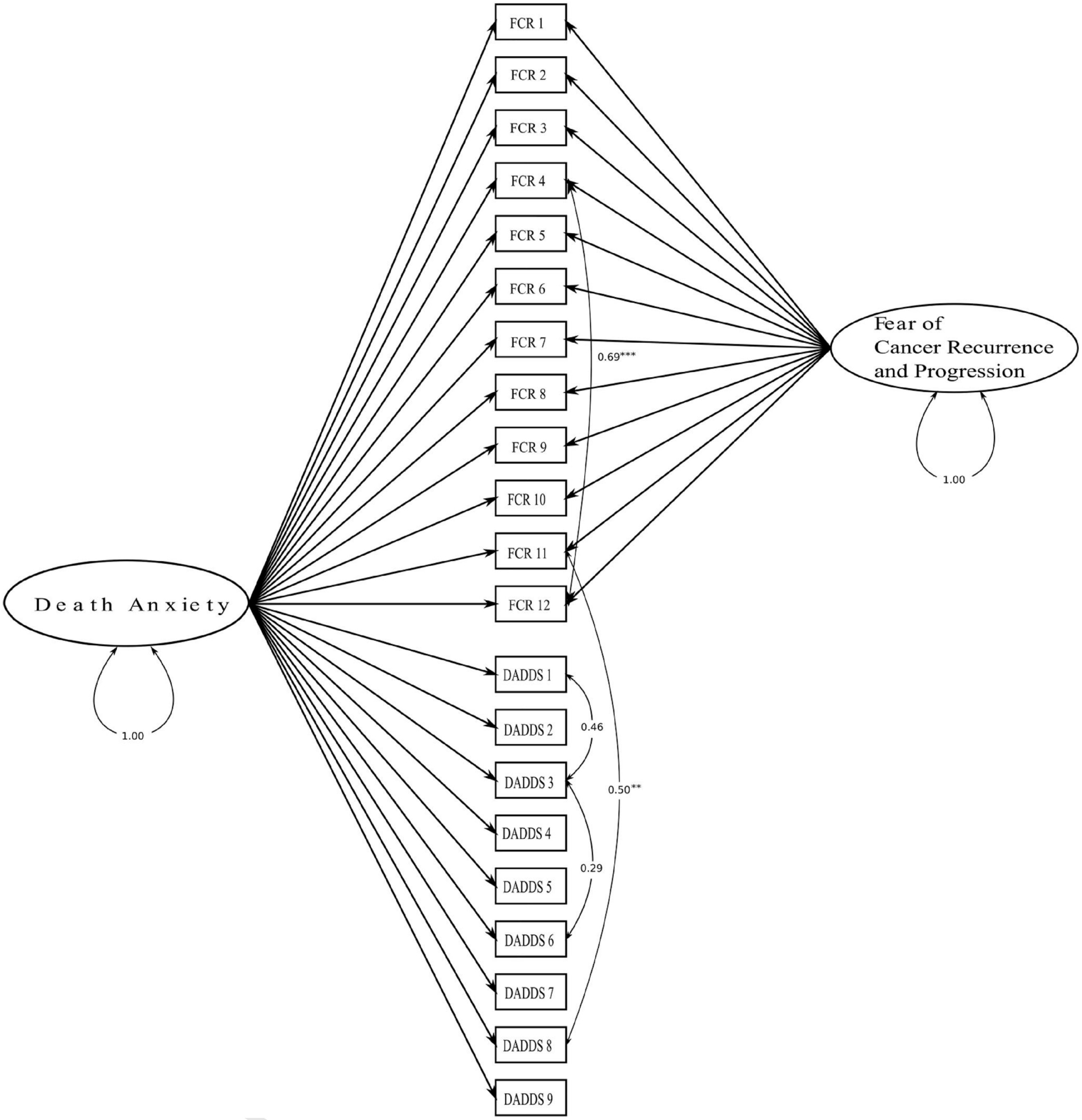

**FIGURE 1** Bifactor model of Death anxiety (DA) as general factor and fear of cancer recurrence or progression as specific group factor with correlations of residuals. Latent variables (ellipses), indicators (rectangles) for 12 items of Fear of Progression Questionnaire-Short Form[14] ($FCR_i$) and nine items of Death and Dying Distress Scale-German Version (DADDS)[19] ($DADDS_j$), covariances (double headed arrows), and estimation (one headed arrows) of latent variables. Significance of correlations ($p > 0.05$, $*p < 0.05$, $**p < 0.01$, $***p < 0.001$)

independent from the general factor ($\omega_s/\omega$). Construct replicability for the general factor (H = 93.10%) was excellent and good for the group factor (H = 74.92%). The results suggest that a multidimensional structure cannot be ignored and additional influences on FCR should be considered. However, impact of DA on fear of cancer recurrence and progression is strongly highlighted by high levels of unidimensionality.

## 4 | DISCUSSION

As universal construct, DA is discussed to be an underlying concept to many psychological disorders.[11] For cancer patients, specific fears of cancer recurrence or progression (FCR) are often expressed in relation to death, dying and its impact on loved ones.[9,20] The present study aimed to provide new insights whether the relationship

**TABLE 3** Bifactor loadings on general and group factor

| | General (death anxiety) | | | Group (fear of progression or recurrence) | | |
|---|---|---|---|---|---|---|
| **Item** | **λ** | **se** | ***p*** | **λ** | **se** | ***p*** |
| DA1 | 0.50 | 0.15 | 0.001 | | | |
| DA2 | 0.50 | 0.16 | 0.001 | | | |
| DA3 | 0.72 | 0.11 | 0.000 | | | |
| DA4 | 0.81 | 0.05 | 0.000 | | | |
| DA5 | 0.77 | 0.08 | 0.000 | | | |
| DA6 | 0.65 | 0.11 | 0.000 | | | |
| DA7 | 0.84 | 0.06 | 0.000 | | | |
| DA8 | 0.70 | 0.07 | 0.000 | | | |
| DA9 | 0.73 | 0.07 | 0.000 | | | |
| FCR1 | 0.63 | 0.10 | 0.000 | 0.35 | 0.17 | 0.036 |
| FCR2 | 0.50 | 0.13 | 0.000 | 0.36 | 0.26 | 0.177 |
| FCR3 | 0.46 | 0.12 | 0.000 | 0.37 | 0.18 | 0.040 |
| FCR4 | 0.25 | 0.15 | 0.106 | 0.45 | 0.16 | 0.006 |
| FCR5 | 0.43 | 0.11 | 0.000 | 0.43 | 0.20 | 0.029 |
| FCR6 | 0.42 | 0.14 | 0.002 | 0.22 | 0.17 | 0.194 |
| FCR7 | 0.48 | 0.12 | 0.000 | 0.54 | 0.15 | 0.000 |
| FCR8 | 0.35 | 0.14 | 0.009 | 0.56 | 0.19 | 0.003 |
| FCR9 | 0.55 | 0.09 | 0.000 | 0.55 | 0.12 | 0.000 |
| FCR10 | 0.34 | 0.13 | 0.008 | 0.58 | 0.12 | 0.000 |
| FCR11 | 0.48 | 0.12 | 0.000 | 0.15 | 0.16 | 0.349 |
| FCR12 | 0.26 | 0.12 | 0.037 | 0.38 | 0.13 | 0.003 |

*Note*: $N = 121$, factor loadings (λ), standard errors (se) and significance value (*p*). Death anxiety (DA) and fear of progression and recurrence (FCR) items.

between DA and FCR is hierarchical and DA can be seen as general construct.

The mean finding of this study was the verification of DA as general factor and FCR as group factor. This is the first psychometric evidence for transdiagnostic impact of DA[11] on FCR experience for cancer patients. It supports researchers who are increasingly emphasizing to include DA in FCR conceptualization[13] and provides statistical evidence for qualitative connection of DA and cancer experience. So far, underestimating the role of DA could have impacted effectiveness of evidence based approaches to reduce FCR, resulting in persistent and stable FCR experiences over survivorship trajectory.[29] For example, do recent conceptualizations of FCR[30] expect cancer related triggers and uncertainty experiences to result in activation of terror management defenses, that are commonly known to be related to DA experience. The incorporation of defense mechanisms emphasizes the need for interventions specifically supporting coping strategies against DA. Therefore, future studies should also evaluate whether DA is the key component to development and persistency of FCR. Longitudinal studies may rely on cross-lagged panel designs to define causality.

Additionally, we found three item inter-correlations that indicate additional factors of interest not fully explained by FCR or DA. First, inter-construct correlation for *Worrying what will become of my family if something happens to me* (FCR11) and *Being a burden to others* (DA8) highlighted the importance of attachment avoidance assessed in both questionnaires. It supported common associations of severe anxiety with perceived burden to others[20] and the possibility to address DA with supportive expressive therapy.[30] Strengthening healthy emotional expression and tolerance for distressing topics, relying on others and experiencing social support improve chances of successful coping with FCR and DA.[32] Therefore, promotion of supportive expressive therapy with inclusion of family members may reduce social constraints and improve general coping abilities. If patients are not constraint to acknowledge mortality and express emotions, they could be able to cope self-efficiently.

Second, the majority of reliable variance of FCR was independent of DA and indicates possible influence of alternative predictors. When focusing on factor loadings, two major aspects become apparent: First, impact of cancer on performance at work is highly relevant to the experience of FCR. Inter-correlation of *Being afraid of becoming less productive at work* (FCR4) and *Being afraid of not being able to work anymore* (FCR12) in addition to stronger and significant factor loadings emphasize moderating influences: Cancer treatment may result in work absences, loss of working place and career opportunities, debt and consequently increases distress for cancer patients.[33] Cancer recurrence or progress becomes a threat to financial security. Conversely, factor loadings indicate independence of work performance but importance of working ability for DA. Proximal defenses could include diversion of attention by focusing on work as opposed to acknowledgement of death. Distal defense mechanisms could include finding meaning and self-esteem in work related activities. They may have buffered against DA experience[34] and reduced availability of death related thoughts Then constrained focus on working ability indicates a dysfunctional coping strategy and is needed to be addressed in psycho-oncological interventions. Therefore, possibility of unemployment is not only an economical, but also existential threat. At present, multi-component interventions may not suffice and interdisciplinary tailored interventions that address functionality of work are needed.

Finally, stronger and significant factor loadings of *Being afraid of relying on strangers for activities of daily living* (FCR 7), *Being afraid of no longer being able to pursue hobbies* (FCR 8) and *Worrying that medications could damage the body* (FCR 10) on FCR compared to DA could represent independent impact of treatment and physical impairment on daily life. However, contrary to items assessing work abilities, physical impairment is a known amplifier to both DA[35] and FCR.[30] Since in the present sample relations to FCR were stronger, interaction with prognosis may be the more relevant moderator: Positive disease trajectory and desire to return to normality may be threatened by recurrence. With palliative diagnosis progress could rather be related to fear of dying. Patients majorly reported curative diagnosis so that fears of physical impairment were stronger related to FCR. Future studies should therefore include measurements that discriminate successfully between fear of cancer progress and fear of cancer recurrence, and evaluate whether disease prognosis may have a moderating, whereas physical impairment may be of mediating influence to FCR and DA experience.

## 4.1 | Clinical implications

Based on these psychometric findings, adaptation in existing interventions are necessary. First, promising additional treatments focus on existential components. Cognitive existential therapies, for example, have targeted appraisal of meaning making to facilitate coping with FCR,[30] in fact addressing distal terror management defense mechanisms.[12] Distal defense mechanisms focus on values, self-esteem, and social connectedness, for example, redefining what is important in life. Consequently, acknowledgement of personal achievements and social relations evoke positive emotions, reduces FRC and DA.[30,31] A combination of cognitive behavioral therapy and existential therapy could target proximal defenses with exposure therapy, and distal defenses with meaning making and communication strategies.[36] End-of-life conversations during exposure therapy of DA may further prove beneficial in increasing sense of control[36] and normalization. Also, addressing psychological flexibility in oncological patients may successfully address distal defenses[37]: High levels of DA and FCR could be reduced through double awareness, the constant flexibility in acknowledging probability and normality of death while enjoying life.[38] This includes engagement in death related health behavior (e.g. check-ups, end-of-life conversations) while aware of possible negative outcomes and being able to focus on a positive perspective. Finally, tailored interventions that focus on individual fears and worries about death and dying, the cost of death rather than on its probability could foster neutral acceptance of death[36]: Preliminary research results support improvements in acceptance, reduction of cognitive avoidance, intolerance of uncertainty and general worry or increased use of emotional support.[39]

## 4.2 | Limitations

Strengths of the present study include high relevance of research topic, innovative conceptualization and demanding psychometric analyses. However, there are some limitations that we discuss critically. Population bias includes affinity to online participation, openness to end-of-live conversations, young age and female gender as known risk factors to FCR. Future studies need expanded sample characteristics for more reliable interpretation. Based on the present sample, we cannot assume representativeness. Also, assessment in varying settings may reveal differences in appraisal of both constructs and needs to be considered. Additionally, international validation of the DADDS[40] now suggests two latent factors: *Dying* and *Finitude*. For the German version, items related to *Dying* were originally removed from the item pool.[19] Therefore, one could argue that the present study does not address worries regarding pain, isolation and unexpectedness but solely focus on the bifactor relationship of *Finitude* and FCR. However, we believe inclusion of specific fears to further strengthen the impact of DA because of similar item content to FCR. Furthermore, there exist several tools for either DA or FCR not used in the present study and the German questionnaire for FCR assessment largely focuses on progression of cancer. Alternative questionnaires (e.g. Cancer Worry Scale) may include more items that cover fear of recurrence and change the impact of DA on common variance. Replication studies therefore should include different questionnaires to strengthen or challenge the interpretation of DA as transdiagnostic construct. Finally, alternative recommendations for size estimation highlight the necessity to replicate our findings in larger samples to avoid misspecification and misinterpretation. At present, our results can mainly be used as inspiration for future research and encouragement to further acknowledge the impact of DA for cancer patients.

## 5 | CONCLUSION

Death anxiety as overarching construct with a specific value to cancer patients when experiencing fear of recurrence or progression needs to be acknowledged and treated more vigorously in psycho-oncology. With improving flexibility and double awareness for cancer patients, providing strategies that not only focus on direct impact due to cancer, cancer treatment and side effects but also to the broader concept of changes in life, goals and end-of-life expectations and death related fears, psycho-oncological interventions hold the possibility to reduce experienced distress and to improve feasibility of interventions for patients.

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### CONFLICT OF INTEREST

We have no conflicts of interest to disclose.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon request.

### ETHICS STATEMENT

Ethical approval was granted by the ethics committee of the psychology department of the Philipps-University of Marburg

(Identification Number: 187-19). The main study was pre-registered at Open Science Framework (Registration DOI: 10.17605/OSF.IO/2VTFY).

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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## Supplemental material

Table 3. Fear of Progression Questionnaire Short Form

| Item | Content |
|---|---|
| 1 | Being afraid of disease progression. |
| 2 | Being nervous prior to doctor's appointments or periodic examinations. |
| 3 | Being afraid of pain. |
| 4 | Being afraid of becoming less productive at work. |
| 5 | Having physical symptoms (e.g. rapid heartbeat, stomach ache). |
| 6 | Being afraid by the possibility that the children could contract the disease. |
| 7 | Being afraid of relying on strangers for activities of daily living. |
| 8 | Being afraid of no longer being able to pursue hobbies. |
| 9 | Being afraid of severe medical treatments in course of illness. |
| 10 | Worrying that medications could damage the body. |
| 11 | Worrying what will become of family if something happens to me. |
| 12 | Being afraid of not being able to work anymore. |

Table 4. Death and Dying Distress Scale German

| Item | Over the past two weeks, how distressed did you feel about … |
|---|---|
| 1 | Not having done all the things that I wanted to do. |
| 2 | Not having said all that I wanted to say to people I care about. |
| 3 | Not having achieved my life goals and ambitions. |
| 4 | Not knowing what happens near the end of life. |
| 5 | Not having a future. |
| 6 | The missed opportunities in life. |
| 7 | Running out of time. |
| 8 | Being a burden to others. |
| 9 | My own death and dying. |

## 7.2 Study II

PLOS ONE

# Need for advance care planning – Development of a screening tool for cancer patients

--Manuscript Draft--

| | |
|---|---|
| **Manuscript Number:** | |
| **Article Type:** | Research Article |
| **Full Title:** | Need for advance care planning – Development of a screening tool for cancer patients |
| **Short Title:** | ACP Screening |
| **Corresponding Author:** | Pia Berlin<br>University of Marburg: Philipps-Universitat Marburg<br>Marburg, GERMANY |
| **Keywords:** | Advance Care Planning; cancer; Screening |
| **Abstract:** | Background<br>If a patient lacks capacity to consent, consent to medical procedures must usually be given by proxy. To provide best medical care concordant to patient wishes advance care planning is a useful tool. Although benefits are widely reported, patients often refrain from uptake and timing is difficult. At present there exists no screening method to reliably identify patients in need. The present study provides the first screening tool for need for advance care planning in hospital settings.<br>Methods<br>In phase one ( $N = 92$), screening items were developed based on three consecutive steps of item development, feasibility analysis and item reduction based on item difficulty and discriminatory value. In phase two ( $N = 201$), reduced screening items were analysed for predictive value of need for ACP. Statistical analysis included item difficulty and discriminatory value, ROC analysis (AUC > .80), identification of optimal cut-off based on sensitivity and specificity, interpretation of Odds-Ratio and construct validity using correlation with death anxiety, communication avoidance within families and relationship with the treating physician.<br>Results<br>Participants in phase one and two were approximately 60 years old, with palliative diagnosis and negative surprise question. After item reduction, predictive value of four items with good item difficulty ($P_i$ =.23-.49) and item discrimination ( $r_{itc}$ =0.60-0.75) were compared for mild, moderate and great levels of death anxiety. The combination of I am burdened by thoughts of an unfavourable course of the disease and I am burdened by the feeling of being ill-prepared for the end of life showed best prediction of death anxiety and communication avoidance. Clinical cut-off was found at sum-score ≥ 6, with high levels of sensitivity (95%) and specificity (81%). Participants with clinical distress experience, levels of depression or anxiety or self-perceived palliative health status were more likely in critical need for ACP. Utilization of psycho-oncological support systems and reported contemplation or preparation stage of health behaviour change was related to higher chance of subjective wish for ACP.<br>Conclusion<br>Screening for need of advance care planning is possible with two objective items and a proposed clinical cut-off of six. Subjective wish for advance care planning is recommended to be assessed additionally and with an uncertainty-option to provide information. Positive screening therefore indicates when to offer ACP discussions and provides routine estimation of ACP-need in clinical practice. |
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| | |
|---|---|
| **Competing Interests**<br>Use the instructions below to enter a competing interest statement for this submission. On behalf of all authors, disclose any competing interests that could be perceived to bias this work—acknowledging all financial support and any other relevant financial or non-financial competing interests.<br>This statement is required for submission and **will appear in the published article** if the submission is accepted. Please make sure it is accurate and that any funding sources listed in your Funding Information later in the submission form are also declared in your Financial Disclosure statement.<br>View published research articles from *PLOS ONE* for specific examples.<br>**NO authors have competing interests**<br>Enter: *The authors have declared that no competing interests exist.*<br>**Authors with competing interests**<br>Enter competing interest details beginning with this statement:<br>*I have read the journal's policy and the authors of this manuscript have the following competing interests: [insert competing interests here]*<br>* typeset | The authors have declared that no competing interests exist. |
| **Ethics Statement**<br>Enter an ethics statement for this submission. This statement is required if the study involved:<br>• Human participants<br>• Human specimens or tissue<br>• Vertebrate animals or cephalopods | The present study received written approval by the ethics committee of the University Hospital of Gießen and Marburg in Marburg (ID: 187-19) and was pre-registered at the German Registration for Clinical Studies (ID: DRKS00024700). |

| | |
|---|---|
| - Vertebrate embryos or tissues<br>- Field research<br><br>Write "N/A" if the submission does not require an ethics statement.<br><br>General guidance is provided below. Consult the submission guidelines for detailed instructions. **Make sure that all information entered here is included in the Methods section of the manuscript.** | |

| | |
|---|---|
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Cover Letter

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01/12/2021

**Dear Mr. Herber,**

hereby we submit the manuscript entitled

**Need for advance care planning – Development of a screening tool for cancer patients**

for publication as research article in *PLOS ONE*.

In this manuscript, we aimed to develop a first screening tool for cancer patients' need for advance care planning in a hospital setting. For cancer patients and their family members, diagnosis, recurrence or progression of cancer have been known to arouse worries and distress about death and dying, respectively. High quality in cancer care therefore includes the discussion of all treatment options and possibilities at the end-of-life. However, for many practitioners and people affected, the specific time to initiate advanced care and end-of-life conversations is difficult to identify. The present study focused on developing a screening tool to assist practitioners in identification and facilitate first contact for patients in need of advance care planning. Items were reduced to a minimum in order to ease implementation in hospital routine care.

The manuscript is 31 pages long, includes seven tables, has not been previously published and is not presently under consideration for publication elsewhere.

All of the authors of this article had access to study data, are responsible for all contents of the article, had authority over manuscript preparation and agreed to submission of the manuscript in this form. Listed authors have significantly contributed to the manuscript in its present form and do not have any conflict of interest. The study has been conducted in accordance with the Declaration of Helsinki and received ethical approval by the medical ethics committee of the Philipps University Marburg.

Please address all correspondence concerning this manuscript to me (berlinp@staff.uni-marburg.de).

We hope that you will find our paper suitable for publication in *PLOS ONE*.

Sincerely on behalf of all authors,

Pia Berlin

# Need for advance care planning – Development of a screening tool for cancer patients

Short title: ACP Screening

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# Abstract

Background: If a patient lacks capacity to consent, consent to medical procedures must usually be given by proxy. To provide best medical care concordant to patient wishes advance care planning is a useful tool. Although benefits are widely reported, patients often refrain from uptake and timing is difficult. At present there exists no screening method to reliably identify patients in need. The present study provides the first screening tool for need for advance care planning in hospital settings.

Methods: In phase one (*N*=92), screening items were developed based on three consecutive steps of item development, feasibility analysis and item reduction based on item difficulty and discriminatory value. In phase two (*N*=201), reduced screening items were analysed for predictive value of need for ACP. Statistical analysis included item difficulty and discriminatory value, ROC analysis (AUC>.80), identification of optimal cut-off based on sensitivity and specificity, interpretation of Odds-Ratio and construct validity using correlation with death anxiety, communication avoidance within families and relationship with the treating physician.

Results: Participants in phase one and two were approximately 60 years old, with palliative diagnosis and negative surprise question. After item reduction, predictive value of four items with good item difficulty ($P_i$=.23-.49) and item discrimination ($r_{itc}$=0.60-0.75) were compared for mild, moderate and great levels of death anxiety. The combination of *I am burdened by thoughts of an unfavourable course of the disease* and *I am burdened by the feeling of being ill-prepared for the end of life* showed best prediction of death anxiety and communication avoidance. Clinical cut-off was found at sum-score ≥ 6, with high levels of sensitivity (95%) and specificity (81%). Participants with clinical distress experience, levels of depression or anxiety or self-perceived palliative health status were more likely in critical need for ACP.

Utilization of psycho-oncological support systems and reported contemplation or preparation stage of health behaviour change was related to higher chance of subjective wish for ACP.

Conclusion: Screening for need of advance care planning is possible with two objective items and a proposed clinical cut-off of six. Subjective wish for advance care planning is recommended to be assessed additionally and with an uncertainty-option to provide information. Positive screening therefore indicates when to offer ACP discussions and provides routine estimation of ACP-need in clinical practice.

## Keywords

Advance Care Planning, Cancer, Screening

# Introduction

Every person has the right to choose and consent to medical decisions and treatment. In case of incapacity to consent, proxy decision-makers are relied on to follow patients' preferences and provide treatment accordingly. Advance care planning (ACP) is a reliable tool for jointly identifying values and preferences with proxy decision-makers in order to determine the best concordant alternate decisions for times of incapacity. It may prevent overtreatment, enhance access to palliative care including hospice care [1–4] and reduce distress for family members during decision-making and post-bereavement [1–3]. ACP may further assure healthcare practitioners in treatment choices according to patients' wishes [4,5], while relieving healthcare systems of undesirably high utilisation and intensive care costs [6].

A recently published position paper by intensive care physicians [7] emphasizes the medical problem of overtreatment in intensive care units in Germany. For one they propose to address overtreatment by further integrating ACP programs nationwide and cost-covering, supporting palliative cancer care guidelines in Germany considering ACP essential for optimal medical care [8]. Their request aligns with suggestions to address multiple levels of an organisational system in order to sustain change [9]. However, timing and initiation of these conversations are difficult, especially in inpatient hospital care, but adequate reflection of patients' values, goals and preferences has been shown to depend on such [10]. Even though ACP or end-of-life discussions are advised to be initiated early [11], favourable time points could not be generalised [10]. With ever-changing medical possibilities, the extent of impact and prognosis may change and disease progression becomes difficult to estimate. Aside from individual circumstances, this heterogeneity complicates identification of a „good" time point for invitation, initiation and preparation of ACP [8]. These uncertainties result in patients with cancer being inconsistently offered access to ACP at early stages, when there are major changes in medical condition, but also regardless of health status.

A possibility to subtly identify persons in need is a screening instrument [12]. Repeated screening enables healthcare practitioners to provide necessary interventions in relation to changes in health status of patients and at critical time points in treatment [13] and is a mandatory core component of cancer care in German clinics [8]. They are economic, easy and fast to perform, expected to be used regularly and constantly as crucial part of routine care [14–17]. At present, screening for distress and following interventions do not include *ACP-need*. Rather, need assessment is multifactorial influenced by prognostic uncertainties, service availability and information deficits among patients [18,19], family members and healthcare professionals [20,21]. Physicians often misjudge readiness for ACP [22] which in turn reduces ACP engagement. For patients, due to various barriers, including death anxiety and accompanying feelings of helplessness, powerlessness or sense of unreality of prognosis, avoidance of necessary end-of-life care preparations occur [23–25]. While patients report to be highly interested in ACP, they further admit to ultimately not using ACP services [26]. Given the importance of ACP to improve patient care at the end of life and the barriers in clinical hospital practice to identify appropriate time points for initiation, the development of a screening tool is necessary to ultimately provide reliable indication that ACP discussions should be offered [27]. Therefore, the present study objective addresses the supply gap and aims to develop the first screening tool to asses *ACP-need* in cancer patients at a university hospital in Germany.

# Methods

## Ethics statement

The present study (ID: 187-19) received approval by the ethics committee of the University Hospital of Gießen and Marburg in Marburg and was pre-registered at the German Registration for Clinical Studies (ID: DRKS00024700).

## Participants

Cancer patients currently undergoing treatment at the University Hospital Giessen and Marburg (Marburg site) were eligible for participation in the study. A minimum age of 18 and sufficient understanding of the German language were mandatory.

## Procedure

A multi-professional expert panel discussed all components for item development and consisted of 7 accomplished researchers in the field who were also trained as ACP facilitators.

A preliminary version was piloted with cancer patients (*n*=10, 50% palliative, 50% female) at the interdisciplinary chemotherapy clinic in March 2020. Patients rated developed items on feasibility, understanding, wording and relevance.

All items were presented to in- and outpatients of the UKGM from May 2020 until March 2021 (both study phases). Questionnaires for validation purposes were asked to be rated accordingly. A recruitment team controlled daily for possible incoming patients. Participants were asked to fill out the questionnaire upon arrival for check-ups, treatment or consultations. After completion of questionnaire, participants who reported self-perceived wish for ACP (“unsure” or “yes”) were contacted and provided with additional information if necessary. If interest remained, appointments were distributed, ACPs provided and documentation in patient files. Patients were asked to update ACPs dependent on health status and changes.

An interim analysis after an initial recruitment phase focused on reduction of potential screening items. Early item reduction was expected to reduce possible emotional strain and exhaustion. Items were evaluated based on quantitative and qualitative results from pilot testing. Extracted items were discussed, revised if necessary and presented to participants in the second recruitment phase. Recruitment limitation was further used to assess whether requests for ACP could be answered sufficiently as we were ethically obligated to provide the intervention we were screening for.

## Item development

Although it is difficult to state specifically which factors lead to ACP being subjectively desired, twelve screening items were developed based on the known and theoretical unmet needs by the expert panel. Items one, three and five combine information about worries of prolonged treatment and inability to consent (table 1), because it was assumed that patients extremely differ in their need for autonomy. Some wish to control and to participate in decision-making processes whereas others prefer to avoid responsibility [28]. Nevertheless, while being confident of their knowledge and understanding, surrogates interpretations often differ from patients’ preferences [29].

Items two, seven, nine and 11 were developed in regard to distress because of communication barriers. Difficulties in family communication include hiding of concerns or fears regarding the disease, the intention to protect others from experience of distress and the expectation of negative aspects of cancer to be harmful [1]. Further, family members may be insecure about initiation of emotional end-of-life conversations and cancer care because of their own fears [30]. Communication processes between family members and cancer patients are influenced by barriers at all disease stages, but tension increases with illness progression [2]. Mortality communication may be affected especially during the last weeks and therefore avoided. ACP is a reliable method to guide mortality communication and sensitively address concerns about death and dying, medical decisions and to support communication processes.

Items four, 10 and 12 were developed to assess aspects of death anxiety in hope to identify those patients who would not initiate conversations because a key element in avoidance or postponing of ACP was found in death anxiety. Patients reported to either avoid end-of-life related topics or feel unprepared, helpless and without support of medical staff or families [25].

Ratings of all eleven items copied the already existent screening instrument for cancer related distress in its short version [31]. If applicable, patients rate their agreement on a scale from one ("hardly applicable") to five ("distresses me immensely"). However, the rating scale acknowledges that items do not have to apply to every patient in terms of content (0 = "does not apply").

Finally, an additional item assesses self-stated *wish for ACP*: *I am interested to partake in advance care planning*. Based on recommendations [32], patients' uncertainty about the amount of information and decision-making was taken into account by offering the possibility of "*unsure*" to the generally offered answers "*yes* " and "*no*". Research has shown that it is important to combine self-perception with external perception of need to identify patients in need [33,34]. Also, while patients may often wait for medical staff to initiate end-of-life conversations [18], a self-report screening item that offers the possibility of guided ACP opens channels of communication. It further releases medical staff of the necessity to identify the perfect time for ACP based on intuition and biased by personal fears or barriers.

## Table 1. Item development by expert panel.

| Nr. | German | English |
|---|---|---|
| 1. | Ich habe Sorge, dass ich nicht über meine medizinische Versorgung bestimmen kann, wenn ich sterbenskrank bin. | I worry that I won't have control over my medical care if I am terminally ill. |
| 2. | Es belastet mich, dass ich nicht über die Themen Tod und Sterben sprechen kann. | It burdens me that I cannot talk about the topics of death and dying. |
| 3. | Ich habe Sorge, dass mein Sterben irgendwann unnötig in die Länge gezogen würde. | I worry that my dying would be unnecessarily prolonged at some point. |
| 4. | Mich belasten Gedanken an Tod und Sterben. | I am burdened by thoughts of death and dying. |
| 5. | Ich mache mir Sorgen darüber, dass ich wegen meiner Erkrankung irgendwann nicht mehr über meine medizinische Behandlung bestimmen kann. | I worry about not being able to control my medical treatment at some point because of my condition. |
| 6. | Mich belastet das Gefühl, für das Lebensende schlecht vorbereitet zu sein. | I am burdened by the feeling of being ill-prepared for the end of life. |
| 7. | Ich habe bisher zu wenig mit meinen Angehörigen darüber gesprochen, was passiert, wenn sich meine Krankheitssituation verschlechtert. | I haven't talked enough with my loved ones about what happens when my disease situation worsens. |
| 8. | Ich habe das Gefühl, meinen Zustand zu verschlechtern, wenn ich eine Patientenverfügung ausfülle. | I feel like I'm making my condition worse by filling out a living will. |
| 9. | Es belastet mich, dass ich mit meinen Angehörigen über das Thema „letzte Lebensphase“ sprechen müsste. | It stresses me out that I would have to talk to my relatives about the topic "last phase of life". |
| 10. | Ich habe Angst davor über das Lebensende zu sprechen. | I am afraid to talk about the end of life. |
| 11. | Ich habe Schwierigkeiten mit meinen Angehörigen über das Lebensende zu sprechen. | I have difficulty talking to my loved ones about the end of life. |
| 12.[1] | Mich belasten Gedanken an einen ungünstigen Krankheitsverlauf. | I am burdened by thoughts of an unfavourable course of the disease. |

[1] The item was added after item reduction processes and expert panel discussion in Phase 1 to acknowledge the connection of fear of progression with death anxiety and possible need for advance care planning.

# Additional measures

## Socio-demographical and medical information

Socio-demographical data was assessed with a standardized questionnaire. Medical data was obtained through digital patient files and included year of diagnosis, diagnosis at present (e.g. cancer free, first diagnosis, recurrence), cancer site and treatment goal (cancer free, curative, palliative). Status of palliative diagnosis was rated based on the “surprise question”. If treating physicians are not surprised when the patient dies within the next six months, surprise question is rated as *negative* and indicates advanced palliative health status, otherwise as *positive*. Psychological data was assessed based on self-report ("I currently use the following support services") and with questionnaires focusing on distress, depression and anxiety.

### Validity measures

Cancer related distress (DT[35]), depression and anxiety levels (PHQ-4[36]), family avoidance of communication (FACC-G[37]), death anxiety (DADDS-G [38]) and readiness for advance care planning engagement (ACP-E [39]) were used to confirm construct validity (S1 Methods). Discriminant validity was assessed with quality of relationship with the treating physician (FACT-G [40]).

## Statistical analysis

### Sample size estimation

Sample size was estimated a-priori for ROC-analysis-comparison with AUC=.80 for both tests and 80% power ($\alpha$=.05) at $n$=90 participants [41] and applied to item reduction ($n$=90), respectively. Consequently, a minimal total sample size of $N$=200 was pursued.

### Item reduction

Items were compared based on item difficulty and variability, discriminatory power and item intercorrelations. Medium item difficulty ($P_i$=20-80) ensured that items are neither too easy to answer or agree to ($P_i$>80) nor too difficult ($P_i$<20). Discriminatory power ($r_{itc}$) between responses was expected to be good ($r_{itc}$>.4) and high, because items were designed for a homogenous questionnaire. Item intercorrelation ($r_{iic}$) were anticipated to be moderate to high ($r_{iic}$>.5).

### Item selection

Items were compared based on item difficulty ($P_i$) and discriminatory power ($r_{itc}$) adopting the same criteria as for item reduction. Additional analyses included correlation with validation measures. For discriminant validity, correlations were expected to be low ($r<.3$) and not significant. For convergent validity, correlations were anticipated to be moderate to high ($r>.3$) and significant. Sensitivity and specificity were used to identify the optimal cut-off point with moderate to high discrimination indicated through partial Area Under the Curve (pAUC≥.80, 42). Screening instruments are recommended to focus on maximization of sensitivity rather than specificity because the offer of additional support or treatment is not expected to deteriorate health [6]. We focused on a minimal sensitivity of 80% for detection of *need for ACP* indicated primarily by experienced death anxiety and exploratory by communication avoidance. Receiver-Operating-Characteristics-Analysis (ROC) was compared for mild (DADDS-G≥14), moderate (DADDS-G≥22) and great (DADDS-G≥29) death anxiety applying generalized linear regression models without missing values and binomial distribution. Exploratory findings from ROC analyses on FACC-G compared mild (FACC-G≥20) and moderate (FACC-G≥40) scores. pAUC of item combinations was compared for significant differences. Optimal cut-off analysis was based on maximization of sensitivity and specificity. Quality of regression models was assessed comparing AIC using ANOVA focusing on residual deviance and difference in AIC. Based on rule-of-thumb difference in models ($\Delta_i$) indicates substantial support for model if $\Delta_i<2$ [43]. The Hosmer-Lemeshow-test was used as additional indicator. Analyses were based on significance level of $\alpha=.05$ if not noted otherwise.

## Construct validity

Convergent and discriminant validity for the objective measure was assessed using correlation indices (Pearson's $r$) of final screening combination with FACC-G and DADDS-G for convergent validity. Additional indication for convergent validity was provided by relation to self-reported health behaviour: Participants without AD or DM were expected to report higher levels of ACP-need. Convergent validity was further based on successful identification of distress, depression and anxiety. For discriminant validity, correlation with FACT-G and predictive value for cancer advance was analysed: Health status was based on reported treatment goal (curative vs. palliative) and surprise question (negative vs. positive). For self-stated wish for ACP convergent validity was analysed based on prior uptake of psycho-oncological support. For all validity indicators, Pearson's $\chi^2$-test for count data and Tukey Honest Significant Differences test were used to identify significant differences in distribution between groups. Odds Ratios were computed for independent interpretation of *critical need for ACP* (≥ cut-off) using Fisher's Exact Test for count data. Homogeneity of variance was controlled for using Levene's test and differences analysed using Students t-test or Welch-test.

# Results

## Phase 1: Item reduction

For item reduction, participant sample consisted of 92 patients (S1 item reduction). In consecutive steps, first items one, two, eight, nine and 11 were excluded because of low item difficulty ($P_i \leq .20$). Items five and 10 were excluded because of lowest discriminatory value ($r_{itc} < .70$) to create homogenous screening items. Item three was excluded because patients rated it to be not relevant, precise or applicable (qualitative analysis). Item four, item six and item seven were presented to the expert panel for further discussion (table 2).

While those three items combined death anxiety, end-of-life preparedness and family communication, the expert panel highlighted the lack of focus on illness progress in general. Since death anxiety and fear of progression or recurrence are strongly related and high levels may lead to avoidance of health behaviour in cancer patients [44], it was argued that inclusion of fear of progression would allow subliminal identification of patients in need without explicitly bringing attention to death and dying. Therefore, an additional item (*I am burdened* *by thoughts of an unfavourable course of the disease*) was included in a second round of recruitment.

**Table 2. Item statistics after item reduction.**

| | Item | *M* | *SD* | $P_i$ | $r_{itc}$ | $r_{4i}$ | $r_{6i}$ |
|---|---|---|---|---|---|---|---|
| 4 | I am burdened by thoughts of death and dying. | 1.31 | 1.28 | 0.26 | 0.71 | | |
| 6 | I am burdened by the feeling of being ill-prepared for the end of life. | 0.90 | 1.08 | 0.23 | 0.75 | .58** | |
| 7 | I haven't talked enough with my loved ones about what happens when my disease situation worsens. | 1.06 | 1.20 | 0.26 | 0.70 | .56** | .67** |

*Note*. ** $p < .001$ $N = 92$, average score (M), standard deviation (*SD*), difficulty ($P_i$), item-total correlation ($r_{itc}$), inter-item correlation ($r_{iic}$)

For item selection, all items were referred to as screening item one (*I am burdened by thoughts of death and dying),* screening item two (*I am burdened by thoughts of an unfavourable course of the disease*), screening item three *(I am burdened by the feeling of being ill-prepared for the end of life)* and screening item four *(I haven't talked enough with my loved ones about what happens when my disease situation worsens).*

## Phase 2: Item selection

### Sample characteristics

Participants (*N*=201) were on average 61 years old, predominantly male, married and living with family. The majority reported having a non-university education degree, being retired and using psycho-oncological support if support was reported (S1 table 1). Most participants were diagnosed in 2019 and reported their first cancer diagnosis. Based on medical files, health status of the majority of participants was palliative and in an advanced stage, surprise question was predominantly negated. The three major diagnoses were haematological malignancies, gastrointestinal and lung cancer. According to the distress thermometer, participants reported an average distress level of clinically significant distress, no clinical levels of depression or general anxiety. The majority of participants reported to have no advance directive and most participants reported to have no designated decision-maker, but 3.5% were unsure. Clear interest in ACP was reported by 34.5%, 14.2% were unsure and 23.4% changed their opinion to disinterest after being contacted and provided with additional information. The ACP process is still ongoing, but at present 42 participants have started and 37 have finalized ACP (Supporting Information, table 2).

## Item selection

Screening items from phase one were compared based on item difficulty, discriminatory value, intercorrelations and correlations with FACC-G, DADDS-G and FACT-G. Item difficulty and discriminatory value were good, discriminatory validity of all items was supported by no correlations with relationship to main physician. Construct validity was also given support by significant correlations of all items with death anxiety (*p*<.001, table 3). Correlations with family communication were small but significant (*p*<.001) for all items except item one (*I am burdened by thoughts of death and dying, p*>.05).

## Table 3. Item statistics and correlation.

| | Screening item | *M* | *SD* | $P_i$ | $r_{itc}$ | $r_{i1}$ | $r_{i2}$ | $r_{i3}$ | *FACC-G* | *DADDS-G* | *FACT-G* |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | I am burdened by thoughts of death and dying. | 1.75 | 1.54 | .35 | .70 | | | | .08 | .67** | -.03 |
| 2 | I am burdened by thoughts of an unfavourable course of the disease | 2.43 | 1.58 | .49 | .67 | .72** | | | .19** | .65** | .01 |
| 3 | I am burdened by the feeling of being ill-prepared for the end of life. | 1.45 | 1.45 | .29 | .70 | .57** | .54** | | .21** | .58** | -.08 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 4 | I haven't talked enough with my loved ones about what happens when my disease situation worsens. | 1.53 | 1.48 | .31 | .60 | .45** | .46** | .69** | .24** | .53** | -.13 |

*Note*. ** $p < .001$ $N = 201$, average score (M*)*, standard deviation (*SD*), difficulty ($P_i$), item-total correlation ($r_{itc}$), inter-item correlation ($r_{iic}$), Family Avoidance of Communication about Cancer Scale (FACC-G [37]), Death and Dying Distress Scale (DADDS-G [38]), Functional Assessment of Cancer Therapy (FACT-G [40])

## Receiver-Operating-Characteristics (ROC) analysis

For all screening items, the severity levels of death anxiety - mild, moderate and severe - were compared. ROC analysis for family communication was compared for mild and moderate levels, no levels of great communication avoidance were reported. Results were only used exploratory, because factor structure was not yet supported in a German sample of cancer patients.

On a single item level only item one and two exceeded pAUC>.80 for moderate and great DADDS, respectively. Comparison of pAUC independent of death anxiety level revealed no significant differences for all screening items ($p$>.05), so that all possible item combinations ($Screening_{ij}$) were analysed in an additive generalized linear model and compared based on pAUC, difference in AIC and deviance. pAUC for mild death anxiety was significantly lower for $Screening_{13}$, $Screening_{14}$ and $Screening_{34}$, respectively, compared to $Screening_{24}$, and $Screening_{12}$ significantly higher than $Screening_{34}$ ($p$<.05). For moderate death anxiety all item combinations showed significantly higher pAUC scores (≥.90) than $Screening_{34}$ (=.68, $p$<.01). For great death anxiety all item combinations except $Screening_{34}$ exceeded pAUC>.80. All other comparisons did not differ significantly (table 4).

**Table 4. ROC Analysis for four screening items (phase two) on varying levels of death anxiety.**

| | DADDS-mild ( ≥ 14) | | | DADDS-moderate (≥ 22) | | | DADDS-great (≥ 29) | | |
|---|---|---|---|---|---|---|---|---|---|
| Item combination | pAUC | 95%-CI | AIC | pAUC | 95%-CI | AIC | pAUC | 95%-CI | AIC |
| Item 1 and 2 | 0.73 | 0.63-0.82 | 173.70 | 0.91 | 0.83-0.97 | 73.98 | 0.86 | 0.80-0.97 | 45.23 |
| Item 1 and 3 | 0.65 | 0.59-0.75 | 180.10 | 0.91 | 0.86-0.96 | 75.83 | 0.89 | 0.87-0.99 | 40.71 |
| Item 1 and 4 | 0.64 | 0.56-0.78 | 175.00 | 0.90 | 0.86-0.95 | 77.90 | 0.85 | 0.81-1.00 | 40.15 |
| Item 2 and 3 | 0.74 | 0.64-0.84 | 171.50 | 0.93 | 0.87-0.97 | 73.53 | 0.88 | 0.82-0.98 | 42.19 |
| Item 2 and 4 | 0.75 | 0.64-0.85 | 167.80 | 0.91 | 0.87-0.96 | 76.34 | 0.82 | 0.75-1.00 | 41.61 |
| Item 3 and 4 | 0.63 | 0.55-0.73 | 195.00 | 0.68 | 0.62-0.84 | 98.94 | 0.69 | 0.56-1.00 | 43.76 |

*Note*. *N* = 192. Additive generalized linear models used for prediction, missing values were excluded. Death and Dying Distress Scale (DADDS-G [38] ), partial area under the curve (pAUC), confidence interval (CI), Akaike's An Information Criterion (AIC).

Compared over the three levels of death anxiety $Screening_{12}$, $Screening_{23}$ and $Screening_{24}$ reached pAUC levels of ≥70% to ≥90%. Difference in AIC favoured $Screening_{24}$ for mild death anxiety, either $Screening_{12}$ or $Screening_{23}$ for moderate and either $Screening_{23}$ or $Screening_{24}$ for great death anxiety (table 5). For moderate and great death anxiety levels $Screening_{23}$ represented the best prediction model ($p>.05$). Exploratory ROC analysis of communication avoidance supported best predictive values for $Screening_{23}$. For mild FACC-G no significant differences in pAUC (*range*=0.51-0.61) between item combinations was found, but $Screening_{24}$ or $Screening_{34}$ held no reliable predictive value (pAU<.50). For moderate FACC-G $Screening_{12}$ ($pAUC_{12}$=0.61, 95%-CI[0.58;0.92], $p<.01$) and $Screening_{23}$ ($pAUC_{23}$=0.71, 95%-CI[0.68;0.97], $p<.05$) predicted family avoidance significantly better than $Screening_{24}$ ($pAUC_{24}$=0.51, 95%-CI[0.49;0.93]). Of all items $Screening_{23}$ exclusively reached pAUC>70%.

**Table 5. Akaike's An Information Criterion for model comparison at three levels of death anxiety.**

| Item combination | Mild DADDS-G | | | Moderate DADDS-G | | | Great DADDS-G | | |
|---|---|---|---|---|---|---|---|---|---|
| | $AIC_i$ | $\Delta_{24}$ | GOF | $AIC_i$ | $\Delta_{23}$ | GOF | $AIC_i$ | $\Delta_{24}$ | GOF |
| Item 1 and 2 | 173.70 | 5.90 | $X^2(8) = 10.50$<br>*p* = .231 | 73.98 | 0.45 | $X^2(8) = 4.25$<br>*p* = .834 | 45.23 | 3.63 | $X^2(8) = 1.92$<br>*p* = .984 |
| Item 2 and 3 | 171.50 | 3.66 | $X^2(8) = 32.60$<br>*p* = .957 | 73.53 | 0.00 | $X^2(8) = 5.13$<br>*p* = .743 | 42.19 | 0.58 | $X^2(8) = 4.90$<br>*p* = .779 |
| Item 2 and 4 | 167.80 | 0.00 | $X^2(8) = 3.12$<br>*p* = .926 | 76.34 | 2.81 | $X^2(8) = 1.57$<br>*p* = .992 | 41.61 | 0.00 | $X^2(8) = 15.29$<br>*p* = .054 |

*Note*. *N* = 192. Death and Dying Distress Scale (DADDS-G [38] ) for mild (≥ 14), moderate (≥ 22) and great (≥ 29) death anxiety, Akaike's An Information Criterion (AIC), item combination (i) and difference to best model ($\Delta_i = AIC_i - AIC_{min}$). Goodness of fit (GOF) was calculated using Hosmer and Lemeshow GOF test based on Chi-Square statistic ($X^2$). Significance (*p*) level was set at α = .05

For the objective assessment of *need for ACP,* sum-scores for *Screening*$_{23}$ were computed. For moderate death anxiety sensitivity and specificity were maximized at an optimal cut-off ≥ 6 with 95% sensitivity and 81.4% specificity ($AUC_{total}$=0.93). Sensitivity ranged from 15% to 100%, specificity ranged from 0% to 99.4%. For great death anxiety optimal cut-off was set at ≥ 8 with 85.7% sensitivity and 90.8% specificity ($AUC_{tota}$= 0.93). Sensitivity ranged from 28.6% to 100%, specificity ranged from 0% to 98.9%. Comparing optimal cut-off ≥ 6 between death anxiety levels, sensitivity for great death anxiety was 85.70% with specificity at 75.1% (table 6), still fulfilling study criteria. Exploratory sensitivity analysis for FACC-G supported the cut-off ≥ 6 with 60% sensitivity and 74.2% specificity.

**Table 6. Sensitivity analysis for moderate and great death anxiety item combination two and three.**

| | Moderate DADDS-G | | Great DADDS-G | |
|---|---|---|---|---|
| Sum Score | Sensitivity | Specificity | Sensitivity | Specificity |

| | | | | |
|---|---|---|---|---|
| 10 | 15,00% | 99,42% | 28,57% | 98,92% |
| 9 | 35,00% | 98,84% | 57,14% | 97,30% |
| **8** | 65,00% | 94,19% | **85,71%** | **90,81%** |
| 7 | 70,00% | 87,79% | 85,71% | 84,32% |
| **6** | **95,00%** | **81,40%** | 85,71% | 75,68% |
| 5 | 100,00% | 69,77% | 100,00% | 64,86% |
| 4 | 100,00% | 53,49% | 100,00% | 49,73% |
| 3 | 100,00% | 37,21% | 100,00% | 34,59% |
| 2 | 100,00% | 20,93% | 100,00% | 19,46% |
| 1 | 100,00% | 13,95% | 100,00% | 12,97% |
| 0 | 100,00% | 0,00% | 100,00% | 0,00% |

*Note*. $N$ = 192. Death and Dying Distress Scale (DADDS-G[38]) for moderate (≥ 22) and great (≥ 29) death anxiety. Optimal cut-off for maximized sensitivity and specificity at 6 (moderate) and 8 (great).

# Convergent validity

Convergent validity of *Screening*$_{23}$ was supported by significant correlations of sum-scores with FACC-G ($r$=.21, $p$<.05) and DADDS-G ($r$=.70, $p$<.001). For *critical need for ACP* (cut-off ≥ 6) validity was not supported by possession of AD ($\chi^2(1)$=1.84, $p$>.05, $OR$=0.60, 95%-CI[0.29;1.22]) or DM ($\chi^2(1)$=1.66, $p$>.05, $OR$=0.61, 95%-CI[0.30;1.25]). Convergent validity was supported by significant predictive values of *critical need for ACP* for distress ($\chi^2(1)$=13.34, $p$<.001, $OR$=5.31, 95%-CI[2.05;16.35]). Participants with *critical need for ACP* ($M$=6.78, $SD$=2.08) reported significantly higher average distress scores ($t(176)$=-5.86, $p$<.001) than participants without ($M$=4.59, $SD$=2.33). Clinically distressed participants were 84% more likely of being in *critical need for ACP*. Participants with *critical need for ACP* reported significant higher mean levels of depression ($M$=2.71, $SD$=1.63) than those without ($M$=1.29, $SD$=1.11, $t(67.60)$=-5.74, $p$<.001), in addition to significantly more levels of clinical depression ($\chi^2(1)$=28.49, $p$<.001, $OR$=8.04, 95%-CI[3.37; 20.05]). General anxiety was more often assessed for participants in *critical need for ACP* ($M$=2.80, $SD$=1.33) compared to participants who did not (*M* =1.22, *SD*=1.95), *t*(67.46)=-5.37, *p*<.001), and frequently reported a clinically significant level ($\chi^2$(1)=33.16, *p*<.001, *OR*=8.09, 95%-CI[3.64;18.58]). Participants experiencing clinically significant levels of depression or anxiety were 89% more likely to report *critical need for ACP*.

## Discriminant validity

Discriminant validity of *Screening*$_{23}$ was supported by no correlations with FACT-G (*r*=-.02, *p*>.05). *Critical need for ACP* was further analysed in regard to discriminatory value of self-reported and physician reported cancer stage (curative vs. palliative). Based on medical files, discriminatory value for advance cancer stages according to the surprise question was additionally analysed. Although participants who believed their diagnosis to be curative (*M*=3.60, *SD*=2.72) reported significantly less average *ACP-need* than participants under the impression of a palliative diagnosis (*M*=4.37, *SD*=2.69, *t*(166)=-1.75, *p*<.05). Participants who reported to be in a palliative stage were 68% more likely to experience *critical need for ACP* ($\chi^2$(1)=4.20, *p*<.05, *OR*=2.16, 95%-CI[1.03,4.59]). Based on medical information participants did not differ in *ACP-need* (*t*(189)=-1.15, *p*>.05) or *critical need for ACP* ($\chi^2$(1)=0.45, *p*>.05) with curative (*M*=3.60, *SD*=2.77) or palliative diagnosis (*M*=4.05, *SD*=2.53). Patients with advanced palliative cancer stage (surprise question negated, *M*=3.97, *SD*=2.55) did not vary from patients with chronic palliative cancer stage (surprise question affirmed, *M*=4.15, *SD*=2.54) in *ACP-need* (*t*(116)=0.38, *p*>.05) or *critical need for ACP* ($\chi^2$(1)=0, *p*>.05). There were no significant differences in *critical need for ACP* based on time of diagnosis or cancer site (*p*>.05).

## Subjective wish for ACP

The majority of participants stated no *subjective wish for ACP* (51.6%). Participants with missing values or report of uncertainty (13.8%) were contacted to provide further information but declined the offer of ACP. Of those who had initially voiced uncertainty or clear interest in ACP (47.4%), in April 2021 44% started and 90% finished the process. Participants who confirmed some degree of interest in ACP (*M*=4.46, *SD*=2.57) did report significantly higher levels of *ACP-need* (*M*=3.36, *SD*=2.59, *t*(186)=-2.92, *p*<.01), but did not differ in *critical need for ACP* ($\chi^2$(1)=1.19, *p*>.05).

For construct validity prior uptake of support was used as indicator for *subjective wish for ACP*. Participants who reported to generally rely on additional psychosocial support did not differ significantly in *subjective wish for ACP* from participants who did not use additional support ($\chi^2$(1)=0.85, *p*>.05). However, participants requiring additional support differed in subjective need (*F*(9)=2.32, *p*<.05) dependent on the support system: Patients relying on psycho-oncological support were 86% more likely to experience *subjective wish for ACP* ($\chi^2$(1)=8.47, *p*<.01, *OR*=6.40, 95%-CI[1.72;27.14]). Patients receiving support from family members were 16% more likely to experience *subjective wish for ACP* ($\chi^2$(1)=5.37, *p*<.05, *OR*=0.17, 95%-CI[0.03;0.80]). Readiness for ACP engagement was negatively related to self-report of *subjective wish for ACP* (*r*=-.25, *p*<.001). A comparable pattern was found for all four questions: Participants in pre-contemplation were evenly distributed in self-reported wish for ACP and participants in action stage predominantly reported no interest in ACP (table 7). Behaviour stages for all aspects of readiness predicted self-reported wish for ACP but interest dependent on stage varied significantly (*p*<.05). For all aspects, participants in action stage were significantly less likely to report wish for ACP than in preparation stage.

## Table 7. Distribution of self-reported wish for ACP between behaviour stages of ACP engagement.

|  | Self-reported wish for ACP | No | Yes | Odds-Ratio | β | *t value* | *p* |
|---|---|---|---|---|---|---|---|
| Advance Care Planning Engagement - Readiness | Behaviour Change Stage |  |  |  |  |  |  |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| How ready are you to sign official papers naming a person or group of people to make medical decisions for you? | Pre-contemplation | 22 | 21 | | 0.49 | 7.33 | *** |
| | Contemplation | 7 | 26 | 1.36 | 0.30 | 2.96 | ** |
| | Preparation | 1 | 19 | 1.63 | 0.46 | 3.91 | ** |
| | Action | 64 | 23 | -3.97 | -0.22 | 0.08 | *** |
| How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life? | Pre-contemplation | 23 | 27 | | 0.54 | 8.32 | *** |
| | Contemplation | 8 | 23 | | 0.20 | 1.92 | . |
| | Preparation | 2 | 14 | 0.89 | 0.34 | 2.54 | * |
| | Action | 64 | 26 | -2.85 | -0.25 | -3.10 | ** |
| How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life? | Pre-contemplation | 38 | 39 | | 0.51 | 9.90 | *** |
| | Contemplation | 10 | 23 | 0.81 | 0.19 | 2.04 | * |
| | Preparation | 3 | 18 | 0.96 | 0.35 | 3.17 | ** |
| | Action | 44 | 9 | -3.38 | -0.34 | -4.20 | *** |
| How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? | Pre-contemplation | 30 | 30 | | 0.50 | 8.95 | *** |
| | Contemplation | 7 | 25 | 1.27 | 0.28 | 2.97 | ** |
| | Preparation | 1 | 19 | 1.67 | 0.45 | 4.03 | *** |
| | Action | 57 | 16 | -4.21 | -0.28 | -3.72 | *** |

*Note*. *N*=181, *p*=.05 (.) *p*<.05 (*) *p*<.01 (**) *p*<.001 (***), regression estimate (β) and t-statistic (*t value*), Odds-Ratio compared to behaviour change stage before, Advance Care Planning Engagement Survey [39] subscale Readiness.

# Discussion

Knowledge about personal preferences, medical choices and values of patients enables healthcare professionals to offer tailored management and treatment of specific needs in case of limited capacity or inability to consent. At present, identification of a convenient time for beneficial *advance care planning* (ACP) discussions is challenging so that offers may be made at inappropriate times. Early detection of potential needs in cancer patients then may increase chances of better patient- and family-reported outcomes. To the best of our knowledge, the present study developed the first screening instrument to identify patients in *need of ACP*.

Items were expected to be feasible, comprehensible and sensitive [6,15]. Based on item reduction and ROC analysis, the best item combination of two items predicted moderate levels of death anxiety (DADDS-G; 38) and communication avoidance (FACC-G; 37): *I am burdened by thoughts of an unfavourable course of the disease* and *I am burdened by the feeling of being ill-prepared for the end of life*. *Critical need for ACP* was detectable at scores greater than five and correctly identified for 93% of patients with great sensitivity (95%) and high specificity (81%) for moderate and great death anxiety (sensitivity = 86%, specificity = 75%), respectively. Alternative cut-off scores were decided against because of reductions in sensitivity.

Validity of screening items and cut-off was supported by correlations with death anxiety, communication avoidance within families, distress, depression and anxiety levels firstly. Patients above threshold would therefore likely struggle in more than one psychological domain. Since death anxiety may be seen as transdiagnostic construct [45] it's reduction and addressing specific fears related to medical decisions and treatment outcomes relying on ACP may hold additional value and reduce experienced distress in the process.

Secondly, although trust in medical staff and high-quality relationships are essential for patient provider communication and treatment experience [46], independence of *critical need for ACP* supports the belief that they do not necessarily reduce burden by treatment and health related fears and worries. Additional programs such as ACP, however, may address specific fears and document wishes while simultaneously strengthening trust [27] and satisfaction with treatment [47]. It is precisely this process and documentation that can set preferences for care even in unforeseen situations outside the known doctor-patient relationships.

Third, aside from successful discrimination between patients in self-perceived palliative and curative diagnosis, screening items were unrelated to physicians' professional interpretation and diagnosis. The developed objective ACP screening may therefore help medical staff to identify patients in need, without reliance on diagnoses and direct confrontation, possibly pressure or emotional burden [48].

Contrary to expectations, *critical need for ACP* was unrelated to prior AD or documentation of DM. However, traditional ADs seldomly involve a value-lead approach addressing specific fears and worries for treatment, are often finalized without discussion and not necessarily communicated with family members [28]. It is arguable that neither AD nor designation of DM reduced death and dying distress in cancer patients and therefore may be equally high and independent of finalization of documents.

Finally, comparable to screening for psycho-oncological support subjective interest in ACP was not significantly related to screened need but showed a tendency for elevated scores in ACP-need [33,34,49] and is likely to increase when ACP is offered. The integration of a subjective item was additionally supported by readiness for ACP engagement [39]: Interest in ACP was likely if participants were in contemplation or preparation stage, therefore had started to think about DM designation and AD finalization. Additional research is needed to explain explicitly focusing on the relationship of readiness and ACP-need. Measurement tools developed in western [39] and eastern countries [50] may provide insights under which circumstances *critical need for ACP* may function as predictor or barrier to ACP-related behaviours. They further allow cultural influences to be compared and considered when working in multi-cultural environments.

Although prior uptake of support services was not related to subjective wish for ACP, participants who had used psycho-oncological services or relied on family indicated higher subjective wish for ACP. This connection of psycho-oncological and advance care planning needs arises attention to psychological distress of seriously ill patients at the end of life. Possible confounders may be impossible to avoid but are all the more relevant for clinical use and integration of advance care planning in specifically targeted psycho-oncological support.

## Clinical implications

Inclusion of cancer patients and family members in decision-making processes and provision of ACP programs is not only essential to reduce emotional burden for all parties involved, but also results in satisfaction with treatment and appreciation of preferences [2,51]. The present screening tool proposes a first step of integration of ACP programs in a hospital setting. It increases the possibility of offering patients an ACP conversation at an early stage, thus ensuring that patients' preferences are known, for example in acute crisis situations or disease deterioration. Precisely because it is known that such conversations are avoided, emotionally straining and often occur too late, a screening tool can open the door to early access. Since all parties involved expect others to be responsible for initiation, are insecure of timing and whether end-of-life conversations may result in distress or relief, screening for ACP-need may increase chances of contemplation and provide a first indicator when to start the communication process that otherwise may have been avoided and postponed [52]. With the combination of subjective wish and cut-off value, responsibility and empowerment is distributed equally for physicians and patients.

Additionally, previous research has supported the possibility of regular prompts as reminder for physicians to engage in advance care planning. Cut-off criteria of screening tools may function as comparable prompts, indicating either interest in or need for action [53]. The developed screening tool therefore eliminates barriers found by researchers in different countries and health care systems [54]: Physicians are supported in decision making processes while the identification and action process is simplified.

In order to provide ACP support services in the future, the developed screening tool needs to be piloted and capacities for uptake of ACP controlled [16]. Since diagnoses may change, cancer may progress or recur, end-of-life conversations may be introduced at a low threshold with asking to rate the screening items and to communicate interest in ACP, repeated screening will be essential to provide the best care possible. Therefore, medical staff needs a clear understanding of the intervention offered, clear structures who to contact and how referral to ACP goes smoothly. Awareness and compliance are necessary to interpret screening results reliably and continue the process of integration at a higher level. Based on the principals of screening implementation [16], the present study has already focused on feasibility and acceptance for patients, inclusion of interdisciplinary work groups, identification and provision of solutions to ACP-need. In the following months, incorporation in routine care in a pilot phase, identification of organisational barriers and individual barriers are expected to be the focus of the funded research process. The final acceptance as necessary routine service at hospitals and financial and leadership support than may be realized, barriers reduced and a continuous ACP program integrated in already existing processes and medical structure of supply.

# Limitations

First, the present study may be limited by sample size due to sample separation. Results however indicate good reliability and can be seen as preliminary. Future studies need to evaluate the screening tool in different populations and settings. Second, patients were explicitly asked to partake in a study about death and dying. Participants who declined may have provided additional insights on items. Screening implementation now holds the possibility to control whether screening items successfully identify patients in *critical need of ACP*. The pilot phase is essential to incorporate lessons learned in subsequent decisions and offers the opportunity to further improve the screening instrument before implemented on a large scale. Finally, development of the screening instrument assumed that death anxiety is a key component of fear in cancer patients and may be reduced by deciding upon medical preferences and advance care planning. However, other components may be of importance that are not included in screening items at present. Future studies are encouraged to verify our instrument and provide further insights and suggestions for improvement.

# Conclusion

Shared decision-making supports autonomy of patients and compliance of medical treatment with personal preferences. To facilitate challenging decisions in times of incapacity to consent, patient preferences should be known beforehand. As such, ACP is a useful tool for determination, documentation and support of patients' preferences in advance. Up until today, no official programs to support ACP are offered in German hospital settings and may result in worries, burden, overtreatment and unreliable advance care directives in time of need. The present study provides the first tool to screen for external and self-perceived ACP-need in cancer patients, providing a possibility to identify patients in need objectively and to supply tailored interventions and management. Further pilot studies are needed to obtain more information on the extent to which the tool can be used in clinical practice. However, this screening tool symbolizes a first step towards improvements in cancer care, reacts to demands in health care and emphasizes the need for advance care programs in Germany.

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# Supporting information

## S1. Methods

### S1. Methods. Convergent validity

## S1. Item reduction

### S1. Item reduction. Sample characteristics

# Supporting information

## S1. Methods

### S1. Methods. Convergent validity

Experienced *distress* (DT) in the past week was rated on a visual scale from zero (“not at all”) to 10 (“extreme distress”). Clinical cut-off is internationally recommended at distress levels greater than four [1].

The *Patient-Health-Questoinnaire-4* (PHQ-4 [2]) is used for screening of depression and anxiety. Items are rated on a 4-pointed Likert scale from zero (“not at all”) to three (“nearly every day”). Scores are interpreted as normal (0–2), mild (3–5), moderate (6–8) or severe (9 – 12). Optimal cut-off for depression and anxiety is ≥ 3 for each respectively. Internal consistency was acceptable for depression (α=.74) and good for anxiety (α=.84).

The *Family Avoidance of Communication about Cancer Scale* (FACC-G) is a self-report measure that assesses perceived avoidance within families [3]. At present, there exists no German validation so that the items were backwards-translated and only used exploratory. Five items were rated on a 5-pointed Likert scale from one (“less avoidance”) to five (“more avoidance”). Scores were transformed to a scale from zero to 100, with higher scores indicating higher levels of avoidance. Internal consistency was good (α=.80). Communication avoidance was categorized as none (0-19), little (20-39), mild (40-59), moderate (60-79) or great (80-100).

The *Death and Dying Distress Scale* (DADDS-G) assesses specific distress, anxieties, insecurities and thoughts about death and dying with nine items [4]. Items are answered on a 5-pointed Likert Scale from zero (“does not apply”) to four (“very much so”) with a minimal score of zero and maximal score of 36. Scores were assigned to five categories [5]: none (<8), little (8-13), mild (14-21), moderate (22-28), great death anxiety (29-36). Internal consistency was excellent (α=.91).

The *Advance Care Planning Engagement Survey* (ACP-E) was developed to identify health behaviour change in patients' readiness to engage in preparations related to advance care. A short version of four items assessed readiness to talk to decision maker or physician, to sign official papers and to name a decision maker (e.g. "How ready are you to officially name a decision maker?"). Items were rated on a scale from one ("I have never thought about it") to five ("I have already taken care of it"). Higher average scores were related to a higher stage of health behaviour. Each item could be categorized into health behaviour change stages: Pre-contemplation (score one and two), contemplation (score 3), preparation (score 4) and action (score 5). Maintenance was not assessed in the present study [6]. At present there exists no German version of the ACP-E Survey so that backwards-translated items were only used for exploratory purposes and convergent validity for self-reported need for ACP. Internal consistency was excellent (α=.90).

*Discriminant validity*

The *Functional Assessment of Cancer Therapy Scale* (FACT-G [7]) was designed to assess cancer related quality of life. The present study used the subscale *relationship with doctor* ("I have confidence in my doctors", "My doctor is available to answer my questions"). Items were rated on a 5-pointed Likert scale from zero ("not at all") to four ("very much"). Internal consistency was good (α=.84).

# S1. Item reduction

## S1. Item reduction. Sample characteristics

Participants (*N*=92, S1. table 1) were 61 years old (*SD*=13.4, *range*=26-85) and predominantly male (58.7%), married (71.9%) and living with family (81.3%). The majority reported an educational level of apprentices (28.3%), to be retired (54.9%) and to use psycho-oncological support if support was reported (47.6%).

## S1. Table 1. Socio-demographic information for phase one (item reduction) and phase two (item selection).

| Phase 1: Item Reduction | | | Phase 2: Item Selection | | |
|---|---|---|---|---|---|
| | % | Valid *n* | | % | Valid *n* |
| Age (*M*, *SD*, *range*) | 61.0 (13.4, 26-85) | 92 | Age (*M*, *SD*, *range*) | 61.2 (11.9, 23-86) | 201 |
| Gender | | 92 | Gender | | 201 |
| Male | 58.7 | 54 | Male | 59.7 | 120 |
| Female | 41.3 | 38 | Female | 40.3 | 81 |
| Family | | 89 | Family | | 200 |
| Single | 7.9 | 7 | Single | 10.0 | 20 |
| Partnership | 4.5 | 4 | Partnership | 6.5 | 13 |
| Married | 71.9 | 64 | Married | 70.0 | 139 |
| Divorced | 9.0 | 8 | Divorced | 8.5 | 17 |
| Widowed | 6.7 | 6 | Widowed | 5.0 | 10 |
| Education | | 92 | Education | | 198 |
| Middle School | 23.9 | 22 | Middle School | 21.2 | 42 |
| Secondary School | 15.2 | 14 | Secondary School | 16.7 | 33 |
| A-level | 6.5 | 6 | A-level | 6.6 | 13 |
| Vocational Baccaulerate | 2.2 | 2 | Vocational Baccaulerate | 5.6 | 11 |
| Trainee | 28.3 | 26 | Trainee | 24.2 | 48 |
| Master | 5.4 | 5 | Master | 7.6 | 15 |
| University | 18.5 | 17 | University | 18.2 | 36 |
| Work | | 91 | Work | | 200 |
| Unemployed | 3.3 | 3 | Unemployed | 3.5 | 7 |
| Student | 1.1 | 1 | Student | 0 | 0 |
| Part-time | 12.1 | 11 | Part-time | 8.0 | 16 |
| Full-time | 20.9 | 19 | Full-time | 28.5 | 57 |
| Housewife/-husband | 4.4 | 4 | Housewife/-husband | 5.0 | 10 |

| | | | | | |
|---|---|---|---|---|---|
| Self-employed | 0 | 0 | Self-employed | 2.5 | 5 |
| Retirement | 54.9 | 50 | Retirement | 48.0 | 96 |
| Other | 3.3 | 3 | Other | 4.5 | 9 |
| Living | | 91 | Living | | 199 |
| Alone | 17.6 | 16 | Alone | 21.1 | 42 |
| Shared flat | 1.1 | 1 | Shared flat | 0 | 0 |
| Family | 81.3 | 74 | Family | 78.9 | 157 |
| Support | | 21 | Support | | 56 |
| Family | 9.5 | 2 | Family | 23.2 | 13 |
| Psycho-oncology/ Psychological support | 52.4 | 11 | Psycho-oncology/ Psychological support | 55.4 | 31 |
| Support group | 4.8 | 1 | Support group | 1.8 | 1 |
| Pastoral care | 9.5 | 2 | Pastoral care | 5.4 | 3 |
| Other | 23.8 | 5 | Other | 14.3 | 8 |

*Note*. Average (*M*) and standard deviation (*SD*). Number (*n*) of participants varies due to missing values.

Participants had been diagnosed in 2019 (*range*=1993–2020) and reported their first cancer diagnosis (67.0%). Based on medical files (S1. table 2), health status of the majority of participants was palliative (56.5%) and in an advanced stage, surprise question was predominantly negated (39.1%). The three major cancer sites were blood cancer, GIT and lung cancer. Participants reported an average distress level of 4 (*SD*=2.6) with no clinically significant distress (59%), depression (88.0%) or general anxiety (91.3%). Average depression (*M*=1.1, *SD*=1.2) and anxiety screening scores (*M*=1.1, *SD*=1.3) were low. Participants reported to have an advance directive (56.2%), 16.9% participated in ACP before. The majority reported to have a designated decision maker (57.8%), but 5.6% were uncertain. Clear interest in ACP was reported by 32.2%, 16.2% were uncertain and 13.3% changed their opinion after being contacted and provided with additional information. At present (ACP process is still ongoing) 20.7% of participants have started ACP.

## S1. Table 2. Medical information for participants in phase one (item reduction) and phase two (item selection).

| Item Reduction | | | Item Selection | | |
|---|---|---|---|---|---|
| | % | Valid *n* | | % | Valid *n* |
| Year of Diagnosis (*MD*, *range*) | 2019 (1993-2020) | 92 | Year of Diagnosis (*MD*, *range*) | 2019 (1980 – 2021) | 201 |
| Diagnosis | | 91 | Diagnosis | | 197 |
| First | 67.0 | 61 | First | 67.0 | 132 |
| Second | 8.8 | 8 | Second | 6.1 | 12 |
| Third | 2.2 | 2 | Third | 1.5 | 3 |
| Recurrence | 9.9 | 9 | Recurrence | 19.8 | 39 |
| Cancer free | 11.0 | 10 | Cancer free | 4.1 | 8 |
| Other | 1.1 | 1 | Other | 1.5 | 3 |
| Health status | | 92 | Health status | | 201 |
| Cancer free | 1.1 | 1 | Cancer free | 1.0 | 2 |
| Curative | 43.5 | 40 | Curative | 37.8 | 76 |
| Palliative | 55.4 | 51 | Palliative | 61.2 | 123 |
| SQ negative | 38.0 | 35 | SQ negative | 32.8 | 66 |
| SQ positive | 17.4 | 16 | SQ positive | 28.4 | 57 |
| Cancer site | | 92 | Cancer site | | 201 |
| Skin | 9.8 | 9 | Skin | 8.0 | 16 |
| Brain | 0 | 0 | Brain | 0.5 | 1 |
| GIT | 20.7 | 19 | GIT | 17.9 | 36 |
| Blood | 44.6 | 41 | Blood | 38.3 | 77 |
| ENT | 4.3 | 4 | ENT | 3.0 | 6 |
| Lung | 10.9 | 10 | Lung | 10.4 | 21 |
| Breast | 6.5 | 6 | Breast | 3.0 | 6 |
| Urinary | 0 | 1 | Urinary | 8.0 | 16 |
| Gynaecological | 1.1 | 2 | Gynaecological | 2.5 | 5 |
| Male reproductive organs | 0 | 0 | Male reproductive organs | 5.0 | 10 |
| Other | 2.2 | 0 | Other | 3.5 | 7 |
| Decision maker | | 90 | Decision maker | | 199 |
| No | 36.7 | 33 | No | 48.7 | 97 |
| Yes | 57.8 | 52 | Yes | 47.7 | 95 |

| | | | | | |
|---|---|---|---|---|---|
| Uncertain | 5.6 | 5 | Uncertain | 3.5 | 7 |
| Advance directive | | 89 | Advance directive | | 196 |
| No | 43.8 | 39 | No | 54.6 | 107 |
| Yes | 56.2 | 50 | Yes | 44.9 | 88 |
| Uncertain | 0 | 0 | Uncertain | 0.5 | 1 |
| Distress (*M*, *SD*, *range*) | 4 (2.6, 0-10) | 78 | Distress (*M*, *SD*, *range*) | 5.2 (2.4, 0-10) | 185 |
| Distress < 5 | 59.0 | 46 | Distress < 5 | 33.0 | 61 |
| Distress ≥ 5 | 41.0 | 32 | Distress ≥ 5 | 67.0 | 124 |
| PHQ-2 (*M*, *SD*, *range*) | 1.1 (1.2, 1-6) | 92 | PHQ-2 (*M*, *SD*, *range*) | 1.7 (1.4, 0-6) | 201 |
| Normal (0-2) | 88.1 | 81 | Normal (0-2) | 82.5 | 166 |
| Mild (3-5) | 10.9 | 10 | Mild (3-5) | 14.0 | 28 |
| Moderate (6-8) | 2.2 | 1 | Moderate (6-8) | 3.5 | 7 |
| Severe (9-12) | 0 | 0 | Severe (9-12) | 0 | 0 |
| GAD-2 (*M*, *SD*, *range*) | 1.1 (1.3, 0-5) | 92 | GAD-2 (*M*, *SD*, *range*) | 1.6 (1.7, 0-6) | 200 |
| Normal (0-2) | 91.4 | 84 | Normal (0-2) | 77.6 | 156 |
| Mild (3-5) | 8.8 | 8 | Mild (3-5) | 18.4 | 37 |
| Moderate (6-8) | 0 | 0 | Moderate (6-8) | 4.0 | 8 |
| Severe (9-12) | 0 | 0 | Severe (9-12) | 0 | 0 |

*Note*. Average (*M*) and standard deviation (*SD*). Number (*n*) of participants varies due to missing values. Year of diagnosis relates to first diagnosis. Health status, surprise question (SQ) and cancer site (GIT = Gastro-intestinal, ENT = Head and Neck Tumor) are based on medical files. Negative answer to SQ indicates advance cancer stage. All other variables are self-reported measures. Patient-Health Questionnaire 4 (PHQ-4) screens for signs of depression, General Anxiety Disorder 2 (GAD-2) screens for signs of anxiety (Kroenke et al., 2009).

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## 7.3 Study III

frontiers in Psychology

ORIGINAL RESEARCH
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# Development and Validation of the Readiness for End-of-Life Conversations (REOLC) Scale

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**Background:** Engaging in end-of-life care considerations is beneficial when the time is right. The purpose of this study is to provide a valid instrument to assess peoples readiness for end-of-life conversations before they are initiated.

**Materials and Methods:** A community sample was recruited in study one for exploratory factor analysis of a 13-item questionnaire. In study two, psychometric properties were analyzed with structural equation modeling in a population affected by cancer. Convergent and discriminant validity were assessed with questionnaires measuring distress, depression, anxiety, fear of progression, and distress of death and dying.

**Results:** In study one ($N = 349$) exploratory factor analysis resulted in three subscales readiness ($\alpha = 0.84$), communication ($\alpha = 0.76$), and values ($\alpha = 0.56$) with a possible common factor ($\alpha = 0.84$) for a community sample. In study two ($N = 84$) the three-factor solution with 13 items was not supported for cancer patients. Factor structure was adapted to 12 items with one common factor readiness ($\alpha = 0.87$). Model fit was good: $\chi^2(50) = 59.18$, $p > 0.05$ (Satorra-Bentler-correction = 1.27), with $\chi^2/df = 1.184$, $rRMSEA = 0.053$ (90%-$CI$[0.000; 0.100]), and $rSRMR = 0.072$. Convergent validity was supported by moderate correlations to trait gratitude, ratings of readiness to provide a living will or talk with family about the end of life. Divergent validity was supported by no or small correlation with distress, depression, general and death anxiety and fear of progression, respectively.

**Conclusions:** Results support usage of the REOLC Scale in different settings with adapted factor structure. The questionnaire is interpreted as valid and reliable instrument to assess objective readiness for end-of-life conversations.

**Keywords: end-of-life, psycho-oncology, cancer, communication, readiness**

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## 1. INTRODUCTION

Independent of health, death, and dying are inevitable parts of life, but preparation for this last challenge is often poor. When asked directly, people support the importance of end-of-life planning (Perkins et al., 2002; Lambert South and Elton, 2017; Banner et al., 2019). Preparations entail order of financial affairs, living painlessly, and maintaining dignity at the end of life

(Steinhauser et al., 2011; Banner et al., 2019). Especially in medical context, participants seek opportunities to set boundaries to interventions and treatment options (Seymour et al., 2004; Steinhauser et al., 2011), minimizing stress and complications for and conflicts between family members (Seymour et al., 2004; Banner et al., 2019). Early end-of-life conversations (e.g., about values, fears, wishes, and preferences at the end of life) empower people to be fully informed and included in decision making processes (e.g., advance care directives) (Abba et al., 2013; Epstein et al., 2017) and have been proven to be beneficial. Wishes are more likely to be honored, quality of life, satisfaction and illness adaptation increase, hospice care is received earlier and more frequently (Detering et al., 2010; Wright et al., 2010; Abba et al., 2013; Bischoff et al., 2013; Brown et al., 2017). Relatives suffer less from depressive symptoms, post-traumatic stress, or anxiety during the final weeks and after bereavement (Detering et al., 2010; Abba et al., 2013; Banner et al., 2019). However, necessary end-of-life preparations are seldom undertaken before it is too late (Abba et al., 2013). Avoidance of preparations and low mortality communication may then result in unexpected financial costs and psychological burden on family members (Banner et al., 2019; Bachner et al., 2020). While patients often reported feelings of isolation, grief, anxiety or depression, caretakers may experience depression or complicated grief (Wright et al., 2010; Abba et al., 2013).

Participation in end-of-life conversations can be defined as health behavior (Fried et al., 2009). In order to understand motivations and intentions to improve and change health behavior, the Transtheoretical Model (TTM) proposes five stages (Prochaska et al., 2015). Precontemplation (no thought or intention to engage), contemplation (thinking about it), preparation (committing to behavior and preparing), action (engaging in health behavior), and maintenance (ongoing health behavior). In the dynamic process of health behavior change people can constantly move between stages and differ in readiness to engage and maintain them, so that challenges in healthcare include identification of ideal time points to initiate conversations about health behavior changes (Seymour et al., 2004; Lambert South and Elton, 2017). Key predictors that foster contemplation of end-of-life planning are having young children, decline in parents health, transition into health-care facility or loss of family members. Barriers to preparation and action for patients are fear of coercion, physicians who blindly follow advance care directives, lack of knowledge about treatment and prognosis or abuse by relatives (Seymour et al., 2004; Lambert South and Elton, 2017). Barriers for caregivers are avoidance of psychological burden and distress (Higginson and Costantini, 2002; Zhang and Siminoff, 2003; Goldsmith et al., 2007; Stone et al., 2012). To receive the best end-of-life care possible, interaction between patients and health care systems is needed without solely focusing on terminally ill patients (Gillick and Fried, 1995; Sinuff et al., 2015). Mortality communication barriers have been found to exist at all disease stages, but to intensify with prolonged illness (Bachner et al., 2020).

In addition to avoidance and unease of family members, one key element to overcome the cleft between wanting to engage in end-of-life discussions and fear to initiate them is trust in physicians. Trust is expected to develop and change in quality over time and contact, and to balance need for autonomy, care or additional need for information (Seymour et al., 2004). Still, it is common for patients to be expected to signal readiness for end-of-life conversations. Health care professionals are expected to successfully interpret signals based on intuition, sensitivity and common sense. However, without an objective assessment of readiness, up to 60% of patients were not approached to discuss end-of-life preparations although they were ready and underwent more aggressive treatment. Over the course of a disease, patients readiness and perceptiveness may change or never develop so that health care professionals need an objective measure assessing readiness more frequently (Maciejewski and Prigerson, 2013). Wrongful initiation of end-of-life conversations may result in emotional burden, lost hope and trust in physicians.

These findings highlight the importance of timing, context and of taking readiness for end-of-life conversations into account, before directly approaching patients (Abba et al., 2013; Simon et al., 2015). Solely relying on people to be terminally ill, physicians interpretation of readiness and trusting caregivers to know of preferences and wishes might lead to distress and rejection of end-of-life programs. Being unprepared or "not ready" could further lead to experiences of grief and death anxiety (McLeod-Sordjan, 2014). The purpose of this study is to develop and validate an evaluated method to assess readiness to engage in end-of-life conversations for a community sample and a population affected by cancer, respectively.

## 2. STUDY ONE

The first study (Clinical Trials: NCT03387436) compared three interventions to decrease experienced death anxiety distress and improve communication about the-end-of-life focusing an a community sample (von Blanckenburg et al., 2020). This paper only reports results relevant for questionnaire development and exploratory factor analysis.

### 2.1. Materials and Methods

#### 2.1.1. Inclusion Criteria and Procedure

Participants were eligible when aged 18 years or older, understood German sufficiently, did not suffer from dementia, suicidal thoughts (Beck et al., 1996), or acute psychosis (Wittchen et al., 1997) (**Supplementary Material**). Recruitment was completed using university email distribution, flyer and announcements or social media. Eligible participants were either provided with a paper-pencil or online form of the questionnaire and recruited in two rounds.

#### 2.1.2. Measures

##### *2.1.2.1. Readiness for End-of-Life Conversations Scale*

A novel self-report scale was developed by experts to assess participants readiness for end-of-life conversations (**Table 1**). Items were based on qualitative research about stages in end-of-life planning, barriers and facilitators. Three domains included first, readiness to engage in end-of-life thoughts and conversations alike (readiness). Second, knowledge about personal barriers, facilitators and topics to discuss

**TABLE 1 |** REOLC Scale for a community sample.

| Item | English | German |
|---|---|---|
| 1 | I believe that dealing with the end of life is part of life. | Die Beschäftigung mit dem Lebensende gehört für mich zum Leben dazu. |
| 2 | For me, experiencing life at the present moment is way more important than talking about the end of life. | Für mich ist das Leben im Hier und Jetzt viel wichtiger als über das Lebensende zu sprechen. |
| 3 | I avoid dealing with the finite nature of my life. | Ich vermeide es, mich mit der Endlichkeit des eigenen Lebens auseinander zu setzen. |
| 4 | For me it makes sense to talk about death and dying with my family/friends. | Für mich ist es sinnvoll, mit meinen Angehörigen/Freunden über das Thema Tod und Sterben zu sprechen. |
| 5 | Dealing with the end of life allows me to experience life more intensively at the present moment. | Die Beschäftigung mit dem Lebensende lässt mich im Hier und Jetzt intensiver leben. |
| 6 | For my friends I would recommend to deal with the finite nature of life. | Einem Freund/ einer Freundin würde ich empfehlen, sich mit der Endlichkeit des eigenen Lebens auseinander zu setzen. |
| 7 | I would like to start talking about the end of my life. | Ich möchte über mein Lebensende ins Gespräch kommen. |
| 8 | I know which topics regarding the last part of my life I would like to talk about with my relatives. | Ich weiß, welche Themen ich in Bezug auf die letzte Lebensphase mit meinen Angehürigen besprechen würde. |
| 9 | I know about my personal barriers when talking about the last part of life. | Ich wei, worin für mich Hürden bei einem Gespräch über die letzte Lebensphase bestehen. |
| 10 | I know what advantages talking about the end of my life holds. | Ich kenne die Vorteile eines Gesprächs über das Lebensende. |
| 11 | I am aware of what in life is important to me. | Ich bin mir darüber im Klaren, was mir im Leben wichtig ist. |
| 12 | Dying with dignity means to end life the way one has lived it so far. | Würdevolles Sterben bedeutet, so aus dem Leben zu treten, wie man es bislang geführt hat. |
| 13 | I have already learned a lot about life. | Ich habe bereits einiges über das Leben gelernt. |

(communication experience) and third, congruence between values and life before and during palliative treatment (importance of values). All items were developed related to five stages of advance care planning behavior (Fried et al., 2010) and qualitative questions asked. Items 2 and 11 were based on findings that end-of-life conversations may be too emotional and frightening, while importance of values in life was simultaneously acknowledged to ensure they were honored at a time, when patients were not able to express themselves (Fried et al., 2009). Items 1, 3, and 10 were based on beliefs in end-of-life conversations to be normal and relevant given a certain age or prognosis (Simon et al., 2015). Additionally, discomfort of end-of-life conversations, expression of emotions and fear of death and dying were considered. Also, the importance to address former experiences with life-sustaining treatments and the understanding of importance of end-of-life conversations were discussed. Items 11 and 13 were developed based on Dignity Therapy (Chochinov et al., 2005) that uses therapeutic life review to express and remember what is important for each individual and to develop an understanding of what people would want at the end of life. Items 4 to 9 and 12 were developed based on personal therapeutic experiences and research (Fried et al., 2010). After development, three independent researchers controlled for content validity. All 13 items were presented as statements and rated on a 6-point Likert-Scale from zero (absolutely disagree) to five (absolutely agree). Items 1 to 7 were expected to be related to participants readiness to engage in end-of-life conversations. Items 2 and 3 were inversely coded. Items 8 to 10 were expected to be related to participants experience with communication and conversation regarding end-of-life, with items 11 to 13 being created in regards to the importance of values at the end of life.

#### *2.1.2.2. Additional Self-Report Measures*

Demographic data was collected using a standardized questionnaire. Divergent validity was assessed with distress (Distress Thermometer) (Mehnert et al., 2006) and depressive symptoms (PHQ-9, $\alpha = 0.89$) (Kroenke et al., 2001). Convergent validity was assessed with trait gratitude (GQ-6, $\alpha = 0.82$) and behavior stages of talking about end-of-life with loved ones and providing a living will (McCullough et al., 2002; Fried et al., 2010) (**Supplementary Material**).

### 2.1.3. Statistical Analysis

A minimum sample size of $N = 260$ participants was based on a ratio of 20:1 (Costello and Osborne, 2005), expected to provide a strong factor structure and prevent miss-specification of factors. Sum scores and average scores were generated without missing values. Participants were excluded from analysis for missing values on REOLC ($n = 15$) or met exclusion criteria ($n = 120$). Correlations were computed using all complete pairs of observations. Early termination lead to exclusion. Drop out analysis ($n = 221$) showed no significant differences in demographic variables except age [$M_{dropout} = 32.74$, $SD_{dropout} = 17.77$, $M_{included} = 41.34$, $SD_{included} = 20.97$, $t(444.35) = -5.31$, $p < 0.001$].

#### *2.1.3.1. Exploratory Factor Solution*

Exploratory factor analysis (EFA) and principal factor analysis determined underlying latent variables (Fabrigar et al., 1999; Costello and Osborne, 2005). Bartlett's Test of Sphericity was used to control for homogeneity of variances (Bartlett, 1950) and Kaiser-Meyer-Olkin (KMO) criterion controlled for factor sample adequacy. Velicers Minimum-Average-Partial-test (MAP) criteria, parallel analysis and scree-test were used to define the number of factors to be extracted (Fabrigar et al., 1999; Costello and Osborne, 2005). Several factor analyses compared extraction recommendations for best model fit using the following criteria: Each factor explained at least three items, item loadings or crossloadings $\geq$ 0.32 excluded from further analysis (Tabachnick and Fidell, 2005). For best possible fit promax rotation was used (Fabrigar et al., 1999). Alternative models were compared for theoretical sensibility and model fit relying on indicators such as improved $\chi^2$-statistic, *Root-Mean-Square-Error of Approximation* (RMSEA) and *Comparative-Fit-Index* (CFI).

## 2.2. Results

### 2.2.1. Participant Characteristics

Participants ($N = 349$) in the community sample were aged from 18 to 88. Clinical distress was low for the majority of participants and more than 70% reported to have not filled out an advance care directive at the time of data collection (**Table 2**). Participants reported to be in pre-contemplation for completion of living will (44.41%) and talking to family about their end-of-life wishes (42.94%), respectively.

### 2.2.2. Exploratory Factor Analysis

Bartlett's Test of Sphericity [$\chi^2(78) = 1574.1$, $p < 0.001$, $N = 349$] and Kaiser-Meyer-Olkin (KMO) criterion supported sample adequacy for factor analysis ($MSA = 0.86$, $range =$ 0.70-0.91). Velicer's MAP and scree test suggested a one-factor solution ($map = 0.028$), parallel analysis suggested a four-factor solution ($map = 0.050$). We conducted several principal factor analyses with promax rotation for comparison. A one-factor solution resulted in exclusion of items 11 and 12 because of low factor loadings, so that the factor was explained by 11 items and explained 38% of variance. Fit indices suggested an unfavorable fit ($RMSEA = 0.12$, 90%-$CI$[0.11; 0.14], $CFI = 0.96$, $\alpha = 0.86$). A four-factor solution resulted in one factor only explaining two items that correlated strongly with another factor ($r = 0.68$) and therefore was disproved. Based on the correlation and theoretical background an exploratory three-factor solution was conducted. Compared to the one-factor solution, three factors [$RMSEA = 0.08$, 90%-CI[0.065; 0.095], $CFI = 0.99$] explained correlations best ($\triangle\chi^2(2) = 138.35$, $p < 0.001$). One factor readiness explained eight items and two factors communication and values explained three items, respectively (**Table 3**). Factor loadings ranged from $\lambda = 0.35$–$0.73$, item difficulty, inter-item correlation and item-whole correlation were good, internal consistency ranged from $\alpha = 0.57$–$84$ (**Table 3**).

### 2.2.3. Validity

Convergent validity was supported by significant correlations of all sub-scales with gratitude and behavior stages for completing a living will and talking to loved ones about end-of-life. Participants with an advance care directive were more likely to report being ready ($r = 0.25$, $p < 0.001$) for EOL conversations, having communication experience ($r = 0.33$, $p < 0.001$) and see their values as important for further treatment ($r = 0.30$, $p < 0.001$). Divergent validity was supported by non-significant and low correlations of all sub-scales with depression and distress (**Table 4**).

# 3. STUDY TWO

Study two (Berlin et al., 2020) compared the effect of two online interventions to reduce burden of end-of-life on former and present cancer patients. The present study relies on data sets prior to intervention start and only presents relevant variables to study cause.

## 3.1. Materials and Methods

### 3.1.1. Inclusion Criteria and Procedure

Participants were eligible when aged 18 years or older, understood German sufficiently, reported cancer diagnosis and had access to internet. Participants were excluded for suicidal thoughts or acute psychosis (**Supplementary Material**). Participants were recruited with flyer, email and media promotion.

### 3.1.2. Measures

#### *3.1.2.1. Readiness for End-of-Live Conversation Scale*

The factor solution found in study one was validated in a sample of cancer patients. No changes were made, but it was controlled for an underlying common factor based on exploratory factor analysis.

#### *3.1.2.2. Additional Self-Report Measures*

Demographic data was collected using a standardized questionnaire. Medical and psychological data were based on self-report. Participants were asked to report the time of diagnosis, cancer site, diagnosis type, treatment status and treatment goal. Usage of psychological support and psychotherapy were assessed. Psychological distress (distress thermometer) and death anxiety (DADDS-G, $\alpha = 0.90$) were used for divergent validity (Mehnert et al., 2006; Engelmann et al., 2016). Additionally, depression and general anxiety were measured using the Patient Health Questionnaire-4 (PHQ-4). It measures the two key criteria for depression (PHQ-2, $\alpha = 0.81$) and generalized anxiety disorder (GAD-2, $\alpha = 0.73$), respectively (Kroenke et al., 2009). Fear of progression (FOP-Q, $\alpha = 0.86$) assessed dysfunctional fear related to cancer recurrence (Herschbach et al., 2005). Correlation with all questionnaires was expected to be small and non-significant. Convergent validity was established based on trait gratitude (GQ-6, $\alpha = 0.75$) (McCullough et al., 2002). Correlations were expected to be moderate and significant.

### 3.1.3. Statistical Analysis

Minimal sample size was estimated in relation to the severity of a cancer diagnosis with 5 times the number of items ($N_{min} = 5x13 = 65$) as sufficient. Three participants were excluded for missing data on REOLC. There were no dropouts in study two.

#### *3.1.3.1. Structural Equation Modeling*

Structural equation modeling (SEM) was used to confirm factor structure. Parameters were fixed in order to standardize factor

**TABLE 2 |** Demographic and medical information.

| Study one - community sample | | | Study two - participants affected by cancer | | |
|---|---|---|---|---|---|
| **Characteristics** | ***n*** | **%** | **Characteristics** | ***n*** | **%** |
| Gender | | | Gender | | |
| Female | 257 | 73.64 | Female | 73 | 86.90 |
| Male | 91 | 26.07 | Male | 11 | 13.10 |
| Education | | | Education | | |
| Secondary High School | 50 | 14.33 | Secondary High School | 6 | 7.14 |
| A-levels | 147 | 42.12 | A-level | 7 | 8.33 |
| University Degree | 148 | 42.41 | University Degree | 49 | 58.33 |
| Other | 4 | 1.15 | Other | 22 | 26.19 |
| Chronic Illness | | | Cancer Diagnosis | | |
| Yes | 81 | 23.21 | First | 46 | 54.76 |
| No | 260 | 74.50 | Second | 3 | 3.57 |
| Psychological Illness | | | Third | 2 | 2.38 |
| Yes | 22 | 6.30 | Recurrence | 11 | 13.10 |
| No | 325 | 93.12 | Free of Cancer | 19 | 22.62 |
| Clinical Distress | | | Other | 3 | 3.57 |
| Score < 5 | 192 | 55.01 | Therapy Goal | | |
| Score ≥ 5 | 152 | 43.55 | Curative | 65 | 77.38 |
| Missing | 5 | 1.43 | Palliative | 19 | 22.62 |
| Advance Care Directive | | | Cancer Type | | |
| Yes | 98 | 28.08 | Lymphoma | 13 | 15.48 |
| No | 251 | 71.92 | Breast Cancer | 36 | 42.86 |
| | | | Other | 30 | 41.67 |
| | | | Active Treatment | | |
| | | | Yes | 58 | 69.05 |
| | | | No | 26 | 30.95 |
| | | | Psycho-oncological Support | | |
| | | | Yes | 41 | 48.81 |
| | | | No | 43 | 51.19 |
| | | | Psychotherapy | | |
| | | | Yes | 21 | 25.00 |
| | | | No | 63 | 75.00 |

loadings and estimated using maximum likelihood (ML) method with Sattora-Bentler-correction and robust standard errors to control for violations of multivariate normality. Evaluation of the model was based on $\chi^2$-test, *Root-Mean-Square-Residual* method (SRMR). A combination of RMSEA (> 0.06) and SRMR (< 0.09) was recommended for small sample sizes ($N \leq 250$) (Hu and Bentler, 1999). The $\chi^2$-test supported model fit if $\chi^2/df < 2$ (Schermelleh-Engel et al., 2003). Item analysis provided factor score, item difficulty, item variance, inter-item correlation ($r_{iic}$), and item-whole correlation ($r_{itc}$).

## 3.2. Results

### 3.2.1. Participant Characteristics

Demographic variables varied between included and excluded participants (**Table 2**). Included participants ($n = 84$, $M = 45.25$, $SD = 13.29$) differed significantly to excluded participants ($n = 18$, $M = 32.06$, $SD = 12.53$) in age [$t(100) = 3.86$, $p < 0.001$] and distress [$t(31.76) = -3.96$, $p < 0.001$]. Excluded participants reported to be more distressed ($M = 6.89$, $SD = 1.64$) than included participants ($M = 5.08$, $SD = 2.21$). There were no significant differences for all other variables ($p > 0.05$). The majority of included participants reported to have been diagnosed in 2019 (25%), had been diagnosed for the first time and were diagnosed with breast cancer. Participants reported ongoing treatment (69.05%) and a palliative treatment goal (22.62%), and more use of psycho-oncological support than psychotherapy. On average, participants reported mild scores of depression and general anxiety, moderate death anxiety, fear of recurrence (54.76%) and clinical significant distress (61.90%, **Table 5**).

### 3.2.2. Structural Equation Modeling

Bartlett's Test of Sphericity [$\chi^2(78) = 402.52$, $p < 0.001$, $N = 84$] and KMO-criterion supported sample adequacy ($MSA = 0.81$, $range = 0.68$-$0.89$). Based on findings in study one, we conducted SEM with one common latent factor of readiness. Item

**TABLE 3 |** Study one.

| Item | Readiness | Communication | Values | M | SD | Difficulty | Variance | $r_{itc}$ | $r_{iic}$ | α |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | 0.73 | | | 3.69 | 1.08 | 61.56 | 1.17 | 0.68 | 0.42 | 0.81 |
| 2 | 0.54 | | | 1.80 | 1.22 | 29.99 | 1.49 | 0.51 | 0.46 | 0.84 |
| 3 | 0.73 | | | 3.24 | 1.30 | 53.96 | 1.70 | 0.59 | 0.44 | 0.83 |
| 4 | 0.52 | | | 3.20 | 1.17 | 53.30 | 1.37 | 0.68 | 0.42 | 0.81 |
| 5 | 0.55 | | | 2.93 | 1.24 | 48.76 | 1.53 | 0.60 | 0.44 | 0.82 |
| 6 | 0.71 | | | 2.70 | 1.37 | 45.03 | 1.87 | 0.78 | 0.40 | 0.80 |
| 7 | 0.56 | | | 2.23 | 1.29 | 37.11 | 1.67 | 0.74 | 0.41 | 0.80 |
| 8 | | 0.52 | | 2.89 | 1.32 | 48.19 | 1.75 | 0.70 | 0.49 | 0.65 |
| 9 | | 0.70 | | 2.59 | 1.20 | 43.17 | 1.44 | 0.61 | 0.57 | 0.73 |
| 10 | | 0.67 | | 2.91 | 1.27 | 48.52 | 1.62 | 0.72 | 0.46 | 0.63 |
| 11 | | | 0.71 | 3.93 | 0.89 | 65.47 | 0.80 | 0.60 | 0.22 | 0.34 |
| 12 | | | 0.35 | 3.21 | 1.25 | 53.58 | 1.57 | 0.38 | 0.43 | 0.60 |
| 13 | | | 0.60 | 3.67 | 0.88 | 61.13 | 0.77 | 0.55 | 0.28 | 0.42 |

*Exploratory factor analysis with promax rotation in a community sample.*
*N = 349. Factor loadings, average score (M), standard deviation (SD), item difficulty and variance, item-whole correlation ($r_{itc}$), inter-item correlation ($r_{iic}$), and α if item was dropped for each factor respectively. Items two and three were coded reverse.*

**TABLE 4 |** Study one.

| | Variable | M | SD | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Living will | 2.63 | 1.62 | | | | | | | |
| 2 | Talking about EOL | 2.80 | 1.73 | 0.38** | | | | | | |
| 3 | PHQ-9 | 7.72 | 5.67 | –0.16** | –0.06 | | | | | |
| 4 | Distress | 4.24 | 2.24 | –0.00 | –0.02 | 0.31** | | | | |
| 5 | GQ-6 | 28.99 | 2.50 | –0.08 | 0.03 | –0.06 | –0.08 | | | |
| 6 | Readiness | 2.83 | 0.89 | 0.28** | 0.29** | –0.04 | 0.05 | 0.14** | | |
| 7 | Communication | 2.80 | 1.04 | 0.34** | 0.30** | 0.03 | 0.07 | 0.09 | 0.57** | |
| 8 | Values | 3.60 | 0.74 | 0.28** | 0.19** | –0.10 | –0.05 | 0.06 | 0.16** | 0.33** |

*Scale inter-correlations in a community sample.*
*N = 349. M and SD are used to represent mean and standard deviation, respectively.*
**indicates $p < 0.05$ **indicates $p < 0.01$.*
*Readiness for End-of-Life Conversation (Readiness), communication experience (Communication), importance of values in life (Values), Distress Thermometer (DT), Patient Health Questionnaire 9 (PHQ-9), Gratitude-Questionnaire (GQ-6). Readiness to fill out an advance directive (Living Will) and readiness to talk about End-of-Life with family members (Talking about EOL) are displayed as numeric values. Low values indicate lower stages of health behavior (e.g., one = pre-contemplation), higher values indicate higher stages of health behavior (e.g., five = maintenance).*

**TABLE 5 |** Study two.

| | | M | SD | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|---|---|---|
| 1 | REOLC | 3.16 | 0.85 | | | | | | |
| 2 | DT | 5.08 | 2.21 | 0.08 | | | | | |
| 3 | PHQ-2 | 1.44 | 1.15 | 0.15 | 0.48** | | | | |
| 4 | GAD-2 | 1.85 | 1.33 | –0.11 | 0.53** | 0.61** | | | |
| 5 | FOP-Q | 33.49 | 9.34 | –0.04 | 0.59** | 0.29* | 0.33** | | |
| 6 | DADDS-G | 26.93 | 8.90 | –0.07 | 0.46** | 0.29* | 0.41** | 0.59** | |
| 7 | GQ-6 | 36.14 | 4.62 | 0.44** | 0.18 | –0.10 | –0.03 | –0.00 | –0.09 |

*Scale inter-correlations in a population affected by cancer.*
*N = 84. M and SD are used to represent mean and standard deviation, respectively.*
**$p < 0.05$ **$p < 0.01$.*
*REOLC, Readiness for End-of-Life Conversation Scale; DT, Distress Thermometer; PHQ-2, Patient Health Questionnaire 2; GAD-2, General Anxiety Questionnaire 2; FOP-Q, Fear of Progression Questionnaire; DADDS-G, Death And Dying Distress Scale German version; GQ-6, Gratitude Questionnaire.*

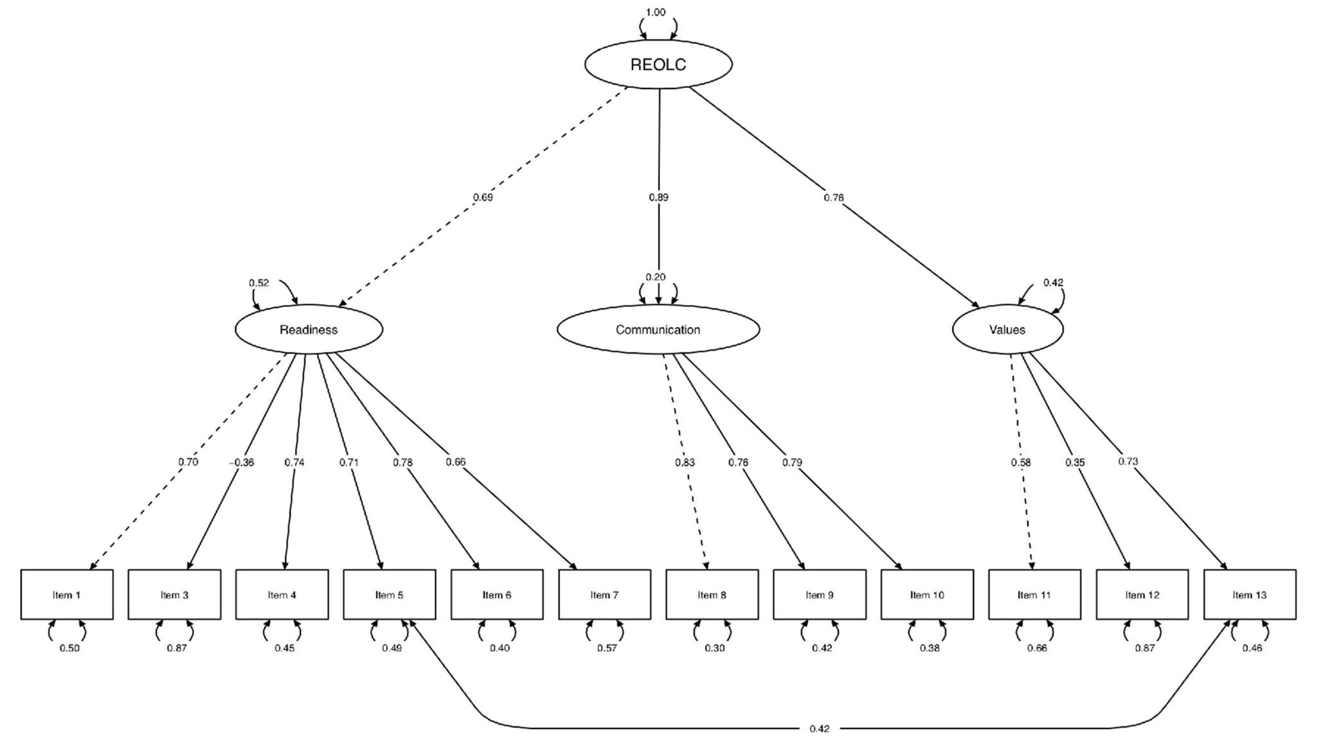

**FIGURE 1 |** Structural equation path model. Maximum-Likelihood method, Satorra-Bentler-correction, robust standard errors and standardized parameter estimation ($N = 84$). One common latent factor readiness (REOLC) for cancer patients. Exclusion of item 2 because of low factor loadings. Variances (one-headed arrows), covariances (double-headed arrows), marked variables (dashed line), manifest variables (rectangles), latent variables (ellipses).

**TABLE 6 |** REOLC scale for a population affected by cancer.

| Item | English | German |
|---|---|---|
| 1 | I believe that dealing with the end of life is part of life. | Die Beschäftigung mit dem Lebensende gehört für mich zum Leben dazu. |
| 3 | I avoid dealing with the finite nature of my life. | Ich vermeide es, mich mit der Endlichkeit des eigenen Lebens auseinander zu setzen. |
| 4 | For me it makes sense to talk about death and dying with my family/friends. | Für mich ist es sinnvoll, mit meinen Angehörigen/Freunden über das Thema Tod und Sterben zu sprechen. |
| 5 | Dealing with the end of life allows me to experience life more intensively at the present moment. | Die Beschäftigung mit dem Lebensende lässt mich im Hier und Jetzt intensiver leben. |
| 6 | For my friends I would recommend to deal with the finite nature of life. | Einem Freund/ einer Freundin würde ich empfehlen, sich mit der Endlichkeit des eigenen Lebens auseinander zu setzen. |
| 7 | I would like to start talking about the end of my life. | Ich möchte über mein Lebensende ins Gespräch kommen. |
| 8 | I know which topics regarding the last part of my life I would like to talk about with my relatives. | Ich weiß, welche Themen ich in Bezug auf die letzte Lebensphase mit meinen Angehärigen besprechen würde. |
| 9 | I know about my personal barriers when talking about the last part of life. | Ich weiß, worin für mich Hürden bei einem Gespräch über die letzte Lebensphase bestehen. |
| 10 | I know what advantages talking about the end of my life holds. | Ich kenne die Vorteile eines Gesprächs über das Lebensende. |
| 11 | I am aware of what in life is important to me. | Ich bin mir darüber im Klaren, was mir im Leben wichtig ist. |
| 12 | Dying with dignity means to end life the way one has lived it so far. | Würdevolle Sterben bedeutet, so aus dem Leben zu treten, wie man es bislang geführt hat. |
| 13 | I have already learned a lot about life. | Ich habe bereits einiges über das Leben gelernt. |

2 was excluded because of low explanatory value and low factor loadings ($R^2_{item2} = 0.036$, $\lambda_{item2} = -0.19$). Correlation of item five and item 13 was high and therefore added to the alternative model (**Figure 1**, **Table 6**). Model fit was good: Corrected $\chi^2$-test was not significant [$\chi^2(50) = 59.18, p > 0.05, Satorra-Bentler-correction = 1.27$], with $\chi^2/df = 1.184$, $rRMSEA = 0.053$ (90%-$CI[0.000; 0.100]$) and $rSRMR = 0.072$. Readiness explained 48.1%, Communication 79.9%, and Values 58.1% of variance.

**TABLE 7 |** Study two.

| | Item | M | SD | Difficulty | Variance | $r_{itc}$ | $r_{iic}$ | α |
|---|---|---|---|---|---|---|---|---|
| 1 | I believe that dealing with the end of life is part of life. | 3.73 | 1.23 | 74.52 | 1.50 | 0.61 | 0.32 | 0.84 |
| 3 | I avoid dealing with the finite nature of my life. | 3.36 | 1.42 | 67.14 | 2.02 | 0.37 | 0.35 | 0.86 |
| 4 | For me it makes sense to talk about death and dying with my family/friends. | 3.04 | 1.34 | 60.71 | 1.79 | 0.69 | 0.31 | 0.84 |
| 5 | Dealing with the end of life allows me to experience life more intensively at the present moment. | 3.32 | 1.42 | 66.43 | 2.00 | 0.66 | 0.32 | 0.84 |
| 6 | For my friends I would recommend to deal with the finite nature of life. | 2.77 | 1.62 | 55.48 | 2.61 | 0.68 | 0.32 | 0.84 |
| 7 | I would like to start talking about the end of my life. | 2.50 | 1.40 | 50.00 | 1.96 | 0.61 | 0.32 | 0.84 |
| 8 | I know which topics regarding the last part of my life I would like to talk about with my relatives. | 2.80 | 1.42 | 55.95 | 2.02 | 0.71 | 0.31 | 0.84 |
| 9 | I know about my personal barriers when talking about the last part of life. | 2.68 | 1.43 | 53.57 | 2.05 | 0.59 | 0.33 | 0.84 |
| 10 | I know what advantages talking about the end of my life holds. | 2.57 | 1.57 | 51.43 | 2.46 | 0.76 | 0.31 | 0.83 |
| 11 | I am aware of what in life is important to me. | 3 86 | 1.11 | 77.14 | 1.23 | 0.41 | 0.34 | 0.85 |
| 12 | Dying with dignity means to end life the way one has lived it so far. | 3.32 | 1.32 | 66.43 | 1.74 | 0.31 | 0.36 | 0.86 |
| 13 | I have already learned a lot about life. | 3.93 | 1.05 | 78.57 | 1.10 | 0.58 | 0.33 | 0.85 |

*Descriptive and item statistics for REOLC in a population affected by cancer.*
*$N = 84$. Average score (M), standard deviation (SD), factor loadings, item difficulty and variance, item-whole correlation ($r_{itc}$), inter-item correlation ($r_{iic}$) and α if item was dropped. Item two For me, experiencing life at the present moment is way more imporant than talking about the end of life. was removed from REOLC because of weak factor loadings $\lambda \leq |0.32|$.*

### 3.2.3. Item Analysis

Average item scores ranged from $M = 2.50–3.93$ ($SD = 1.05–1.62$). Items rated highest were *I have already learned a lot about life* (item 13), *I am aware of what in life is important to me* (item 11) and *I believe that dealing with the end of life is part of life* (item 1). Item difficulty ($d = 50.00–78.57$, $\sigma = 1.10–2.61$), item-whole correlations ($r_{itc} = 0.31–0.76$) and inter-item correlations ($r_{iic} = 0.31–0.36$) were acceptable. Internal consistency was good ($\alpha = 0.86$, 95%-$CI$[0.81; 0.90], **Table 7**).

### 3.2.4. Criterion Validity

Results showed no significant correlations with general anxiety, fear of recurrence, death anxiety, distress, and depression. Readiness correlated positive and significant with gratitude (**Table 5**).

## 4. DISCUSSION

A challenge in end-of-life conversations is the moment of confrontation and prevention of emotional burden for all participants. The purpose of this study was to create and validate a questionnaire that reliably assesses readiness for end-of-life conversations in a community sample and a population affected by cancer. Study one found three underlying factors in a community sample. Participants were ambivalent to avoid (item 3) or include (item 1) end-of-life discussions in life. Contrary to acceptance of necessity and beneficence regarding end-of-life conversations, average avoidance tendencies were high. These findings are in alignment with previous research: When illness and impeding death become a reality, caregivers often experience a reduction in readiness to engage in mortality communication, avoiding confrontation by subconsciously trying to reduce psychological burden (Bachner et al., 2020). Distraction or delay in conversations may be used to prevent individuals from the experience of negative affect (Arndt et al., 2007). This emphasizes the need for repeated reminders and sensitive strategies to support individuals in their choice to address fears when talking about death and dying.

Study two controlled for a common latent factor *readiness*. For cancer patients, clear separation of death from life (item 2) was of low explanatory value and therefore excluded. In comparison to a community sample, ignoring the possibility of death is impossible for cancer patients, because it is unwillingly introduced at time of diagnosis (Ferrell et al., 1998; Baum and Andersen, 2001). Death related health behavior, however, may still be avoided (item 3), because subconscious defense mechanisms prevent the accessibility of death-thoughts when making decisions under emotional strain. Then hope and beliefs in a just world are maintained in order to minimize threats to self (Arndt et al., 1997, 2007). A direct approach by physicians may increase accessibility of death-thoughts and avoidance of end-of-life conversations. An indirect approach using a questionnaire may reduce accessibility or decrease emotional strain, subsequently increasing interest in health behavior (Arndt et al., 2007). Further, constant changes in health status may repeatedly suppress and activate thoughts about death. Patients would report a change in readiness for end-of-life conversations accordingly. Indirect routine assessments may then increase chances for timely identification by health care providers. Items with high explanatory value were related to knowledge about personal preferences in topics and advantages of end-of-life conversations (item 8 and 10). Cancer patients have broader knowledge about medical side effects and treatment options compared to the average person. Also, thoughts about end-of-life preferences possibly have been necessary based on prognosis, family history or personal experiences. Knowledge about topics and advantages may not result in increased health behavior action, but includes contemplation and possible openness toward end-of-life conversations.

Despite openness for end-of-life conversations, hesitation may result from lack of trust in physicians, avoidance of psychological burden and informational deficits (Higginson and Costantini, 2002; Zhang and Siminoff, 2003; Goldsmith et al., 2007; Stone et al., 2012; Lambert South and Elton, 2017). Additionally, oncologists may experience difficulties to anticipate the moment to start and to engage in end-of-life conversations, often waiting for patient cues. Patients, however, may be reluctant, not ready or waiting for physicians initiation. Further, families may avoid end-of-life conversations in order to protect patients and themselves (Granek et al., 2013). A comparable questionnaire in the United States of America provided insights on the discrepancy of physicians assessment. Although patients reported to be ready, 83% of physicians did not initiate end-of-life conversations, 44.7% felt their patients were not ready and 13% were utterly surprised by self-reports (Kogan and Taguchi, 2020). An indirect assessment of readiness offers information without activation of resistance and provides a neutral tool for patients to voice and practitioners to identify readiness. Strategies and information to overcome barriers in the way of best medical and psychological care can be provided accordingly.

For both studies, readiness was associated with gratitude. Research found that focusing on life with gratitude and evaluating past events gratefully reduced death anxiety and increased likelihood of health behavior engagement (Lau and Cheng, 2011). Results of the present study indicate that high levels of gratitude lead to a broader understanding of positive outcomes associated with end-of-life conversations and thereby increase readiness to engage in such. Also, neither distress nor any other measure of psychological burden was associated with readiness for end-of-life conversations. Readiness for end-of-life conversations is an unrelated construct that assesses the openness to engage in a behavior despite high distress, highlighting the importance of an additional measurement in cancer care.

Findings of the present study underlie the following statistical limitations: First, different measures for convergent and discriminant validity were used in both studies, reducing comparability. However, measurements taken were still viable measures to yield empirical justification for discriminant validity in general. Second, sample size in study two did not meet requirements for structural equation modeling. Therefore, statistical corrections were performed to ensure adequate interpretation of the results. Third, uptake of health behavior after participation was not assessed. Scores of readiness could not be compared with behavior intention and action. Fourth, selection of participants may bias our results. Participants may have generally been open to and interested in the subject of end-of-life. Finally, due to item modification in study two we additionally recommend further validation using comparable samples of cancer patients. Overall, development and validation were based on two highly selective and small study samples with different health status and relation to end-of-life. Future studies should include larger samples and compare factor structure across varying conditions. Based on the present findings, generalizabilty of factor structure is not given and should be considered when questionnaire is used.

For clinical implications, sample size in the population affected by cancer was too small to make further assumptions about differences in factor structure and readiness for end-of-life conversations based on health status. In addition to larger sample sizes, future studies should use medical information provided by clinicians to make assumptions about differences in readiness across cancer site, active treatment or treatment goal. Readiness may vary dependent on treatment and expected treatment outcome. For curative patients, readiness at the time of diagnosis may not be high but change over the course of treatment, experiences with negative side effects, personal loss and changes in health status. For palliative patients, end-of-life conversations are important to provide patient-centered advanced care and decrease burden. Routine assessment of readiness would enable clinicians to identify changes in readiness and to provide information, guidance and support accordingly. In Germany, the S3-guidelines for palliative care (Leitlinienprogramm Onkologie, 2020) preset criteria for patient-centered care and shared decision making processes. They include incorporation of patient and family needs in addition to relief of strain, assessment of need for information, hopes and fears regarding treatment and knowledge before additional information is presented. They further highlight the importance of sensible conversations about death and dying, medical decisions at the end of life and early and repeated options to discuss end-of-life plans. Patients and families are expected to be included in the decision making process and offered guidance from health professionals. The REOLC scale may be used to identify overall readiness, but also to focus on individual barriers that may prevent patients to address the topic of end-of-life care first. It further may ease the initiation of end-of-life conversations for clinicians, patients and families alike. However, at present additional research is needed to explicitly validate the REOLC scale for palliative cancer patients.

While it has been proven beneficial for palliative patients to engage in advance care planning (Bischoff et al., 2013), research of the effect on former cancer patients or curative patients is scarce. However, assessing readiness for end-of-life conversations and different time points in cancer care should not be undervalued. For one, difficulties to unalterably interpret treatment as palliative, possible changes from curative to palliative treatment because of complications, changes in possibilities of a cure and advances in cancer stage add to the uncertainty of diagnosis not only for patients, but also for physicians (Leitlinienprogramm Onkologie, 2020). Also, readiness for end-of-life conversations may be higher if the death threat is not imminent, but still relevant because of diagnosis with cancer (Arndt et al., 2007). Until today, the S3-guidelines recommend questionnaires and screening methods for a variety of burden (Leitlinienprogramm Onkologie, 2020), but no tool to assess readiness for end-of-life conversations. The REOLC scale fills this gap in palliative care and offers a possibility to support health care practitioners by indicating readiness for end-of-life conversations in patients and family members alike. By application of the questionnaire independently of health status, practitioners gain insights in readiness of not only palliative patients, but also curative patients and are able to track and act accordingly over the course of diagnosis, treatment and follow ups.

One possibility to successfully screen for readiness would be the identification of a clinical cut-off, readiness scores in relation to health behavior stages and the minimal amount of readiness needed to start conversations and interventions (Westley and Briggs, 2004; Fried et al., 2009, 2010). Based on cut-off criteria and health behavior stages, interventions can address and modify specific barriers and support facilitators of end-of-life conversations. Additional qualitative analyses including patients and care-givers perspectives may provide insights and highlight mechanisms that can be targeted specifically. The REOLC scale enables researchers to evaluate such interventions for a community sample and cancer patients, respectively von Blanckenburg et al. (2020). With the REOLC Scale we may be one step closer to develop strategies that enable cancer patients and caregivers to change between stages more easily.

## 5. CONCLUSION

Conversations about end-of-life are referred to as necessary and beneficial. Readiness for these conversations, however, varies and therefore needs to be assessed before interventions or conversations are issued. A questionnaire to assess readiness is the Readiness for End-of-Life Conversations (REOLC) Scale of the present study. For a community sample, 13 items cover readiness, communication experience and importance of values thereby acknowledging the paradox of simultaneous desire to engage and avoid end-of-life conversations. For a population of cancer patients, a one-factor model with 12 items was suggested. The factor *readiness* acknowledges the difficulty for cancer patients to avoid the topic of death and end-of-life preparations. Model fit, convergent and discriminant validity were good. Future studies should validate the questionnaire in larger populations and different settings and assess changes in readiness and health behavior intentions.

## DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because: Data will only be shared at request after data collection of accompanying studies is completed. Requests to access the datasets should be directed to pia.berlin@uni-marburg.de.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee of the department of psychology at Philipps-University of Marburg. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

PB, PvB, WR, NL, and KN contributed to study design. PvB, WR, NL, and KN designed the questionnaire. PB and PvB analyzed and interpreted the data. PB and PvB drafted the manuscript are responsible for the content of manuscript. NL, KN, CS, and WR provided critical feedback and revisions. All authors approved the final draft for submission.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2021.662654/full#supplementary-material

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**Conflict of Interest:** The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

# *Supplementary Material*

## 1 STUDY ONE

### 1.1 Materials and Methods

#### 1.1.1 Exclusion Criteria

Exclusion criteria were assessed using the Beck-Depression Inventory II (BDI-II) and Brief Symptom Inventory (BSI). One item of the BDI-II (*During the past two weeks including today, did you have any suicidal thoughts?*) (Beck et al., 1996) was answered on a 4-point Likert Scale from zero (*I do not think about harming myself*) to three (*I would kill myself if I had the chance to*). Participants were excluded from study when scores were equal to or higher than two. Items (e.g. perception of voices or conversations nobody else could hear, the perception of phantoms) of the BSI were answered on a dichotomous scale (yes/no) (Wittchen et al., 1997). Participants who agreed to more than three items were excluded prior to data analysis.

#### 1.1.2 Measures

Distress (Distress Thermometer) over the past week was assessed on a visual scale from zero to 10 (Mehnert et al., 2006). Clinical cut-off is internationally recommended at values greater than four. Depressive symptoms were rated on a 4-point Likert-Scale ranging from zero (never) to three (always). Trait gratitude (GQ-6) was assessed on six items and scores were rated on a 7-point Likert-Scale from one (strongly disagree) to seven (strongly agree), higher values indicating higher gratitude (McCullough et al., 2002). Behavior stages were categorized into five stages: Pre-contemplation, contemplation, preparation, action and maintenance. Higher scores indicated a higher stage (Fried et al., 2010).

## 2 STUDY TWO

### 2.1 Materials and Methods

#### 2.1.1 Exclusion Criteria

Exclusion criteria were assessed using the BDI-II (see study one) and BSI. In study two, the five items of BSI were rated from zero to three. Cut-off was based on normative ratings for acute psychosis at BSI $\geq 70$.

#### 2.1.2 Measures

Death anxiety was assessed with the Death and Dying Distress Scale (DADDS-G) (Engelmann et al., 2016). Nine items were rated from zero (*I was not distressed by this thought or concern*) to four (*I experienced extreme distress*). Higher values indicate severe distress. The Patient Health Questionnaire-4 (PHQ-4) is successfully used as screening instrument for panic, social anxiety and post-traumatic stress disorders. Items are rated on a 4-point Likert-Scale from zero (not at all) to three (nearly every day) with a total score ranging from zero to 12. For both criteria cut-offs separate between normal (zero to two), mild (three to five), moderate (six to eight) and severe (nine to 12) depression or general anxiety (Kroenke et al., 2009). Fear of recurrence (FOP-Q) was rated on a 5-point Likert-Scale from one (never) to five ("very often"). Total scores range from 12 to 60, with a cut off at FOP-Q $\geq 34$ (Herschbach et al., 2005).

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## 7.4 Study IV

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# Validation of the Readiness for End-of-Life Conversations (REOLC) scale in a German hospital setting

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validation

ABSTRACT

*Objective:* For every health behavior, readiness to engage is a necessary and crucial foundation for following conversations, interventions or behavior changes. The present study aims to support a one-factor structure for the Readiness for End-of-Life Conversations (REOLC) scale (Berlin et al., 2021) in a population of cancer patients ($N = 295$).
*Methods:* For validation purposes, data of patients participating in a screening development study at a university clinic was used. Model adequacy was analyzed with structural equation modelling and controlled for with goodness of fit indices: $\chi^2$-test, SRMR, rRMSEA. Discriminant and convergent validity were assessed with correlations of REOLC and psychological or health behavior measures.
*Results:* Factor structure was supported with good fit indices, discriminant validity and convergent validity. Readiness correlated significantly with age and reported death anxiety.
*Conclusion:* The REOLC scale is a reliable instrument to assess cancer patients' readiness for end-of-life conversations. Future studies may further address moderating and mediating effects of socio-demographic, medical and psychological factors.
*Innovation:* The assessment of readiness may further indicate anxiety levels of cancer patients and enables practitioners to provide interventions accordingly. However, in a clinical setting and especially for patients with a palliative prognosis, end-of-life care conversations may need to be introduced early.

## 1. Introduction

Before people engage in interventions or seek help, motivation and readiness need to be high enough to outweigh the majority of possible aversive consequences. Similar to other health behaviors, end-of-life conversations (e.g. advance care planning) may be interpreted as straining or emotional burden with only a small chance of delayed gratification [1]. As a consequence, end-of-life conversations are often feared and outright avoided [2], although they may proof beneficial in understanding wishes and preferences for life-prolonging measures and reduction of worries [3,4]. Especially for cancer patients, early communication about advance care preferences reduces inpatient days and invasive treatment choices [5], increases utilization of hospice care [6] and satisfaction with treatment [3]. For family members of cancer patients, uncertainty about scope of action when faced with emotional and stressful medical decisions and risk to develop psychological disorders after bereavement are reduced [7]. Aside from organizational barriers, individual readiness for cognitive and behavioral change to engage in end-of-life conversations may need to be taken into account [1].

The Transtheoretical Model [8] proposes five dynamic steps of health behavior change from pre-contemplation (unawareness and no consideration of health behavior) to maintenance. Engagement and readiness vary dependent on the situation or behavior and are highly individual. In order to change perspective of health behavior and stage of engagement, psychological interventions [9] in addition to face to face conversations with trusted physicians [10] or family communication [11] may be used. To support success of interventions, measurement tools in usage are expected to be valid and reliable. The following report aims to further support factor structure recently found in the readiness of end-of-life conversations (REOLC) scale [12] and to provide specific insights for cancer patients.

## 2. Methods

### 2.1. Ethics statement

Ethical approval for the main study was granted by the ethics committee of the university clinic Gießen and Marburg (Identification Number:

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187–19) located in Marburg and pre-registered at the German Registration for Clinical Studies (DRKS00024700).

### 2.2. Participants

Participants were eligible for study participation when diagnosed with cancer, in curative or palliative treatment, capable to consent and sufficiently understand German. Patients younger than 18 years where excluded from participation because they were legally underaged and original development of the questionnaire focused on adult cancer patients. Exclusion criteria entailed participation in other studies with focus on advance care planning, physical or cognitive impairment due to side effects of treatment and disease (i.e. difficulties in concentration, fatigue, pain, advanced palliative state).

### 2.3. Procedure

Patients were approached in the treatment area and asked to participate in a screening development study focusing on need for advance care planning and provided written consent. Paper-pencil questionnaires could be filled out independently or with assistance of a study nurse, recruiting psychology or medical student. Patients, who used help, often referred to difficulties because of sore eyes, swollen hands or difficulties reading due to side effects of treatment. Socio-demographical, medical and psychological self-report information was assessed with standardized questions as part of the paper-pencil questionnaire. Additionally, medical data regarding diagnosis and cancer state (curative vs. palliative) were accessed by a study nurse from electronic medical files and in cooperation with the head physician of the department. The present manuscript is based on data from a larger study and therefore only presents results relevant to validation purposes.

### 2.4. Measures and statistical analysis

Participants rated agreement for the *REOLC* [12], the *Advance Care Planning Engagement Survey* (ACP-E [13]) for convergent validity and the *Death and Dying Distress Scale* (DADDS-G [14]), the D*istress Thermometer* [15], *General anxiety* (GAD-2) and D*epression* (PHQ-2, [16]) for discriminant validity (Supplementary Material). Statistical analysis followed instructions of scale development: Convergent and discriminant validity was assessed with correlations (Pearson's *r*), differences in socio-demographical and medical data between groups were assessed with *t*-tests for normally distributed data, Mann-Whitney *U* tests otherwise. Categorical comparisons were analyzed with $\square^2$-tests. Model adequacy for REOLC was analyzed with structural equation modelling (SEM), standardized factor loadings, maximum likelihood (ML) method with Sattora-Bentler correction and robust standard errors to confirm factor structure [12]. Goodness of fit was indicated by $\square^2$-test ($p > .05$), Standardized Root Mean Square Residual (SRMR<0.09) and robust Root Mean Square Error of Approximation (rRMSEA<0.08) for large sample sizes ($N > 250$). The $\square^2$ statistic supported structural model for relative $\square^2/\mathrm{df} < 2$ [17].

## 3. Results

### 3.1. Participant characteristics

Participants' ($N = 295$) age ranged from 23 years to 86 years ($M = 61.2$, $SD = 12.3$, $N = 295$) and 59.7% identified as male. The majority of participants were married (70.8%), living with family (79.5%), retired (50.2%), had received educational training of some sort (26%) and used psycho-oncological support (54.5%). The median year of diagnosis was 2019 with the earliest diagnosis in 1980 and latest diagnosis in 2021. Most patients reported having been diagnosed for the first time (66.9%) and receiving curative treatment (67.3%). Based on medical files 39% were treated for hematological tumors and 59.3% were in palliative treatment with physicians surprised if the patient was to die within the following six months (57.7%). The majority of patients reported clinical levels of distress (59.1%), but no clinical levels of depression (84.4%) or anxiety (82.0%) and with mild level of death anxiety ($M = 18.65$, $SD = 7.60$, *range* = 0–45). For readiness to name a DM (52.1%), to talk with DM about end-of-life care preferences (50.3%) or to sign official documents (45.0%) the majority of patients were in action stage. For readiness to talk with the treating physician about end-of-life care preferences most patients were in pre-contemplation stage (44.6%).

### 3.2. Structural equation modeling

The Bartlett test of sphericity ($N = 281$, $\chi^2(78) = 1176.81$, $p < .001$) and the Kaiser Meyer Olkin criterion (KMO = 0.83, *range* = 0.59–0.91) supported sample adequacy. The previously found factor structure was supported by a good model fit ($N = 261$, $rRMSEA = 0.064$ [0.044;0.083], $SRMR = 0.065$) with a significant $\chi^2$ statistic ($\chi^2(50) = 94.51$, Sattora-Bentler-scaling factor = 1.19, $p < .001$) but good relative $\chi^2$ value ($\chi^2/\mathrm{df} = 1.89$). Item 3 *I avoid dealing with the finite nature of my life* showed low but significant factor loadings ($\lambda_3 = 0.20$, $p < .05$) and therefore was not excluded (Fig. 1).

### 3.3. Validity measures

Convergent validity was supported by significant moderate correlations with ACP-E. Independent of topic, patients were less ready for end-of-life conversations in precontemplation stage or contemplation stage. Discriminant validity was supported by no correlations with depression or anxiety and low correlations with distress experience. Death anxiety correlated significantly but weakly with REOLC (Table 1). Regarding socio-demographic variables, only age and self-reported treatment goal were significantly correlated with REOLC. Palliative diagnosis predicted readiness of participants ($F(1,252) = 4.40$, $p < .05$, $R^2 = 1.72\%$). Patients who believed treatment to be palliative ($M = 3.11$, $SD = 0.86$) were more likely to be ready for communication than curative patients ($M = 2.88$, $SD = 0.82$, $t(252) = -2.01$, $p < .05$). Patients aged younger than 35 years ($M = 2.28$, $SD = 0.47$) reported significantly lower readiness scores than patients aged between 35 and 65 years ($M = 2.90$, $SD = 0.85$, $t(14.8) = -3.96$, $p < .01$) or patients older than 65 years ($M = 3.09$, $SD = 0.76$, $t(125) = -3.44$, $p < .001$). There were marginally significant differences in patients aged 35 to 65 and patients older 65 years ($t(281) = -1.90$, $p = .058$).

## 4. Discussion and conclusion

### 4.1. Discussion

For every person engagement in a specific behavior depends on the experience of 'being ready' to act. In the context of health care, the Transtheoretical Model (TTM [8]) interprets readiness for health behavior as dynamic process that is impacted by contemplation, initiation and maintenance. Readiness is seen as flexible state that can adapt to life changes, relevance of behavior and situational factors. As such health behavior, engagement in end-of-life conversations [18] also depends on peoples' readiness to contemplate necessity, prepare and initiate conversations, and is influenceable and highly dynamic. Since life is finite, there are times when end-of-life conversations could be beneficial for everyone, but especially people with life-threatening diseases, i.e. cancer, could benefit from these conversations [1]. The REOLC Scale is the first German instrument to reliably measure cancer patients' readiness end-of-life conversations (REOLC). Factor structure and correlations with advance care engagement in addition to non-existent correlations with general anxiety, depression or distress screenings confirmed good psychometric properties.

Weak but significant factor loadings for avoidance of the finiteness of life (item nr. 3) and death anxiety could be explained by gender effects and participation bias. First, the majority of patients was male and reported higher death anxiety levels if readiness for end-of-life conversations was high. Women, however, reported higher levels of death anxiety but

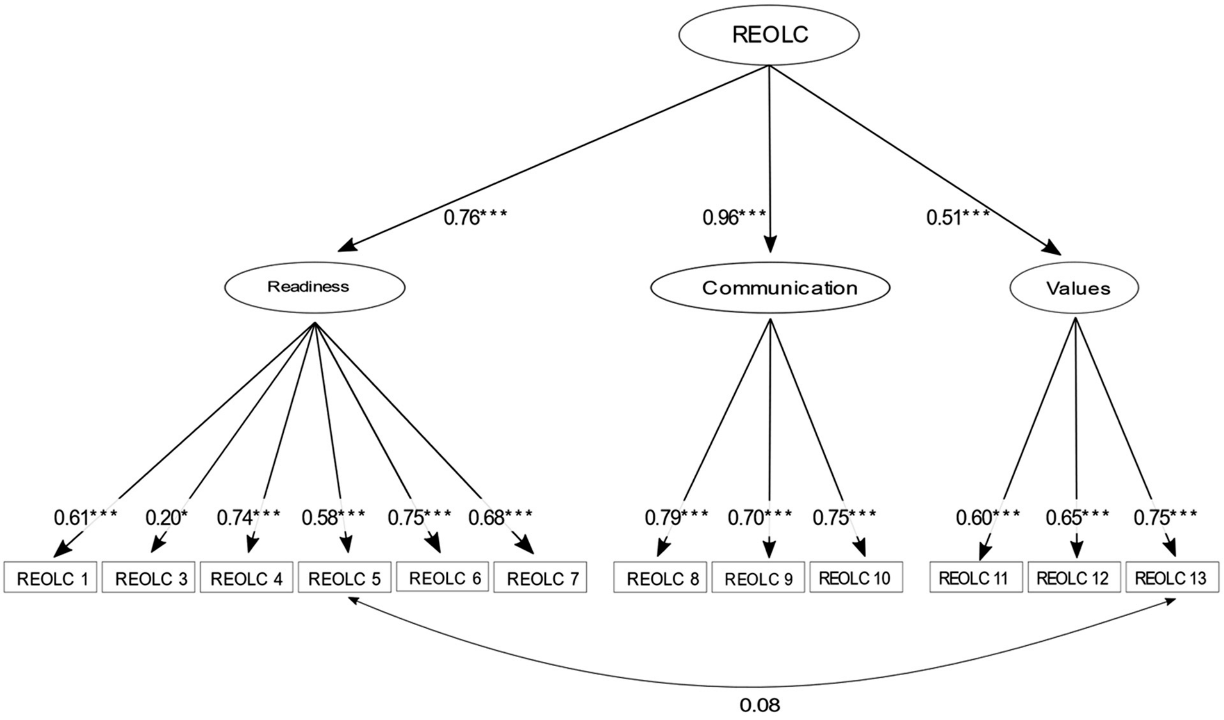

**Fig. 1.** Structural Equation Model of readiness for end-of life conversations ($N = 295$). Latent variables in ellipses, items in rectangles, factor loadings represented with significance values and one-headed arrows. Covariances represented with two-headed arrows. $^*p < .05$ $^{***}p < .001$.

**Table 1**
Correlation table.

| Variable | *M* | *SD* | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|---|---|
| 1. Age | 61.17 | 12.31 | | | | | | |
| 2. Distress | 4.83 | 2.55 | −0.10 | | | | | |
| 3. Depression | 1.30 | 1.39 | −0.11 | 0.55** | | | | |
| 4. General Anxiety | 1.28 | 1.53 | −0.02 | 0.59** | 0.65** | | | |
| 5. Death Anxiety | 16.42 | 9.35 | −0.09 | 0.59** | 0.66** | 0.68** | | |
| 6. ACP Engagement | 3.50 | 1.34 | 0.31** | 0.02 | 0.04 | 0.06 | 0.07 | |
| 7. REOLC | 2.95 | 0.82 | 0.19** | 0.12 | 0.04 | 0.09 | 0.13* | 0.31** |

*Note.* Average score (*M*), standard deviation (*SD*)
$^*p < .05$ $^{**}p < .01$ $N = 264–295$.
Distress thermometer (DT) [15], depression and general anxiety (PHQ-4) [16], death anxiety (DADDS-G) [14], ACP Engagement (ACP-E) [13] and Readiness for End-of-Life Conversations (REOLC) scale [12].

comparable readiness scores and no significant correlation between both concepts. Despite a higher risk of developing anxiety disorders, experiencing irritability or distress, women tend to report emotional burden, ask for help [19] or engage in end-of-life conversations [20], negating a necessary connection between emotional burden and health care utilization. Future studies should therefore investigate whether readiness for end-of-life conversations for women may be independent of death anxiety levels and facilitated by openness to discuss emotionally challenging topics. For men, the experience of intense negative affect may function as a moderator to help-seeking behavior and necessary factor in readiness change.

Second, significant relation of avoidance and readiness was small but acknowledged its relevance. Recruited during active treatment and surrounded by others in varying cancer stages, avoidance of end-of-life aspects may have been impossible for patients. Future studies need to evaluate differences in REOLC for moderating and mediating effects of treatment and location.

Third, the present study supported a positive effect of age on readiness, as previously found by von Blanckenburg and colleagues [9]. Younger patients may focus on fighting cancer and avoid end-of-life related discussions because they may not feel the pressure to do so. However, in a clinical setting and especially with palliative prognosis or high risk of recurrence, end-of-life care conversations may need to be introduced early and regardless of age or gender. Future studies could focus on possible interaction of age and prognosis to analyze how young age and palliative prognosis impact readiness for end-of-life conversations. Then, Intervention studies may provide solutions and support to facilitate end-of-life conversations in this particular setting and sample of cancer patients.

The study is mainly limited by participation bias: participants who refused to fill out the questionnaire may add value to a factor structure expected to explain changes in readiness for all cancer patients. Also, treatment, side effects or previous experiences with end-of-life conversations were not assessed and should be considered in the future.

### 4.2. Innovation

In daily life, barriers to end-of-life conversations between practitioners and patients are found in identification of patients who wish to engage [21], responsibility and time for engagement [4]. More importantly, patients express need to take time and think about implications of end-of-life conversations, an environment to express emotions [4] and the necessity of conceptualizing conversations as process [10]. With the REOLC Scale we provide a tool of assistance to assess readiness in specific situations: For example prior to consultation appointments for patients with high risk of recurrence, in psycho-oncological treatment or at times of disease worsening. Aside from readiness it indicates personal barriers (i.e. *I know what advantages talking about the end of my life holds*, item nr. 10) and permission to act (i.e. *I would like to start talking about the end of my life*, item nr. 7). Questionnaire completion could function as prompt and increase awareness for end-of-life conversations. Individual questions could be addressed directly, fears identified, emotions validated and acknowledged. Practitioners could emphasize and normalize benefits of end-of-life care and highlight individual advantages. In cases of progressed palliative state, the REOLC Scale may be used as interview tool and prompt for further advance care planning, identification of medical preferences, communication and documentation.

Despite benefits in specific clinical situations, routine implementation in a hospital setting may be challenging. However, referral of patients for in depth conversations could be based on REOLC score-related prompts: First, low readiness scores may result from younger age and few contact points with end-of-life. If diagnosed very young or for the first time, coping with mortality presumably is unpracticed. Also, previously contemplation of end-of-life preferences was not relevant due to young age or health. Deficiencies in end-of-life literacy [22] and emotional coping strategies [23] for death anxiety (i.e. diversion of attention towards the present [24]) may prevent readiness. Patients with curative diagnosis may try to avoid possibility of recurrence and refrain from confrontation with mortality [25]. It is essential to be aware of pressuring patients to engage could result in distress, reluctance and avoidance. Repeated reminder of support programs and initiative of practitioner addressing end-of-life conversations may then suffice.

Second, for moderate readiness and patients who already contemplate end-of-life conversations or presently in preparation stage, inhouse referral and information about support services could be convenient. These patients may simply expect physicians to initiate the conversations process [10].

Third, low engagement but high readiness scores may either indicate a final external barrier that prevents patients from end-of-life conversations or that patients are already in action or maintenance. One possible external barrier to action is fear to burden family members [14]. Although this is not addressed specifically with the REOLC Scale, indications could be found in patients' openness to include family and friends in end-of-life conversations (*For me it makes sense to talk about death and dying with my family/friends*, item nr. 4) and knowledge about personal barriers (*I know about my personal barriers when talking about the last part of life*, item nr. 9). Practitioners could provide research-based information on positive outcomes and emotional relief for caretakers (i.e. in determination and execution of patients' wishes [26], reduced anxiety and depression after bereavement [3]). Additionally, they could highlight reduction of emotional burden during end-of-life conversations if the process is guided by a professional. Initiation of conversations by practitioners may then reduce fear to breach the subject with family members and reduce emotional distress experiences for everyone long-term.

Another possible barrier is avoidance and low readiness score of family members while patients' readiness is high [27,28]. Although the REOLC Scale was originally developed in a community setting [12], at present only the adaptation for cancer patients is validated. Practitioners may have to rely on patient information regarding personal barriers to end-of-life conversations during consultation. If psycho-education during consultations including family members is not successful to increase readiness for engagement or patients arrive alone, practitioners may need to focus on supporting patients in their independent desire for end-of-life conversations. Researchers, however, are encouraged to validate the REOLC Scale for a community sample and develop interventions that gently increase readiness for family members. Independent of readiness score, referral to specific trained nurses [29], psycho-oncological support services or services focusing on provision of end-of-life conversations may provide needed guidance and programs [4]. Overall, a multidisciplinary team approach seems to be indicated in order to address all factors of influence when talking about the end of life.

For researchers, reliable assessment facilitates development and evaluation of interventions to improve readiness. First attempts with focus on values and preferences show promising results in improvements in a community sample using the REOLC Scale [9]. Future studies may adapt this program to different populations, health states and ages. With focus on age, application and adaptation of the REOLC for adolescents and young adults (AYA) with cancer may be of additional interest: End-of-life care discussions often occur late, practitioners and family feel unprepared, while AYA are ready to engage [30]. In a family-centred approach, an adapted REOLC Scale could be used as interview tool to initiate conversations and guide practitioners through the emotional process.

Common physician related barriers to initiation are lack of communication skills and training, feelings of unpreparedness for emotional conversations and lack of specific support services [27]. Especially at times when conversations would be helpful (i.e. advanced palliative state) but readiness does not increase, practitioners may feel unprepared. More frequent practitioner and patient engagement in clinical studies is needed to identify difficulties and desired support services. Patients' motivation for answering, individual interpretation of consequences and needs could be assessed with qualitative interviews. Subsequently, trainings for practitioners could target key components of readiness and provide emotional and behavioral skills to rely on during consultation. Then, the REOLC Scale could prompt initiation and use of different skill sets for engagement dependent on patients' readiness level. Continuous evaluation of trainings could improve patient-provider communication, built trust and result in reduction of fears to engage in end-of-life conversations. These stage-matched interactions with practitioners have the capacity to provide detailed information on incremental changes in readiness and to provide robust effects of interventions [31].

Finally, gender differences in the present study highlight the importance of providing individual interventions for men who report higher readiness and emotional burden. Also, it could be of interest to assess whether gender differences are mediated by illness burden and are irrelevant when cancer progresses. Since family communication and inclusion in end-of-life conversations may be of importance at all ages, gender effects in relationships could be of additional value and interest. Besides gender, age, treatment and location when approached for end-of-life conversations may impact uptake of conversations and participation in interventions. Researchers and practitioners may therefore rely on the REOLC as indicator for readiness but need to further consider additional external and internal barriers.

### *4.3. Conclusion*

The Readiness for End-of-Life Conversations (REOLC) scale is a reliable instrument to assess cancer patients' readiness. Psychometric criteria support a general score and inclusion of avoidance factors into the construct of readiness. Future studies should focus on socio-demographic differences, moderating and mediating effects of age, gender, treatment choice, disease prognosis and severity or the experience of death anxiety and avoidance patterns. Practitioners and researchers are encouraged to base interventions and improvement of communication skills on readiness levels of patients and family members.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2022.100045.

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# 1. Supplementary Material

## 1.1. Measures

### *1.1.1. Readiness for End-of-Life Conversations (REOLC) scale*

Participants rated agreement on a six-point Likert scale of the 12-item version of REOLC [1] from zero ("absolutely disagree") to five ("absolutely agree") with minimum score of zero and maximal score of 60. Higher average scores indicated greater readiness for end-of-life conversations, internal consistency was good (α=0.83).

### *1.1.2. Construct validity*

The *Advance Care Planning Engagement Survey* (ACP-E, α=0.90) identifies health behavior stages of patients to engage in preparations related to advance care [13], e.g. talk to decision makers (DM) or physician, to sign official papers and to name a DM. Items were rated on a scale from one ("I have never thought about it") to five ("I have already taken care of it"). Higher average scores were related to a higher stage of health behavior.

### *1.1.3. Discriminant validity*

Death anxiety was measures with the *Death and Dying Distress Scale* (DADDS-G, α=0.91, 14). Nine items were rated from zero ("does not apply") to four ("very much so") on a five-point Likert scale, with sum scores from zero to 36. Death anxiety was categorized in five levels from none (<8), little (8-13), mild (14-21), moderate (22-28) to great death anxiety (29-36, 15).

Self-reported cancer related distress was assessed with the *distress thermometer* and rated from zero ("not at all") to 10 ("extreme distress") during the past week. Clinical cut-off of the visual scale is recommended at levels greater than four [16].

*General anxiety* (GAD-2, α=0.84) and *depression* (PHQ-2, α=0.74) were screened for with the Patient-Health-Questionnaire-4 (PHQ4, 17). Symptom occurrence for two items each were rated from zero ("not at all") to three ("nearly every day") on a four-point Likert scale. Sum scores indicated levels categorized as normal (0-2), mild (3-5), moderate (6-8) or severe (9-12) with an optimal cut-off at scores greater than two, respectively.

### *1.1.4. Statistical analysis*

Convergent and discriminant validity was assessed with correlations (Pearson's *r*), differences in socio-demographical and medical data between groups were assessed with *t*-tests for normally distributed data, Mann-Whitney U-tests otherwise. Categorical comparisons were analyzed with $\chi^2$-tests. Model adequacy for REOLC was analyzed with structural equation modelling (SEM), standardized factor loadings, maximum likelihood (ML) method with Sattora-Bentler correction and robust standard errors to confirm factor structure [1]. Goodness of fit was indicated by $\chi^2$-test ($p$>.05), Standardized Root Mean Square Residual (SRMR<.09) and robust Root Mean Square Error of Approximation (rRMSEA<.08) for large sample sizes ($N$>250). The $\chi^2$ statistic supported structural model for relative $\chi^2$/df<2 [18].

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## 7.5 Study V

# Research Article

# Effects of an online Motivational and Value based Intervention or Loving-and-Kindness Meditation for people affected by cancer: A randomized controlled online study

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## Abstract

Introduction: End-of-life conversations have proven beneficial for people affected by cancer but are often postponed and avoided. Common psychological barriers include death anxiety and fear of cancer recurrence (FCR), whereas gratitude experience broadens attention and perspectives.

Objective: To compare effects of two different online interventions on (a) readiness for end-of-life conversations and (b) common stressors and alleviating factors in cancer experience.

Methods: Participants ($N = 118$) were randomly and equally assigned to either Loving-and-Kindness Meditation (LKM) or the online Motivational and Value based intervention (eMoVa). LKM was weekly practiced as guided meditation, for eMoVa weekly exercises were presented for six weeks. Primary outcome was readiness for end-of-life conversations, secondary outcomes were death anxiety, FCR and gratitude. We assessed outcomes prior and posterior intervention, at three and six-months-follow-up. Statistical analysis included Bayesian Linear Mixed Models with joint imputation and estimation, interpretation of evidence based on Bayesian Factors (BF).

Results: LKM and eMoVa increased readiness with a stable effect ($d_{LKM} = 0.13$-$0.29$, $\mathrm{BF}_{\mathrm{LKM} =}$ 4-18, $d_{eMoVa} = 0.40$, $\mathrm{BF}_{\mathrm{eMoVa}} > 100$). eMoVa increases were stronger compared to LKM ($d = 0.17$-$0.34$, $\mathrm{BF} > 100$). LKM reduced death anxiety and FCR after intervention, whereas in eMoVa FCR and death anxiety increased. Effects of both interventions were not stable to follow-up. Only LKM resulted in elevated gratitude.

Conclusions: LKM and eMoVa as online interventions are successful in increasing readiness for end-of-life conversations. When recommending auxiliary interventions for people affected by cancer, effects on death anxiety and FCR experience should be contemplated.

## Introduction

People affected by cancer are confronted with multiple physical and psychological challenges over the course of diagnosis, treatment and survivorship. Challenges include coping with side effects, emotional pressure and medical treatment choices. Since cancer is often interpreted as existential threat (1) and holds a risk of mortality, considerations of decisions for the end of life are essential. If introduced early, end-of-life (EOL) conversations such as advanced care planning can reduce intensive treatment, increase hospice days and result in greater satisfaction with palliative treatment (2–4). Although necessity for and benefits of EOL conversations are known (5), avoidance and postponement are common. As a result, conversations often take place close to death (6) and under emotional distress (7).

Easily accessible and cost-effective psycho-oncological interventions that increase readiness for engagement (8) could bridge the gap between benefits of early EOL conversations and low patient engagement (5). A shift towards mindfulness and acceptance interventions may prove beneficial in broadening patients´ perspective and enhancing adaptive coping mechanisms: They might lead to experience of events without relying on maladaptive defenses (9) and increase psychological flexibility (10), thus leading to better cancer self-management (11). First insights in effectiveness of acceptance and commitment therapy over cognitive-behavioral therapy support reduction in anxiety or distress and increases in quality of life, living meaningful despite side-effects and uncertainty (12–15).

A first specifically designed intervention to increase readiness for EOL conversations (Motivational and Value based intervention, MoVa) in a community sample was based on relevant topics for EOL care (16) and used motivational interview techniques to guide through the intervention (17). Psychological aspects included individual values, anxieties and personal worries combined with reflection of achievements, identification of wishes for loved ones, important milestones and facilitators for EOL conversations. Since successful in a community setting, adaptation of the eMoVa for cancer patients may also prove beneficial in increasing readiness for EOL conversations and strengthen double awareness. Double awareness describes the ability to acknowledge death and life simultaneously, without reducing meaningful living or  avoidance of death related topics and preparations (18). For patients to uphold double awareness, it is crucial that attention and focus do not narrow on stressors and anxiety related cues, but rather is broadened and open to changes.

An additional possibility to achieve double awareness may be the experience of gratitude and focus on positive emotions. According to the broaden-and-built theory (19) positive emotion broaden attention and perspective and thereby facilitate access to psychological, cognitive, social and physical resources. Furthermore, life challenges and opportunities are met more effectively, resources are further strengthened and well-being is improved long-term (19). In oncology, known effects of gratitude are post-traumatic growth, contentment and relaxation, lower levels of anxiety, less distress (20) as well as decreases in death related fear of recurrence or progress (FCR) (21). Further, enhancing gratitude experience yielded adaptive psychological functioning, higher social support, self-esteem and acceptance of illness, independent of time since first diagnosis (22). Importantly, increases in gratitude also resulted in healthier lifestyle choices and engagement in health behavior (23), in addition to more compliance with medical treatment (24). One method to induce and increase gratitude experience is the Loving-and-Kindness-Meditation (LKM). LKM derives from Buddhism and focuses on a mental state of unselfish and unconditional kindness. Positive energy and kindness are directed towards others, oneself, someone one dislikes and every being. Attention and awareness are not only brought to mindful repetition, but also broadened to the meaning and feelings that consequently arise whether positive or negative. The practice of LKM has been found to enhance perception of positive affect (e.g. gratitude) and simultaneously reduce negative affect (e.g. distress (25)).

Aside from organizational barriers, psychological barriers for uptake of EOL conversations include distress experience due to cancer, FCR, or death anxiety (26). They are known to impact quality of life, reduce well-being (27–29), treatment compliance, follow-up visits, and impact overall health care behavior (30). Specifically, death anxiety and FCR can lead to avoidance of doctoral appointments and negligent health behavior (31). As shared mechanism, narrowing of attention towards anxiety cues may reduce the capacity to consider medical decisions such as EOL care (32, 33) and result in defense mechanisms against aversive emotions that include denial and avoidance of EOL care conversations (6).

Although the original MoVa was designed as face-to-face intervention and LKM is often practiced as group interventions, digitalization evades known barriers of up taking cancer care support services (e.g. physical, economic and cultural (34)). Participation in an online version could further include patients who, due to isolation, immune system or side effects, would otherwise be unable to attend interviews or group sessions. Thus, the present study aimed to increase accessibility of interventions for cancer patients.

The primary objective was first, to adapt the already existing MoVa (17) to an online format (35) for people affected by cancer, and second, to compare effects of eMoVa and LKM on readiness for EOL conversations. Both interventions were expected to broaden perspectives and therefore increase readiness in cancer patients. Consequently, the secondary objective was to exploratory analyze effects of both interventions on FCR, death anxiety and gratitude. Whereas FCR and death anxiety were believed to be reduced because of gratitude experience (LKM) and addressing values and meaningful life (eMoVa), gratitude was expected to be increased in participants who practiced LKM. Since distress experience is a common burden for cancer patients that may vary weekly, is strongly related to FCR, death anxiety and impacts health behavior, we included weekly assessments as possible moderators. Importantly, we based analyses on the Bayesian framework testing the probability of parameter estimation. Analyses allowed quantification of the alternative, that is change due to parameter or change in favor of one intervention over another.

## Materials and Methods

### Study Design

We aimed to analyze two different interventions in a sample of cancer patients using a randomized controlled design. The study was preregistered in the Open Science Framework (DOI: 10.17605/OSF.IO/2VTFY). Ethical approval was granted by the respective Ethics Committee of the Department of Psychology (ID: 2020-12k). Recruitment started in April 2020 and continued for exactly one year. Flyer were posted on community bulletin boards or public places at study site. In addition, participants were recruited through general physicians and psychotherapists, social media, email distribution, magazine articles and support groups. Participation was possible in all German speaking countries and was rewarded with a raffle for vouchers. Inclusion criteria for participation included age of 18 years or older, former or acute cancer diagnosis, proficiency in German and access to internet. Participants were directly excluded from study participation if scoring high on suicide assessment (BDI-II ≥ 2 (36) e.g. *"I would like to kill myself"*), thanked for participation and presented with supportive contact information. Participants who scored high on psychosis screening (BSI > 70) were excluded from data analysis but not from participation. All interested participants received a link to online study information. When informed consent was given, participants were asked to answer socio-demographic, medical, and psychological questionnaires. They further provided an email address for subsequent contact and participation in interventions and were randomly assigned to one intervention. For both interventions, participants were contacted weekly via email, provided with a hyperlink to follow and asked to rate their weekly distress before engaging in weekly sessions. If participants did not active the link directly, they received an alert after two days that asked for participation. After approximately six weeks of intervention, participants were asked to answer all initial questionnaires and to state interest in raffle. They were further contacted three and six months for follow-up assessments.

## Loving-and-Kindness Meditation (LKM)

Participants were provided with an audio file of guided meditation. The developed meditation was based on Loving-and-Kindness Meditation (37). Meditation consisted of six consecutive parts: First, background information was given and meditation practice started with a singing bowl. Participants were asked follow the mantra: “May you feel safe. May you feel happy. May you feel healthy. May you live with ease.” The mantra was to be silently repeated and it was emphasized to not focus on the phrases but on the feelings evoked, to practice mindful perception of developing sensations. In consecutive steps, LKM focuses within one session on an extended circle of individuals: The mantra is applied to a person with whom the relationship is difficult, the participant him/herself, and finally to all people the participants deem important (shown in Fig. 1). The present intervention changed the original wording of the mantra from “being” to “feeling”. For cancer patients, being safe and being healthy may not be an option due to palliative state or chronicity, so that we feared the phrases to evoke feelings of helplessness and frustration rather than gratitude. Feeling safe or feeling healthy, however, was expected to be a possibility albeit palliative prognosis. Further, the original meditation practice focuses on people who are loved and befriended, combined with neutral people, while the German translation also includes and ends practice with people one has disagreements with and directing positive feelings to oneself. Since directing kindness to challenging people or self in a state of cancer diagnosis were expected to be more difficult than loved ones or a group of important people, we changed the sequences and embedded the more difficult parts within parts deemed easier. At the end of meditation practice, participants were educated that these feelings of kindness and warmth are creatable at any time. They were invited to use a few minutes of their day to practice, so that long-term effects of gratitude might hold. Participants were asked to follow the meditation for approximately 20 minutes and to continue practice between weekly assessments. The same audio file was sent weekly and additionally stored for download on a secure server of the university.

Insert Figure 1 here

## Intervention eMoVa: online Motivational and Value based Intervention

The online Motivational and Value based Intervention (eMoVa) was based on the original semi-structured value-based and motivation-focused intervention by von Blanckenburg and colleagues (17). Participants were invited weekly to answer presented questions or participate in exercises online. After the last session, participants were offered to receive a summary of all questions answered as PDF file. Transfer into a compatible and comparable online format resulted in minor adaptions: First, content was divided in six parts, each presented weekly and building on prior content (shown in Fig. 2). Second, supplementary questions that originally were only presented to the interviewer were now universally integrated in the material. Also, a selection of values was presented in week one to all participants that they were asked to rate according to importance, whereas in a face-to-face setting examples would only have been given if participants came up with nothing themselves. Comparable adaptations were made for week three: Suggestions for important topics of discussion were embedded in open-ended questions to allow associations to be made freely but provide support if participants could not think of topics. With the prompt of suggestions, we hoped to create a comparable process of answers to interview structure. We also changed the sequence in order to end the intervention with a focus on advantages rather than barriers to end-of-life conversations. Furthermore, we did not ask participants to imagine own death and feelings that arise with these imaginations. The reason for this was to avoid emotional duress without direct provision of psychological support.

Insert Figure 2 here

## Assessment

### *Socio-demographic and medical data*

Socio-demographic data included age, gender, marital status, highest educational level, present employment status, living situation and spirituality. Medical information was based on self-report and included last diagnosis and time of diagnosis, treatment goal (curative vs. palliative) and cancer site (free entry field). Cancer sites were self-reported but grouped into categories during data analysis (ICD-10), current treatment, psychological care utilization (psycho-oncological support or psychotherapy during the past six months) were answered with *yes* or *no*. Anxiety and depression (PHQ-4 (38), *α = .87*) symptoms over the past two weeks were assessed on a 4-point Likert Scale *(*0 = *not at all;* 3 = *nearly every day).*

### *Primary outcome measures*

The Readiness for End-of Life Conversation (REOLC) Scale (39) consists of 12 items rated on a 6-point Likert scale (0 = *absolutely incorrect*; 5 = *absolutely correct*). Items address individual readiness (e.g. *"For me it makes sense to talk about death and dying with my family/friends"*)*,* communication (e.g. *"I know which topics regarding the last part of my life I would like to talk about with my relatives."*) and values (e.g. *"I am aware of what in life is important to me.").* Average scores range from zero to five. Internal consistency was good (α = .87).

### *Secondary outcome measures*

Death anxiety was measured using the German version of the Death and Dying Distress Scale (DADDS-G(40)). It includes nine items rated on a 5-point Likert scale (0 = *I was not distressed by this thought or concern*, 4 = *I experienced extreme distress*). Total scores range from 0 to 36 with higher scores indicating greater death anxiety. Internal consistency was excellent (α = .90). Fear of cancer recurrence or progression was measured with the Fear of Cancer Recurrence and Progression Questionnaire (FOPQ-SF-12 (41), α = .87). The short form consists of twelve items rated on a five-point Likert scale from one (*never*) to five (*very often*), sum scores range from 12 to 60. Gratitude was measured with the German version of The Gratitude Questionnair-5 (GQ-5 (42), α = .80). The self-report grateful disposition is assessed by five items with a 7- point Likert scale (1 = *strongly disagree*; 7 = *strongly agree*), item 3 is reversed. Average scores range from one to seven. Distress was assessed with the German version of the NCCN Distress Thermometer (DT (43)). It contains a single-item visual analogue scale to quantify the global level of distress experienced in the past week including the current day (0 = *no distress*; 10 = *extreme distress*) with values greater 4 indicating clinically significant levels of distress.

### *Manipulation Check*

Participants practicing LKM were asked to rate the frequency of meditation practice during the past week. It was emphasized that all times applied counted, even if the audio file was not used. Frequency was transformed for analysis in numerical values indicating the minimal amount of practice: *Not once* (0), *1-2 times* (1), *3-4 times* (3), *5-6 times* (5), *7 times or more* (7). Practice was only assessed during intervention period. Participants in eMoVa were offered a summary of answers at the end of study participation. As manipulation check, only participants who finished the study were interpreted as interested in summary (*yes*) or not-interested (*no*).

## Data Analysis

### *Missing Data*

Missing data was controlled for using Little’s Missing Completely at Random test (44) at each time point excluding dropped out participants from analysis. General scores were created for all participants missing less than 50% of item answers, else given as missing. Bayesian linear mixed models jointly imputed data based on distribution under the assumption of data missing at random. For REOLC, death anxiety and FOP data was imputed using gaussian gamma distribution. Due to evident skewness in gratitude scores, imputation and model estimation was based on gaussian lognormal distribution.

### *Main analysis*

For manipulation check, differences in gratitude in LKM were compared between participants who reported to have meditated at least one time a week and those who did not answer control items during the intervention or explicitly stated to not have meditated. The effect of eMoVa was assessed comparing differences in readiness for end-of-life conversation scores between participants who asked for summary of answers compared to those who did not. Analyses were based on frequentist approach at significance level of α = 5% and complete data only.

For analysis of main outcomes, intervention effect on readiness for end-of-life conversations was analyzed with Bayesian linear mixed models (45) under the assumption of intention to treat (shown in Fig. 3). Dummy coded variables time (pre, post, FU1, FU2), intervention group (LKM, eMoVa) and control variables were defined as fixed effects, random effects included intercept, individuals were set as grouping variable. Control variables were only included if the correlation with outcome variables was at least moderate, models were compared for additive or moderating effect using Bayes Factor. For all analyses, pre-assessment and LKM were defined as reference categories. Model estimation was based on five chains of Monte Carlo estimation and sample size of 1000 for each chain. Analyses of contrasts were based on tail-probability of Bayesian models. Comparisons between time points and groups were conducted using Bayes Factor (BF). Interpretation was based on Jeffreys (46): No (BF = 1), anecdotal (BF = 1-3), moderate (BF = 3-10), strong (BF = 10-30), very strong (BF = 30-100) and extreme evidence (BF > 100) for the alternative hypothesis. Change in scores and credible intervals were calculated using predicted estimates based on Bayesian estimation models. Effect sizes were estimated with Cohen's d based on ten multiple imputed data sets. For exploratory purposes, intervention effect of both interventions on death anxiety, fear of cancer recurrence and gratitude were analyzed identically.

## Results

### Participants

The participant's socio-demographic and medical characteristics were based on self-reports (shown in Tab. 1). Participants did not differ in screening for depression (PHQ2 = 3.59-3.83) or general anxiety (GAD2 = 3.62-4.17) at any time point of assessment ($p > .05$). Differences in cancer state (e.g. first diagnosis vs. cancer free) did not impact any outcome variable ($p > .05$). Reported cancer sites varied largely, but the most common was breast cancer (37.9%).

Insert Table 1 here

### Manipulation check

For LKM, participants who reported to have meditated at least one time a week did not differ in distress experience ($p > .05$) and reported more gratitude than participants who did not answer control questions or did not meditate ($p < .05$). Most frequently, participants reported to meditate one to two times a week (40.67%), whereas 32.20% meditate less or did not answer the weekly assessment. In eMoVa, 67.50 % of participants requested intervention summaries at post-assessment. These participants reported greater overall readiness for end-of-life conversations ($p < .001$).

## Primary objective

Readiness for end-of-life conversations did only correlate significantly with trait gratitude of participants, so that no control variables were included and only two-way interactions were estimated. Evidence for growth in readiness in LKM from pre-assessment to three and six-month-follow-up was very strong. There was moderate evidence for growth in readiness for LKM at post and strong evidence for growth at follow-up assessments (shown in Tab. 2). Growth in readiness was stable over time of three months but continued to increase to six-month follow-up. For participants in eMoVa growth in readiness compared to pre-assessment of participants in LKM was of extreme evidence and stable after post assessment for the following six months (shown in Tab. 3).

Insert table 2 and 3 here

Group differences in changes from pre- to post-assessment ($d$ = 0.34, CI[0.22, 0.45] and from pre-assessment to FU1 ($d$ = 0.29, CI[0.17, 0.41]) were of extreme (BF > 100) and very strong evidence at FU2 ($d$ = 0.17, CI[0.05, 0.28], BF = 33.5) and supported growth in eMoVa over LKM (shown in Fig. 4). Participants in eMoVa descriptively reported higher levels of readiness for EOL conversations at post, FU1 and FU2 than participants in LKM (shown in Tab. S1a).

Insert Figure 4 here

## Secondary objective

Fear of cancer recurrence (FCR) correlated with clinical levels of distress ($r$ = .59, BF > 100). Clinical distress (DT > 4) at pre-assessment was calculated as *baseline levels of clinical distress* (bcDT) and included in estimation modeling after testing for significance ($r$ = .57, BF > 100). There was moderate evidence for moderating effects of bcDT on FCR compared to additive effects (BF = 4.32) so that a three-way interaction was considered for estimation. For participants without bcDT (shown in Fig. 5A) in eMoVa, increases in FCR to post were of very strong evidence, with moderate evidence for reduction to pre-assessment levels at six-months-follow-up (shown in Tab. S3a). Changes in FCR due to LKM were only of anecdotal evidence (shown in Tab. S2a). Participants in eMoVa descriptively reported higher FCR scores at all time points (shown in Tab. S1b). For participants who reported bCDT (shown in Fig. 5B), in eMoVa, there is increasing evidence over time for reduction of FCR (anecdotal at post to extreme at FU2, as shown in Tab. S2a and S3a). Contrary, in LKM reduction in FCR to post was of strong evidence, but increases at follow-up were of very strong to extreme evidence (shown in Tab. S3a). Increase in FCR from pre- to post-assessment for participants with no bcDT in eMoVa was of strong evidence compared to LKM (*d* = 0.56, CI[0.35, 0.76], BF = 36.13). Difference in changes was of moderate evidence at FU1 (*d* = 0.52, CI[0.32, 0.73], BF = 7.05) and of anecdotal evidence for FU2 (*d* = 0.34, CI[0.13, 0.54], BF = 1.81) for participants in eMoVa compared to LKM. For participants with bcDT, evidence for differences at FU1 (*d* = 0.39, CI[0.26, 0.54], BF = 20.74) in eMova compared to LKM was strong. At post-assessment, there was no evidence for difference of change between groups (*d* = 0.24, CI[0.11, 0.38], BF = 8.45). For FU2, there was no evidence for absolute change in FCR (BF = 0.81), but participants in LKM reported an increase in FCR ($\Delta_{\text{pre-FU2}}$ = 4.71). Participants in eMoVa reported a comparable strong reduction in FCR ($\Delta_{\text{pre-FU2}}$ = -3.45) and the effect of difference was large (*d* = 0.95, CI[0.80, 1.10]).

Death anxiety correlated with clinical levels of distress (*r* = .48, BF > 100), so that bcDT was tested for significant correlation (*r* = .46, BF > 100) at pre-assessment and included as control variable into the estimation model. There was stronger evidence for the additive compared to the moderating Bayesian estimation model (BF = 31.93). Elevated scores of death anxiety were likely to occur because of clinical levels of distress ($\beta_{baselineClinicalDistress}$ = 21.38 [15.54; 27.32], SD = 1.51, tail probability < .001, GR-crit = 1.0, MCE/SD = .02). In LKM, evidence for significant reduction in death anxiety at post was strong, extreme at FU1, but anecdotal at FU2, because of moderate to strong evidence for increase in death anxiety (shown in Tab. S2b and S3b). In eMoVa, reduction from pre-assessment to FU2 was of moderate evidence, whereas all other changes were of anecdotal evidence (shown in Tab. S3b). Evidence for differences in reduction for LKM compared to increase eMoVa was of extreme evidence for FU1 (d = 0.46, CI[0.35, 0.58], BF > 100) and strong evidence for post assessment (d = 0.29, CI[0.18, 0.41], BF = 17.36). At FU2, difference in change between groups anecdotal evidence because of increases in LKM and decreases in eMoVa (d = 0.09, CI[-0.02, 0.20], BF = 2.75). Participants in eMoVa descriptively reported higher descriptive scores of death anxiety at all time points except for FU2 (shown in Tab. S1a and figure 5C).

For trait gratitude, no control variables were included in model estimation. Growth in gratitude between interventions compared to pre-assessment showed strong evidence for greater increase in LKM than eMoVa at FU1 (*d* = 0.14, CI[0.03, 0.25], BF = 17.14) and moderate evidence at FU2 (*d* = 0.03, CI[-0.08, 0.15], BF = 3.28) but anecdotal evidence for differences at post (*d* = 0.09, CI[0.02, 0.21], BF = 2.09). Whereas gratitude was stable or increased in LKM with only a slight reduction between follow-up-assessments, reduction of gratitude in eMoVa was continuous compared to pre-assessment (shown in Tab. S1a). For participants in eMoVa, there was only anecdotal evidence for growth in gratitude for all timepoints (shown in Tab. S3b). For participants in LKM, all comparisons were of moderate to very strong evidence, only growth from pre to post was of anecdotal evidence (shown in Tab. S2b).

Insert Figure 5 here

## Discussion

The primary objective of the present study was first to adapt an already implemented interview-intervention (MoVa) for a population affected by cancer in an online setting (eMoVa), and second, to assess intervention effects of two interventions (LKM, eMoVa) on readiness for EOL conversations. Both interventions were successful in increasing readiness in people affected by cancer. Effects in eMoVa were stronger, emerged directly after the intervention period, and remained stable over the course of six months, whereas effects of LKM occurred slower but consistently increased over the course of intervention and follow-up.

The increase in readiness due to both interventions confirms and extends previous research. For eMoVa, present findings support application as online version for a sample of cancer patients. Focusing on personal achievements, milestones and values combined with focus on loved ones during the first two weeks may have strengthened positive emotions and social connectedness. Consequently, broadened perspective and activation of cognitive resources (47) may have strengthened flexibility regarding EOL conversations and double awareness.

For LKM, the first successful increase in readiness for EOL conversations is added to previous findings on beneficial effects on health and well-being, interpersonal communication skills and social connectedness (48, 49). Through the focus of LKM on compassion and empathy, intolerance to aversive affect experience is reduced (50). Adaptive health behavior is facilitated (50) through a socio-emotional pathway (51, 52). Additionally, working memory capacity could have improved so that resources for problem solving and planning were released (52).

Therefore, secondary findings of increases in gratitude in LKM are consistent with previous research (37) and could be interpreted as mechanism of change in readiness in line with the broaden-and-built theory (19). Unsurprisingly, there were no changes of gratitude for participants in eMoVa. During the intervention perspective was directed towards challenges and benefits of end-of-life conversations. Gratitude experience may have changed dependently session by session.

For FCR effects were moderated by baseline levels of clinical distress: Without distress prior to intervention, no changes in FCR were found in LKM. In line with previous research on FCR triggers (53), confrontation with EOL care topics in eMoVa led to strong increases during the intervention and return to baseline levels after six months. As such, participation in both interventions had no long-term negative effect for cancer patients. For distress prior to intervention, FCR was reduced during LKM but increased strongly thereafter. In contrast, after increases of FCR during eMoVa, long-term symptom reduction was very strong. eMoVa provided a foundation for further discussion and might have encouraged participants to engage in conversations with family members (17). These findings hold several aspects of importance for clinical practice. For one, LKM practice has no harming effect if practiced regularly. However, increases at follow-up could be identified as trigger reaction due to prompts of assessment, while there were no invitations to meditate.

Further, we found reduction of death anxiety during LKM but return to baseline levels after six months, whereas eMoVa reduced death anxiety experience at six months despite increase during intervention period. In LKM, gratitude experience could have promoted social connectedness and attachment security. Both are known buffering effects of death anxiety defenses (54) and could have resulted in stable death anxiety reductions. However, it is possible that return to baseline occurred because of reduced meditation practice or frequency. Previous research in healthy participants (55) indicated that guided LKM group practice paired with psychoeducation and planned integration of meditation effects into daily life produced stable reduction of anxiety and stress for one year. Transferred to the present study objective, the combination of LKM with eMoVa and information on meditation effects could stabilize readiness increases for future health behavior and reduction of negative affect. Also, death anxiety experience during eMoVa was likely activated due to weekly confrontation with aspects that activated mortality salience.

Based on these findings, several future research objectives emerge: For one, moderating factors such as gender or prognosis might be of interest for clinical practice. Specifically comparing intervention effects for patients with palliative and curative diagnosis, different age groups and gender could ease recommendation processes. Secondly, meditation practice may not address every cancer patient so that alternative gratitude increasing interventions paired with eMoVa may be helpful in reaching a variety of patients. Possible alternatives include daily listing of reasons to feel grateful (22) and weekly writing of a gratitude letter (21).

Further it would be of interest whether a combination of both interventions (56) could increase gratitude experience: To circumvent barriers to change, experience of positive emotions during health behavior (e.g. EOL conversations) can increase likelihood of action and maintenance (47). Increases of positive emotions paired with guided value based motivational tasks could further increase readiness for and engagement in EOL conversations. Importantly, during participation in LKM neither death anxiety nor FCR experience increased. Future studies should assess whether the combination of interventions could buffer against death anxiety and FCR. Additionally, it would be of interest to evaluate whether increased positive affect reduces barriers for initiation while repeated confrontation with EOL conversations has an exposure effect (57). FCR after repeated confrontation with EOL conversations might reliably return to baseline or even decrease. Since EOL conversations such as advance care planning are recommended to be introduced timely (58), supportive results could reduce health care professionals' hesitancy of initiation (59).

Finally, future studies should carefully assess meditation frequency and persistency after post assessments for buffering effects against FCR increase. For LKM specifically, it would be of interest to compare impact on FCR between participants asked to answer EOL related, neutral and positively framed questions. Research on eMoVa, however, could further assess intention of EOL engagement and likelihood of EOL conversations following eMoVa participation.

### Strengths and Limitations

The present study holds several strengths and value for future research. The study was designed as randomized controlled trial, focused directly on readiness for EOL conversations and was based on a sample of cancer patients. Also, first insights on intervention effects on common stressors in oncology are presented. Attrition rate was reduced with offer of monetary compensation, repeated reminder to participate and online accessibility through laptops, tablets or smartphones.

However, we are aware that our research may have some limitations. First, we acknowledge methodological limitations. Due to online assessment, medical information was based on self-report and no medication intake or treatment information was gathered. Present findings, for example, can provide insights of effects for mainly female participants with curative diagnosis. For future studies, co-operations with physicians for effect interpretation based on oncological parameters may be beneficial and provide more general interpretations.

Also, we did not control meditation practice objectively. Future studies may combine assessment with data from already existing applications (60) and specifically focus on meditation frequency and duration. However, we copied processes of meditation applications: Users were offered to be reminded to practice meditation repeatedly and guided meditations were offered to use in self-management. Therefore, we believe our procedure for meditation to be comparable to real-life conditions.

Additionally, we compared two active treatment conditions, with slightly adapted interventions. Therefore, we cannot differentiate whether effects are superior to a passive control group. Specifically, for increases in FCR after participation it would be of interest to assess whether the changes are comparable to “normal” FCR trajectories when confronted with possible triggers of death anxiety.

Although online participation allowed for extensive recruitment, high drop-out rates of up to 30% may have affected our results. While we were able to statistically compensate with joint imputation and estimation, online assessment prevented us from understanding reasons for dropout, processes participants went through and whether interventions were continued without response to questionnaires. Future studies may include assessment of reasons for dropout. Further, it would be of interest to assess whether simple confrontation with EOL related questionnaires at times of assessment can function as prompt for EOL conversations and increase readiness. Future studies may therefore not only include a passive control group for intervention effects, but also a control condition in which unrelated questionnaires to EOL are presented.

Finally, participants reported high levels of readiness prior to intervention, so it is likely that they were in contemplation stage of health behavior change (61) rather than pre-contemplation and eMoVa was able to foster motivation for preparation and action. Future studies could control for stage in health behavior change in addition to behavioral intention and maintenance assessment after intervention. Further, control of baseline values might strengthen interpretation of intervention effects.

## Conclusion

Weekly online interventions that ask for active participation in end-of-life related considerations are successful in increasing readiness for end-of-life conversations. They result in long-term reduction of fear of cancer recurrence for highly distressed cancer patients meanwhile not increasing death anxiety. Comparably, Loving-and-Kindness meditation is successful in increasing feelings of gratitude and readiness for end-of-life conversations in cancer patients long-term, and allow for short-term reduction of death anxiety and fear of cancer recurrence. Further research is needed to assess possible combination effects in varying groups of cancer patients.

# Statements

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## Statement of Ethics

This study protocol was reviewed and approved by the Ethics Committee of the Department of Psychology at the Philipps-University of Marburg, approval number [2020-12k]. Participants provided informed consent by agreeing to study participation online prior to assessments.

## Conflict of Interest Statement

Data collection and analysis was funded by German Cancer Aid (Recipient PvB, Funding ID: 70113532). The authors have no conflicts of interest to declare.

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## Author Contributions

PB was responsible for design of study, administration, analysis and content of the drafted manuscript. TK contributed to interpretation of data and provided critical feed-back on analysis and draft. PvB supervised all processes and provided critical revision. All authors approved the final draft for submission.

## Data Availability Statement

The data that support the findings of this study are not publicly available due to containing information that could compromise the privacy of research participants but are available from PB in anonymized form upon reasonable request.

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## Figure Legends

Fig. 1. Content of Loving-and-Kindness-Meditation (LKM) practice.

Fig. 2. Content of online intervention for each week.

Fig. 3. Flow of participants. ITT = Intention to Treat.

Fig. 4. Estimated intervention effects of Loving-and-Kindness Meditation (LKM) compared with online Motiva-tional and Value based Intervention (eMoVa).

Fig. 5. Exploratory average prediction based on Bayesian Linear Mixed-Models for Fear of Cancer Recurrence (FCR), death anxiety (C) and trait gratitude (D). Moderating influence of baseline levels of clinical distress (bcDT) displayed in A and B. Loving-and-Kindness Meditation (LKM) and online Motivational and Val-ues Based Intervention (eMoVa).

| Introduction | Focus I | Focus II | Focus III | Focus IV | End of Practice |
|---|---|---|---|---|---|
| Background Information | Someone loved | Someone challenging | Self | Group of people | Mindful comeback |
| General information about loving and kindness, suggestions for practice and instructions on body position and breath. | Picturing a person, that one felt warm feelings towards. | Picturing a person, with whom the relationship at present is difficult or challenging. | Picturing oneself, focusing on the body and on challenges and achievements in the past. | Picturing all people, that are important. Participants are free to include family, friends, acquaintances or all people. | Focus on feelings during the session and body sensations. Information on availability of meditation throughout every day and activity. |

Figure 1. Content of Loving-and-Kindness-Meditation (LKM) practice.

| Week I | Week II | Week III | Week IV | Week V | Week VI |
|---|---|---|---|---|---|
| Milestones I | Milestones II | Topics of Importance | Difficulties and Barriers | Advantages and Facilitators | Open Discussion Points |
| Reminiscence of previous years, milestones and rating of values. | Focus on things participants would like to be remembered about, advises they would want to give or wishes for loved ones. | Provision of back-ground information on importance of end-of-life conversations and on existing programs. Additional open ended and multiple choice questions focusing on topics of personal importance. | Focus on possible difficulties and barriers of end-of-life conversations. Selection of examples relevant for individual and open ended questions regarding personal barriers and experiences. | Focus on advantages of end-of-life conversations, selection of examples and open ended questions regarding facilitators and personal experiences. | Open questions and topics participants personally would like to talk about. |

Figure 2. Content of online intervention for each week.

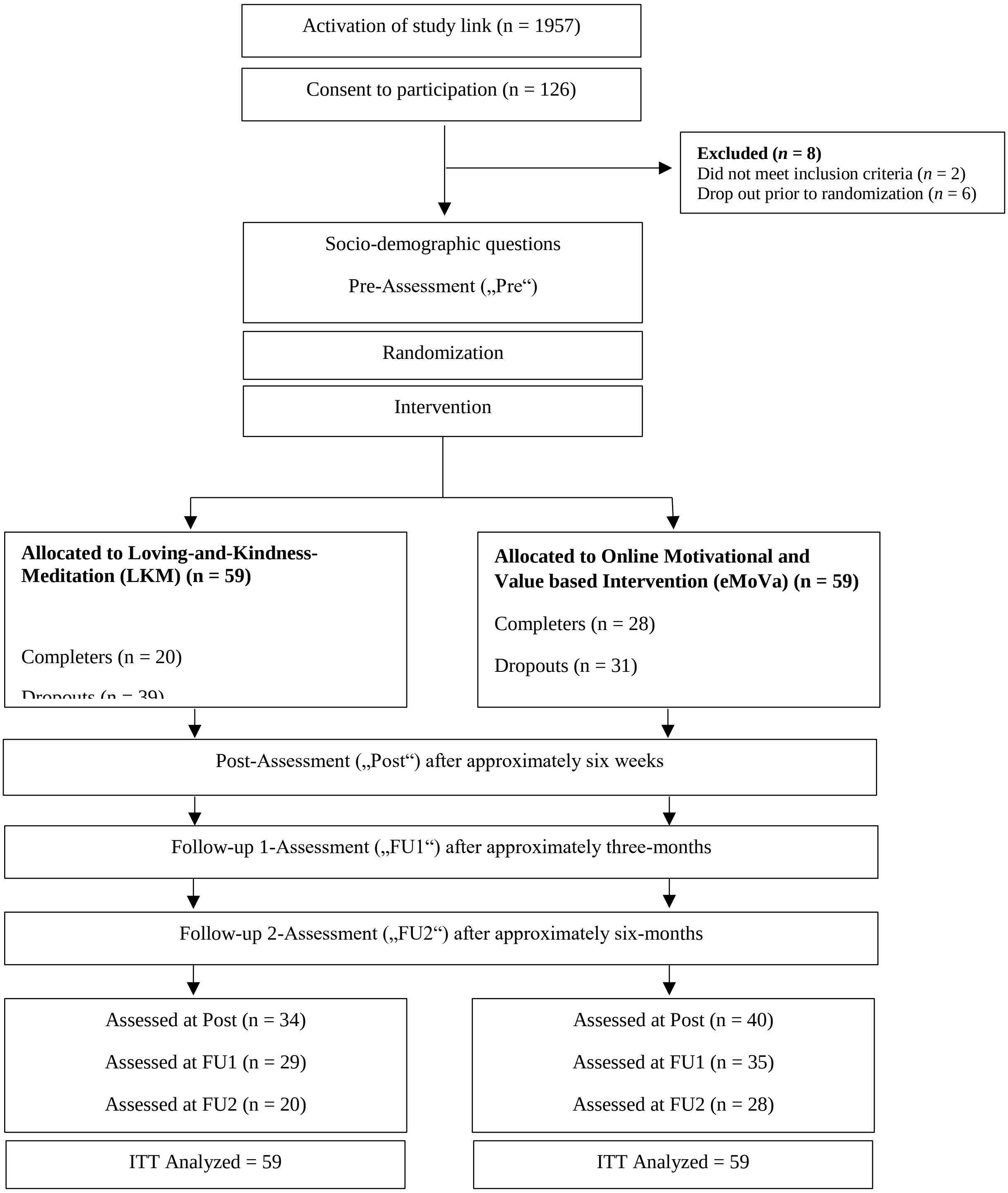


Figure 3. Flow of participants. ITT = Intention to Treat.

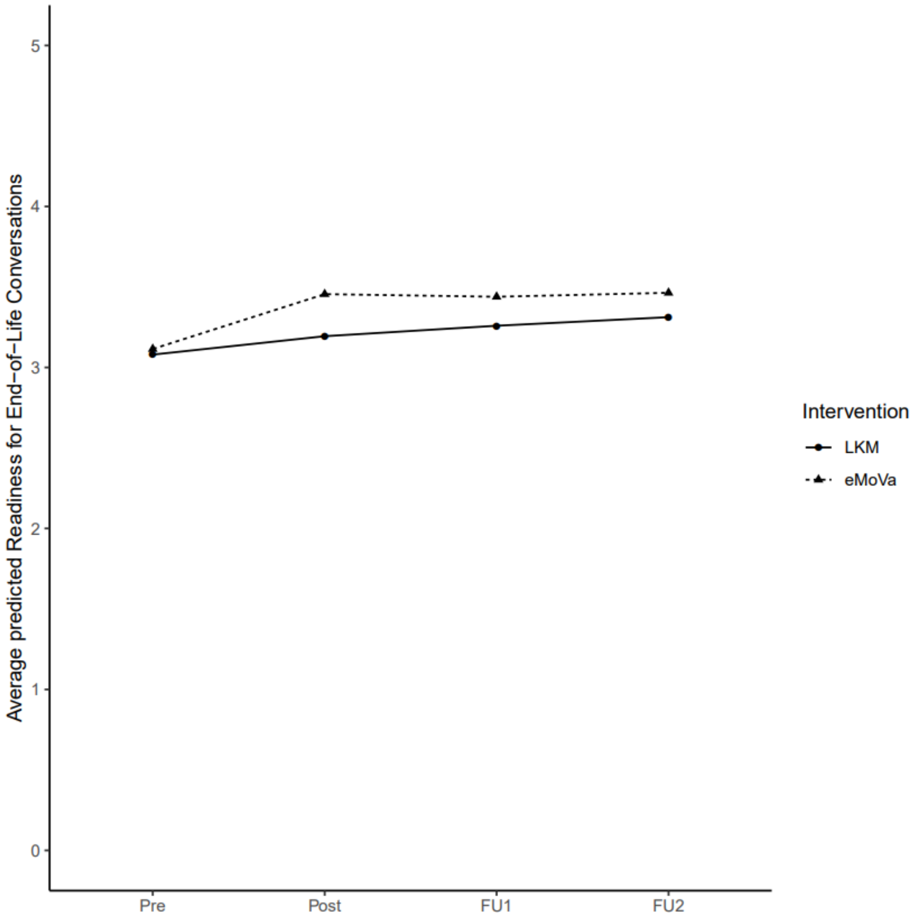
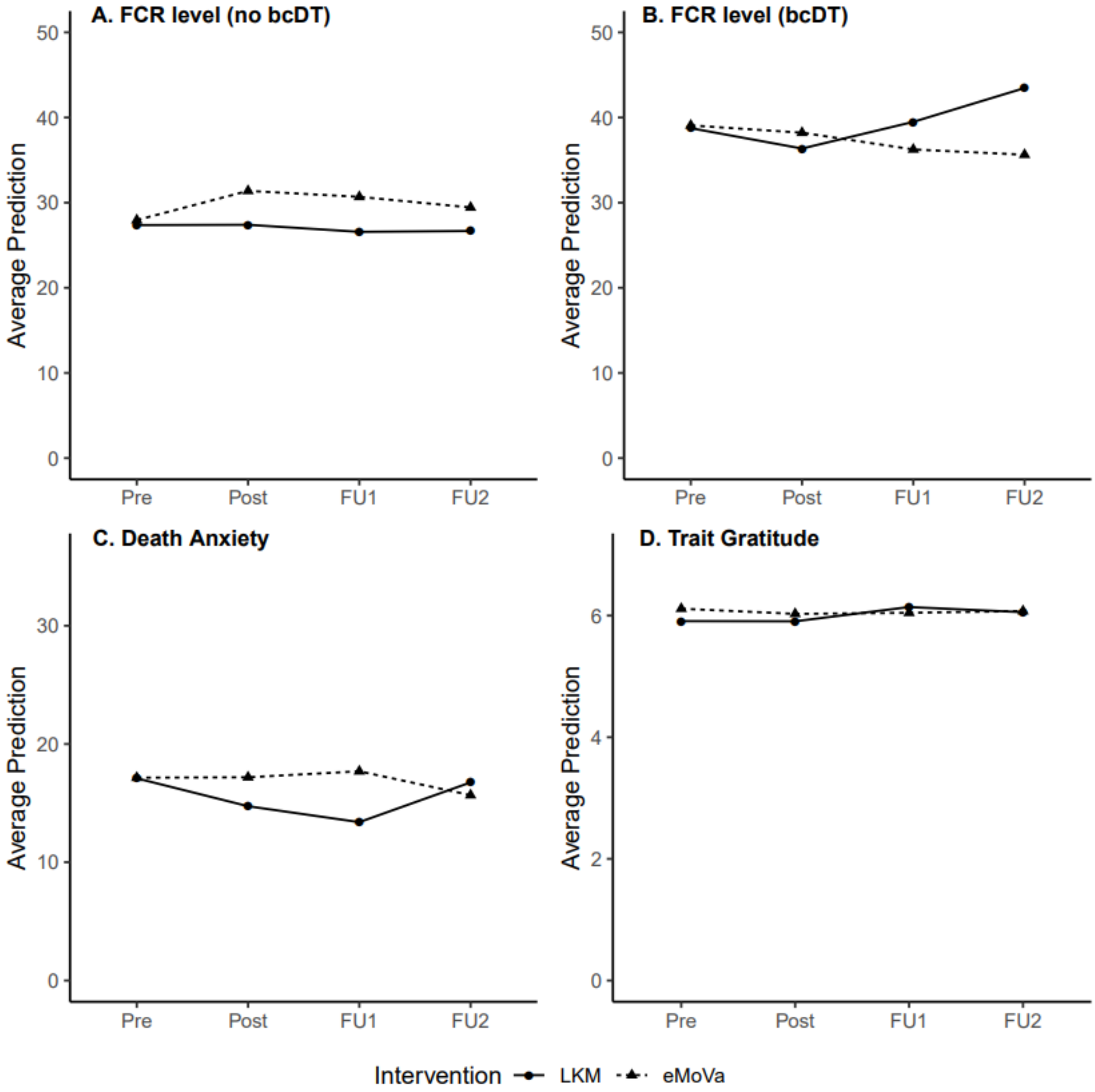


Figure 4. Estimated intervention effects of Loving-and-Kindness Meditation (LKM) compared with online Motivational and Value based Intervention (eMoVa).



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Tables - LKM and eMoVa on readiness for EOL conversations

Table 1. Characteristics of participants (*N* = 118).

| | **LKM** | **eMoVa** | ***p*** | | **LKM** | **eMoVa** | ***p*** |
|---|---|---|---|---|---|---|---|
| Age | 41.8 (13.5) | 44.3 (13.3) | .314 | Religion | | | .977 |
| Gender | | | 1.00 | Protestant | 17 (28.8%) | 17 (28.8%) | |
| Female | 53 (89.8%) | 52 (88.1%) | | Catholic | 18 (30.5%) | 15 (25.4%) | |
| Male | 6 (10.2%) | 7 (11.9%) | | Muslim | 1 (1.69%) | 0 (0.00%) | |
| Family | | | .162 | Buddhist | 0 (0.00%) | 1 (1.69%) | |
| Single | 11 (18.6%) | 8 (13.6%) | | Spiritual | 4 (6.78%) | 4 (6.78%) | |
| Partner | 13 (22.0%) | 24 (40.7%) | | None | 16 (27.1%) | 18 (30.5%) | |
| Married | 33 (55.9%) | 26 (44.1%) | | Other | 3 (5.08%) | 4 (6.78%) | |
| Divorced | 1 (1.69%) | 0 (0.00%) | | Cancer state | | | .018 |
| Widowed | 1 (1.69%) | 1 (1.69%) | | First | 34 (57.6%) | 37 (62.7%) | |
| Education | | | .518 | Second | 0 (0.00%) | 6 (10.2%) | |
| High school | 2 (3.39%) | 1 (1.69%) | | Third | 1 (1.69%) | 1 (1.69%) | |
| Secondary school | 6 (10.2%) | 3 (5.08%) | | Recurrence | 5 (8.47%) | 7 (11.9%) | |
| A-level | 9 (15.3%) | 14 (23.7%) | | Free | 16 (27.1%) | 8 (13.6%) | |
| Trainee | 9 (15.3%) | 13 (22.0%) | | Other | 3 (5.08%) | 0 (0.00%) | |
| Master | 1 (1.69%) | 0 (0.00%) | | Prognosis | | | .130 |
| University Degree | 32 (54.2%) | 28 (47.5%) | | Curative | 49 (83.1%) | 41 (69.5%) | |
| Work | | | .496 | Palliative | 10 (16.9%) | 18 (30.5%) | |
| None | 4 (6.78%) | 4 (6.78%) | | Treatment | | | .833 |
| Stay at home | 3 (5.08%) | 1 (1.69%) | | Yes | 45 (76.3%) | 43 (72.9%) | |
| Part-time | 12 (20.3%) | 16 (27.1%) | | No | 14 (23.7%) | 16 (27.1%) | |
| Full-time | 21 (35.6%) | 13 (22.0%) | | Psycho-oncological support | | | 1.00 |
| Retirement | 9 (15.3%) | 10 (16.9%) | | Yes | 30 (50.8%) | 31 (52.5%) | |
| Other | 10 (16.9%) | 15 (25.4%) | | No | 29 (49.2%) | 28 (47.5%) | |
| Living | | | .083 | Psychotherapeutic support | | | 1.00 |
| Alone | 11 (18.6%) | 6 (10.2%) | | Yes | 16 (27.1%) | 15 (25.4%) | |
| Shared flat | 1 (1.69%) | 6 (10.2%) | | No | 43 (72.9%) | 44 (74.6%) | |
| Family | 47 (79.7%) | 47 (79.7%) | | | | | |

*Note*. Group differences (*p*) in socio-demographic and medical characteristics of participants in Loving-and-Kindness Meditation (LKM, *n* = 59), online Motivation and Value Based Intervention (eMoVa, *n* = 59).

Table 2. Bayesian linear mixed model for intervention effect on readiness for end-of-life conversations.

| Time | Group | Mean | σ | 2.5% | 97.5% | Tail-prob. | Evidence | GR-crit | MCE/SD |
|---|---|---|---|---|---|---|---|---|---|
| Pre | LKM | 3.08 | 0.11 | 2.86 | 3.30 | .0000 | Very Strong | 1.01 | 0.03 |
| Pre | eMoVa | 0.03 | 0.15 | -0.27 | 0.34 | .8088 | Anecdotal | 1.01 | 0.03 |
| Post | LKM | 0.11 | 0.10 | -0.08 | 0.31 | .2376 | Moderate | 1.05 | 0.06 |
| FU1 | LKM | 0.18 | 0.11 | -0.03 | 0.39 | .0908 | Strong | 1.03 | 0.06 |
| FU2 | LKM | 0.23 | 0.12 | -0.001 | 0.47 | .0536 | Strong | 1.03 | 0.06 |
| Post | eMoVa | 0.23 | 0.14 | -0.04 | 0.49 | .1008 | Strong | 1.04 | 0.06 |
| FU1 | eMoVa | 0.15 | 0.15 | -0.16 | 0.44 | .3272 | Moderate | 1.04 | 0.06 |
| FU2 | eMoVa | 0.12 | 0.16 | -0.20 | 0.43 | .4716 | Moderate | 1.04 | 0.06 |

*Note. N* = 118, standard deviation (σ), credible interval of true score (2.5-97.5%), tail-probability against zero (Tail-prob.), Gelman-Rubin criterion for convergence (GR-crit), Monte-Carlo error of MCMC sampling precision (MCE/SD). Interpretation of Bayesian tail-probability was provided in evidence for the probability of impact on outcome variable (Evidence). Fixed effects time of assessment (prior to intervention, six-week-post intervention, three- and six-months follow-up) and intervention (Loving-and-Kindness Meditation, online Motivational and Value based Intervention), random intercept and grouping variable for the individual (ID).

Table 3. Change in readiness for end-of-life conversations between assessments.

| | LKM | | | | | | eMoVa | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Change | Δ | CI | BF | Evidence | *d* | CI | Δ | CI | BF | Evidence | *d* | CI |
| Pre-Post | 0.11 | [0.05, 0.18] | 4.21 | Moderate | 0.13 | [0.07,0.19] | 0.34 | [0.28, 0.40] | >100 | Extreme | 0.40 | [0.34, 0.46] |
| Pre-FU1 | 0.18 | [0.11, 0.25] | 11.01 | Strong | 0.17 | [0.10, 0.23] | 0.32 | [0.26, 0.39] | >100 | Extreme | 0.40 | [0.34, 0.47] |
| Pre-FU2 | 0.23 | [0.15, 0.31] | 18.66 | Strong | 0.29 | [0.22,0.35] | 0.35 | [0.28, 0.42] | >100 | Extreme | 0.40 | [0.34, 0.47] |
| Post-FU1 | 0.07 | [-0.01, 0.14] | 1.91 | Anecdotal | 0.04 | [-0.02, 0.10] | -0.02 | [-0.08, 0.05] | 1.09 | Anecdotal | 0.02 | [-0.03, 0.07] |
| Post-FU2 | 0.12 | [0.04, 0.20] | 3.42 | Moderate | 0.17 | [0.10, 0.23] | 0.01 | [-0.06, 0.08] | 1.01 | Anecdotal | 0.02 | [-0.03, 0.07] |
| Fu1-FU2 | 0.05 | [-0.03, 0.14] | 1.42 | Anecdotal | 0.12 | [0.05, 0.18] | 0.02 | [-0.05, 0.10] | 1.37 | Anecdotal | 0.02 | [-0.03, 0.07] |

*Note*. Difference (Δ) in average estimates (M), standard deviation of estimates (SD), 95%-confidence interval (CI), Bayes Factor comparing tail-probabilities (BF) and evidence for likelihood of change (Evidence), Cohen's d (d). Love-and-kindness meditation (LKM), online Motivational and Value based Intervention (eMoVa), change at prior (pre) to and after (post) intervention, in addition to follow-up assessments three months (FU1) and six months after (FU2).

Table S1a. Average score for each outcome variable dependent on group and assessment based on multiple imputations.

| | | Readiness for end-of-life Conversations | | | | Death Anxiety | | | | Trait Gratitude | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Time | Intervention | Mean | SD | 2.5% | 97.5% | Mean | SD | 2.5% | 97.5% | Mean | SD | 2.5% | 97.5% |
| Pre | LKM | 3.08 | 0.81 | 2.50 | 3.58 | 18.64 | 8.99 | 11.00 | 25.00 | 5.91 | 0.82 | 5.40 | 6.80 |
| Post | LKM | 3.14 | 0.83 | 2.58 | 3.83 | 16.35 | 8.33 | 10.70 | 22.75 | 5.91 | 0.91 | 5.40 | 6.60 |
| FU1 | LKM | 3.25 | 0.81 | 2.61 | 3.97 | 15.14 | 8.60 | 8.64 | 21.72 | 6.14 | 0.83 | 5.80 | 6.80 |
| FU2 | LKM | 3.27 | 0.87 | 2.59 | 3.92 | 18.27 | 8.53 | 11.87 | 24.30 | 6.05 | 0.81 | 5.77 | 6.75 |
| Pre | eMoVa | 3.12 | 0.86 | 2.42 | 3.58 | 19.08 | 8.12 | 12.00 | 26.00 | 6.11 | 0.70 | 5.80 | 6.80 |
| Post | eMoVa | 3.45 | 0.80 | 2.75 | 4.00 | 19.29 | 7.96 | 12.00 | 25.00 | 6.03 | 0.71 | 5.55 | 6.60 |
| FU1 | eMoVa | 3.44 | 0.89 | 2.92 | 4.11 | 19.07 | 7.82 | 14.00 | 24.31 | 6.05 | 0.80 | 5.65 | 6.80 |
| FU2 | eMoVa | 3.44 | 0.79 | 3.00 | 4.00 | 17.63 | 8.21 | 12.00 | 23.95 | 6.07 | 0.79 | 5.48 | 6.72 |

*Note*. (*n* = 295 for each combination) Love-and-Kindness Meditation (LKM), online Motivation and Value Based Intervention (eMoVa), average estimates (M), standard deviation (SD) and credible interval (25%-75%) for prior (pre), after (post) intervention, follow-up at three months (FU1) and six months (FU2).

Table S1b. Average score for fear of cancer recurrence dependent on group, assessment and baseline clinical distress levels.

| | | No clinical distress level[a,c] | | | | Clinical distress level[b,d] | | | |
|---|---|---|---|---|---|---|---|---|---|
| Time | Intervention | Mean | SD | 2.5% | 97.5% | Mean | SD | 2.5% | 97.5% |
| Pre | LKM | 27.57 | 5.89 | 26.00 | 41.00 | 38.79 | 8.58 | 41.00 | 55.00 |
| Post | LKM | 27.44 | 5.99 | 28.39 | 39.70 | 36.56 | 8.19 | 36.64 | 51.76 |
| FU1 | LKM | 26.15 | 6.74 | 26.70 | 41.61 | 39.19 | 9.15 | 40.06 | 68.75 |
| FU2 | LKM | 26.00 | 6.68 | 25.00 | 39.00 | 43.25 | 8.91 | 43.64 | 65.58 |
| Pre | eMoVa | 27.88 | 6.95 | 28.00 | 42.00 | 39.10 | 7.78 | 40.50 | 54.00 |
| Post | eMoVa | 31.49 | 7.76 | 30.00 | 48.75 | 38.42 | 7.85 | 39.00 | 59.47 |
| FU1 | eMoVa | 30.85 | 8.95 | 28.00 | 51.42 | 35.86 | 7.93 | 34.62 | 54.00 |
| FU2 | eMoVa | 29.07 | 6.72 | 28.00 | 48.44 | 35.80 | 7.19 | 35.35 | 57.76 |

*Note*. Love-and-Kindness Meditation (LKM), online Motivation and Value Based Intervention (eMoVa), average estimates (M), standard deviation (SD) and credible interval (25%-75%) for prior (pre), after (post) intervention, follow-up at three months (FU1) and six months (FU2) dependent on control variable baseline clinical levels of distress (bcDT). Varying sample sizes within LKM ($n_a$ = 105, $n_b$=190) and eMoVa ($n_c$ = 85, $n_d$ = 210).

Table S2a. Bayesian linear mixed model for intervention effect on fear of cancer recurrence.

| Time | Intervention | Mean | σ | 2.5% | 97.5% | Tail-prob. | Evidence | GR-crit | MCE/SD |
|---|---|---|---|---|---|---|---|---|---|
| Pre | LKM | 27.36 | 1.81 | 23.92 | 30.73 | .0000 | Extreme | 1.03 | 0.04 |
| Pre | LKM x bcDT | 11.38 | 2.16 | 7.23 | 15.70 | .0000 | Extreme | 1.00 | 0.03 |
| Pre | eMoVa | 0.59 | 2.56 | -4.51 | 5.51 | .8300 | Anecdotal | 1.03 | 0.03 |
| Pre | eMoVa x bcDT | -0.26 | 3.16 | -6.38 | 6.07 | .9268 | Anecdotal | 1.02 | 0.03 |
| Post | LKM | 0.04 | 1.65 | -2.99 | 3.16 | .9828 | Anecdotal | 1.14 | 0.09 |
| FU1 | LKM | -0.79 | 1.73 | -3.84 | 2.29 | .6180 | Anecdotal | 1.05 | 0.09 |
| FU2 | LKM | -0.69 | 1.76 | -3.86 | 2.68 | .6536 | Anecdotal | 1.07 | 0.09 |
| Post | LKM x bcDT | -2.43 | 2.22 | -6.78 | 1.80 | .2536 | Moderate | 1.05 | 0.08 |
| FU1 | LKM x bcDT | 1.53 | 2.32 | -3.23 | 5.96 | .5052 | Anecdotal | 1.04 | 0.09 |
| FU2 | LKM x bcDT | 5.41 | 2.62 | 0.21 | 10.63 | .0412 | Strong | 1.02 | 0.09 |
| Post | eMoVa | 3.39 | 2.24 | -1.06 | 7.72 | .1164 | Strong | 1.16 | 0.10 |
| FU1 | eMoVa | 3.52 | 2.30 | -1.19 | 7.90 | .1272 | Strong | 1.05 | 0.09 |
| FU2 | eMoVa | 2.18 | 2.41 | -2.81 | 6.56 | .3488 | Anecdotal | 1.06 | 0.09 |
| Post | eMoVa x bcDT | -1.86 | 3.02 | -7.83 | 4.07 | .5368 | Anecdotal | 1.10 | 0.10 |
| FU1 | eMoVa x bcDT | -7.09 | 3.10 | -12.82 | -0.78 | .0276 | Very strong | 1.06 | 0.08 |
| FU2 | eMoVa x bcDT | -10.34 | 3.45 | -16.84 | -3.46 | .0064 | Extreme | 1.02 | 0.09 |

*Note. N* = 118, average estimates (Mean), standard deviation (σ), credible interval of true score (2.5-97.5%), tail-probability against zero (Tail-prob.), Gelman-Rubin criterion for convergence (GR-crit), Monte-Carlo error of MCMC sampling precision (MCE/SD). Interpretation of Bayesian tail-probability was provided in evidence for the parameter (Evidence). Fixed effects time of assessment, baseline levels of distress (no distress vs. clinical levels *bcDT*) and intervention (LKM, online Motivation and Value Based Intervention), random intercept and grouping variable for the individual (ID). Pre-assessment, LKM and no clinical distress at baseline were used as reference categories.

[a] Gratitude estimations are lognormal transformed due to skewness.

Table 2b. Bayesian linear mixed model for intervention effect on death anxiety and trait gratitude.

| Outcome | Time | Intervention | Mean | σ | 2.5% | 97.5% | Tail-prob. | Evidence | GR-crit | MCE/SD |
|---|---|---|---|---|---|---|---|---|---|---|
| Death anxiety[a] | | | | | | | | | | |
| | Pre | LKM | 12.82 | 1.49 | 9.87 | 15.69 | .0000 | Extreme | 1.01 | 0.03 |
| | Pre | eMoVa | 0.06 | 1.59 | -3.05 | 3.19 | .9776 | Anecdotal | 1.02 | 0.04 |
| | Post | LKM | -2.36 | 1.20 | -4.69 | -0.03 | .0472 | Strong | 1.03 | 0.06 |
| | FU1 | LKM | -3.70 | 1.34 | -6.34 | -1.21 | .0052 | Extreme | 1.02 | 0.06 |
| | FU2 | LKM | -0.34 | 1.45 | -3.17 | 2.49 | .8076 | Anecdotal | 1.03 | 0.05 |
| | Post | eMoVa | 2.39 | 1.69 | -0.91 | 5.63 | .1696 | Moderate | 1.05 | 0.06 |
| | FU1 | eMoVa | 4.25 | 1.84 | 0.74 | 7.75 | .0176 | Very strong | 1.04 | 0.06 |
| | FU2 | eMoVa | -1.13 | 1.97 | -4.95 | 2.80 | .5656 | Anecdotal | 1.04 | 0.06 |
| Gratitude[b] | | | | | | | | | | |
| | Pre | LKM | 1.78 | 0.02 | 1.74 | 1.81 | .000 | Extreme | 1.01 | 0.03 |
| | Pre | eMoVa | 0.03 | 0.03 | -0.02 | 0.09 | .215 | Moderate | 1.01 | 0.02 |
| | Post | LKM | -0.001 | 0.02 | -0.03 | 0.03 | .973 | Anecdotal | 1.04 | 0.06 |
| | FU1 | LKM | 0.04 | 0.02 | 0.004 | 0.08 | .026 | Very strong | 1.05 | 0.06 |
| | FU2 | LKM | 0.02 | 0.02 | -0.01 | 0.06 | .206 | Moderate | 1.03 | 0.06 |
| | Post | eMoVa | -0.01 | 0.02 | -0.06 | 0.03 | .553 | Anecdotal | 1.04 | 0.06 |
| | FU1 | eMoVa | -0.05 | 0.02 | -0.10 | -0.004 | .032 | Very strong | 1.05 | 0.05 |
| | FU2 | eMoVa | -0.03 | 0.03 | -0.08 | 0.02 | .225 | Moderate | 1.02 | 0.05 |

*Note. N* = 118, average estimates (Mean), standard deviation (σ), credible interval of true score (2.5-97.5%), tail-probability against zero (Tail-prob.), Gelman-Rubin criterion for convergence (GR-crit), Monte-Carlo error of MCMC sampling precision (MCE/SD). Interpretation of Bayesian tail-probability was provided in evidence for the parameter (Evidence). Fixed effects time of assessment and intervention (LKM, online Motivation and Value Based Intervention), random intercept and grouping variable for the individual (ID). Pre-assessment, LKM and no clinical distress at baseline were used as reference categories. [a]Death anxiety estimations are represented for no baseline clinical distress experience. [b]Gratitude estimations are lognormal transformed due to skewness.

Table S3a. Changes in fear of cancer recurrence.

| | Fear of Cancer Recurrence | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | LKM | | | | | | eMoVa | | | | | |
| Change | Δ | CI | BF | Evidence | *d* | CI | Δ | CI | BF | Evidence | *d* | CI |
| No bcDT | | | | | | | | | | | | |
| Pre-Post | 0.04 | [-1.1, 1.11] | 1.02 | Anecdotal | 0.01 | [-0.12, 0.14] | 3.43 | [2.34, 4.48] | 36.76 | Very strong | 0.48 | [0.39, 0.56] |
| Pre-FU1 | -0.79 | [-1.96, 0.29] | 1.62 | Anecdotal | 0.18 | [0.05, 0.31] | 2.73 | [1.65, 3.8] | 11.42 | Strong | 0.31 | [0.20, 0.43] |
| Pre-FU2 | -0.69 | [-1.83, 0.34] | 1.53 | Anecdotal | 0.12 | [-0.01, 0.25] | 1.48 | [0.35, 2.62] | 2.77 | Anecdotal | 0.18 | [0.08, 0.28] |
| Post-FU1 | -0.83 | [-1.86, 0.2] | 1.53 | Anecdotal | 0.19 | [0.08, 0.29] | -0.70 | [-1.76, 0.40] | 1.52 | Anecdotal | 0.13 | [0.04, 0.22] |
| Post-FU2 | -0.73 | [-1.88, 0.44] | 1.44 | Anecdotal | 0.13 | [0.08, 0.29] | -1.95 | [-3.07, -0.79] | 4.19 | Moderate | 0.31 | [0.20, 0.42] |
| Fu1-FU2 | 0.10 | [-1.02, 1.22] | 1.03 | Anecdotal | 0.05 | [-0.06, 0.16] | -1.25 | [-2.41, -0.10] | 2.14 | Anecdotal | 0.15 | [0.05, 0.26] |
| bCDT | | | | | | | | | | | | |
| Pre-Post | -2.39 | [-3.42, -1.45] | 13.09 | Strong | 0.30 | [0.20, 0.39] | -0.86 | [-1.73, -0.08] | 2.09 | Anecdotal | 0.11 | [0.04, 0.17] |
| Pre-FU1 | 0.74 | [-0.35, 1.79] | 1.60 | Anecdotal | 0.11 | [0.02, 0.21] | -2.82 | [-3.73, -1.98] | 29.76 | Strong | 0.34 | [0.26, 0.41] |
| Pre-FU2 | 4.71 | [3.33, 6.03] | 64.10 | Very Strong | 0.55 | [0.46, 0.65] | -3.45 | [-4.46, -2.50] | 52.08 | Very strong | 0.42 | [0.35, 0.50] |
| Post-FU1 | 3.13 | [2.04, 4.20] | 18.52 | Strong | 0.41 | [0.32, 0.50] | -1.97 | [-2.89, -1.04] | 6.27 | Moderate | 0.23 | [0.16, 0.30] |
| Post-FU2 | 7.10 | [5.72, 8.50] | > 100 | Extreme | 0.86 | [0.74, 0.98] | -2.59 | [-3.57, -1.61] | 11.63 | Strong | 0.31 | [0.23, 0.39] |
| Fu1-FU2 | 3.98 | [2.56, 5.35] | 23.81 | Strong | 0.44 | [0.35, 0.52] | -0.62 | [-1.63, 0.38] | 1.44 | Anecdotal | 0.07 | [0.00, 0.14] |

*Note*. Difference (Δ) in average estimates (M), credible Interval (CI), Bayes Factor (BF) and evidence for change (Evidence) based on Jeffreys (1961), and Cohen’s d (*d*). Love-and-Kindness-Meditation (LKM), online Motivation and Value Based Intervention (eMoVa), change at prior (pre) to and after (post) intervention, in addition to follow-up assessments three months (FU1), six months after (F U2) and control variable baseline clinical levels of distress (bcDT). Average estimates of Trait Gratitude are lognormal transformed. Based on multiple imputations.

Table S3b. Changes in death anxiety and trait gratitude.

| | Death Anxiety | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | LKM | | | | | | eMoVa | | | | | |
| Change | Δ | CI | BF | Evidence | *d* | CI | Δ | CI | BF | Evidence | *d* | CI |
| Pre-Post | -2.36 | [-3.18, -1.53] | 21.19 | Strong | 0.22 | [0.16, 0.27] | 0.03 | [-8.48, 8.58] | 1.19 | Anecdotal | 0.01 | [-0.06, 0.08] |
| Pre-FU1 | -3.70 | [-4.64, -2.76] | >100 | Extreme | 0.36 | [0.30, 0.42] | 0.54 | [-7.98, 9.06] | 1.88 | Anecdotal | 0.03 | [-0.04, 0.10] |
| Pre-FU2 | -0.34 | [-1.32, 0.65] | 1.24 | Anecdotal | 0.02 | [-0.04, 0.07] | -1.48 | [-9.99, 7.07] | 3.41 | Moderate | 0.17 | [0.10, 0.24] |
| Post-FU1 | -1.35 | [-2.27, -0.46] | 2.99 | Anecdotal | 0.15 | [0.09, 0.22] | 0.51 | [-0.27, 1.32] | 1.50 | Anecdotal | 0.02 | [-0.05, 0.09] |
| Post-FU2 | 2.01 | [1.01, 3.04] | 4.75 | Moderate | 0.20 | [0.13, 0.26] | -1.51 | [-2.37, -0.63] | 3.82 | Moderate | 0.18 | [0.10, 0.26] |
| Fu1-FU2 | 3.36 | [2.28, 4.41] | 21.74 | Strong | 0.34 | [0.29, 0.39] | -2.02 | [-2.88, -1.13] | 7.94 | Moderate | 0.20 | [0.14, 0.27] |
| | Trait Gratitude | | | | | | | | | | | |
| | LKM | | | | | | eMoVa | | | | | |
| Change | Δ | CI | BF | Evidence | *d* | CI | Δ | CI | BF | Evidence | *d* | CI |
| Pre-Post | 0.00 | [-0.07, 0.06] | 1.03 | Anecdotal | 0.03 | [-0.02, 0.09] | -0.09 | [-0.15, -0.02] | 2.99 | Anecdotal | 0.12 | [0.06, 0.17] |
| Pre-FU1 | 0.23 | [0.16, 0.30] | 38.46 | Very strong | 0.29 | [0.23 0.35] | -0.07 | [-0.13, 0.00] | 2.24 | Anecdotal | 0.08 | [0.02, 0.13] |
| Pre-FU2 | 0.15 | [0.07, 0.31] | 4.85 | Moderate | 0.20 | [0.14, 0.25] | -0.04 | [-0.11, 0.03] | 1.48 | Anecdotal | 0.07 | [0.01, 0.12] |
| Post-FU1 | 0.23 | [0.16, 0.23] | 32.89 | Very strong | 0.25 | [0.19, 0.30] | 0.02 | [-0.05, 0.08] | 1.16 | Anecdotal | 0.04 | [-0.02, 0.09] |
| Post-FU2 | 0.15 | [0.07, 0.00] | 5.32 | Moderate | 0.16 | [0.11, 0.21] | 0.05 | [-0.02, 0.12] | 1.54 | Anecdotal | 0.04 | [-0.02, 0.11] |
| Fu1-FU2 | -0.08 | [-0.17, -0.02] | 2.10 | Anecdotal | 0.09 | [0.04, 0.15] | 0.03 | [-0.04, 0.10] | 1.22 | Anecdotal | 0.01 | [-0.05, 0.07] |

*Note*. Difference (Δ) in average estimates (M), credible Interval (CI), Bayes Factor (BF) and evidence for change (Evidence) based on Jeffreys (1961), Cohen's d (*d*). Love-and-Kindness-Meditation (LKM), online Motivation and Value Based Intervention (eMoVa), change at prior (pre) to and after (post) intervention, in addition to follow-up assessments three months (FU1), six months after (FU2) and control variable baseline clinical levels of distress (bcDT). Average estimates of Trait Gratitude are lognormal transformed. Based on multiple imputations.

## 8. Appendix B: Curriculum Vitae

Pages 177-178 (CV) contain private data. Therefore they are not part of this online publication.

# Curriculum Vitae

# 9 Appendix C: Contribution to science

## Peer-reviewed articles

Kloos, T., Elßner, A.C., **Berlin, P.**, Rief, W., Riecke, J. (in prep.). Smartphone-based Meditation as a Secondary Prevention Tool for Chronic Pain? A Randomized Controlled Trial. *Journal of Pain.*

**Berlin, P.**, Kloos, T., & von Blanckenburg, P. (submitted). Effects of an online Motivational and Value based Intervention or Loving-and-Kindness Meditation for people affected by cancer: A randomized controlled online study. *Psychotherapy and Psychosomatics*.

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**Berlin, P.**, Leppin, N., Nagelschmidt, K., Seifart, C., Rief, W., & von Blanckenburg, P. (2021). Development and validation of the readiness for end-of-life conversations (REOLC) scale. *Frontiers in psychology*, *12*, 795.

**Berlin, P.**, Seifart, C., & von Blanckenburg, P. (2022). Validation of the Readiness for End-of-Life Conversations (REOLC) scale in a German hospital setting. *PEC Innovation*, 100045.

## Conference contribution

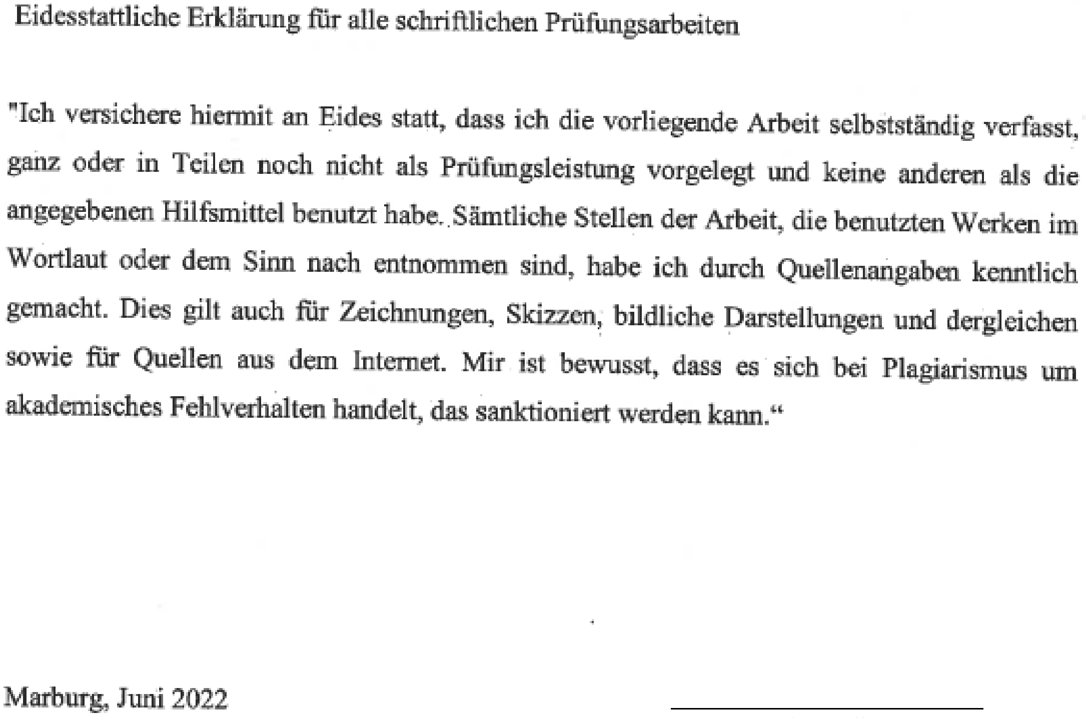
**Berlin, P.**, Leppin, N., Nagelschmidt, K., Seifart, C., Rief, W., & von Blanckenburg, P. (2020). Development and validation of the readiness for end-of-life conversations (REOLC) scale. Poster presentation at the 34th German cancer conference, Berlin, Germany.

**Berlin, P.**, Leppin, N., Nagelschmidt, K., Seifart, C., Rief, W., & von Blanckenburg, P. (2021). Entwicklung und Validierung der Readiness for End-of-Life Conversations (REOLC) Scale. Online poster presentation at the 38th symposium of the German expert group clinical psychology and psychotherapy (DGGP), Mannheim, Germany.

**Berlin, P.**, Göggelmann, L., Herzog, S., Pedrosa Carrasco, A. J., Hauk, J., Timmesfeld, N., Kruse, J., Rief, W., Riera-Knorrenschild, J., von Blanckenburg, P., and Seifart, C. (2021).

Advance Care Planning for Cancer Patients – Development of a Screening Method in German Health Clinics. 10 minute online oral presentation at the 22nd World Congress of Psycho-Oncology and Psychosocial Academy, Tokyo, Japan.

# 10 Appendix E: Declaration of honesty



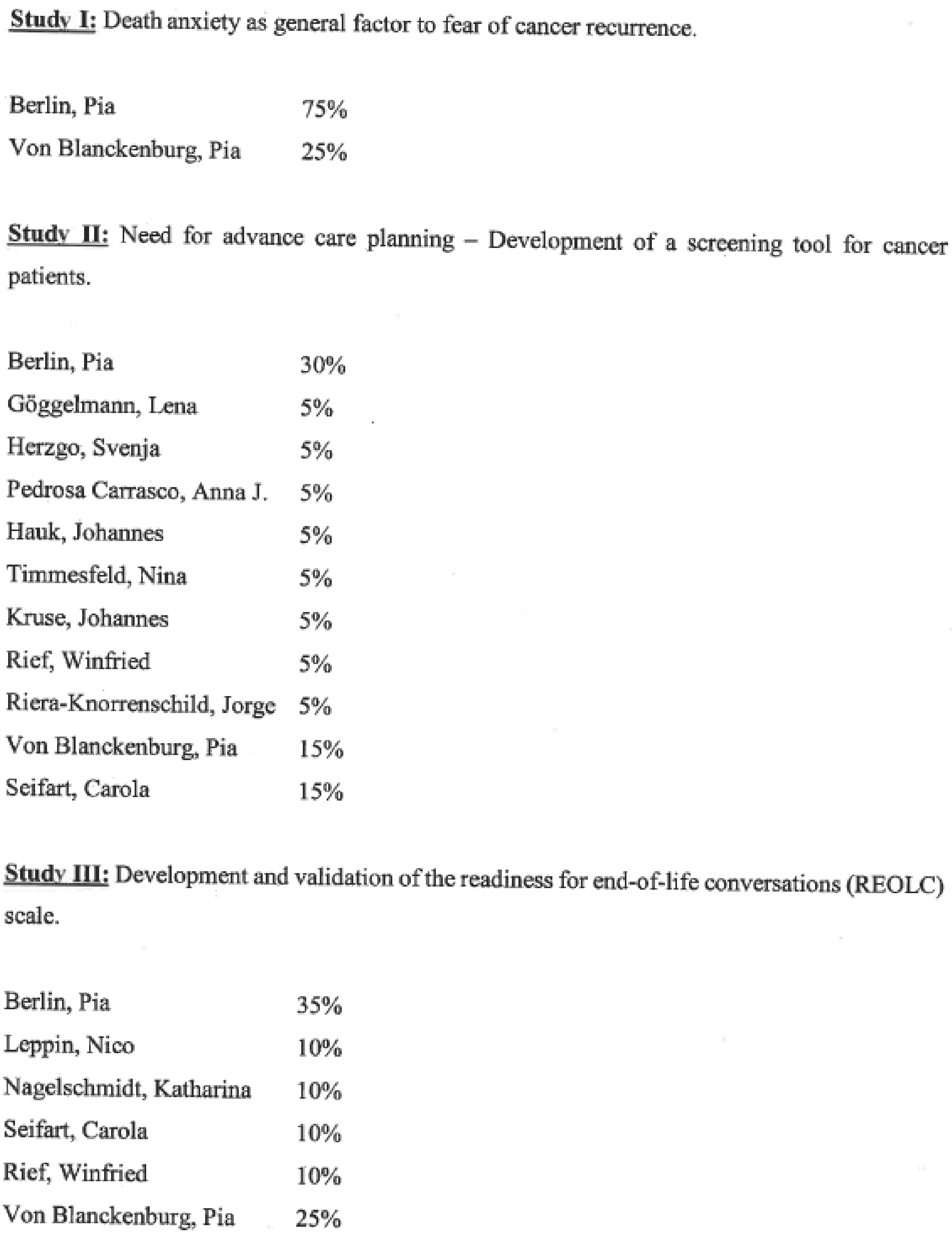
Eidesstattliche Erklärung für alle schriftlichen Prüfungsarbeiten

"Ich versichere hiermit an Eides statt, dass ich die vorliegende Arbeit selbstständig verfasst, ganz oder in Teilen noch nicht als Prüfungsleistung vorgelegt und keine anderen als die angegebenen Hilfsmittel benutzt habe. Sämtliche Stellen der Arbeit, die benutzten Werken im Wortlaut oder dem Sinn nach entnommen sind, habe ich durch Quellenangaben kenntlich gemacht. Dies gilt auch für Zeichnungen, Skizzen, bildliche Darstellungen und dergleichen sowie für Quellen aus dem Internet. Mir ist bewusst, dass es sich bei Plagiarismus um akademisches Fehlverhalten handelt, das sanktioniert werden kann.“

Marburg, Juni 2022

Pia Berlin

## 11 Appendix F: Percentage distribution



**Study I:** Death anxiety as general factor to fear of cancer recurrence.

| | |
|---|---|
| Berlin, Pia | 75% |
| Von Blanckenburg, Pia | 25% |

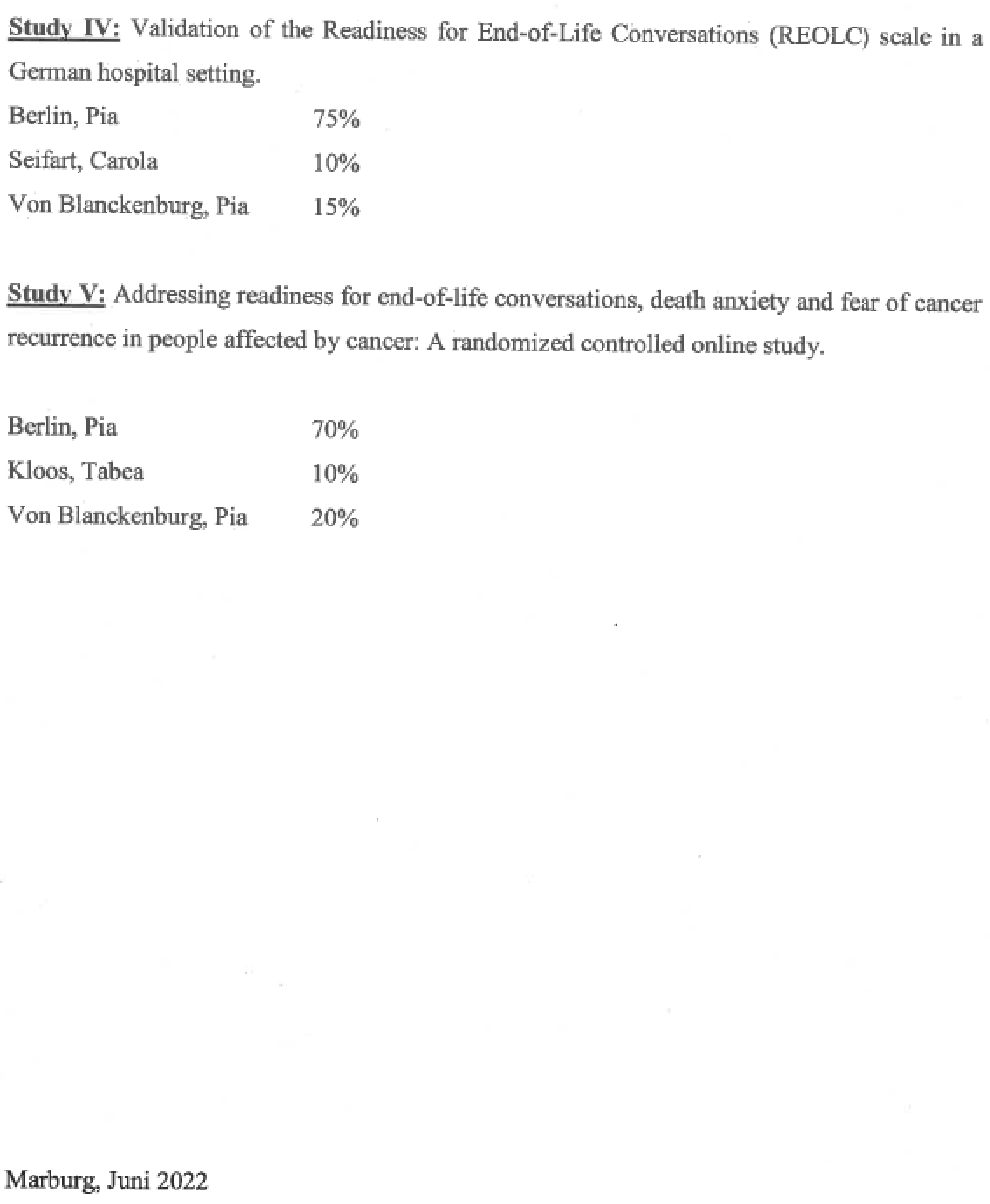
**Study II:** Need for advance care planning – Development of a screening tool for cancer patients.

| | |
|---|---|
| Berlin, Pia | 30% |
| Göggelmann, Lena | 5% |
| Herzgo, Svenja | 5% |
| Pedrosa Carrasco, Anna J. | 5% |
| Hauk, Johannes | 5% |
| Timmesfeld, Nina | 5% |
| Kruse, Johannes | 5% |
| Rief, Winfried | 5% |
| Riera-Knorrenschild, Jorge | 5% |
| Von Blanckenburg, Pia | 15% |
| Seifart, Carola | 15% |

**Study III:** Development and validation of the readiness for end-of-life conversations (REOLC) scale.

| | |
|---|---|
| Berlin, Pia | 35% |
| Leppin, Nico | 10% |
| Nagelschmidt, Katharina | 10% |
| Seifart, Carola | 10% |
| Rief, Winfried | 10% |
| Von Blanckenburg, Pia | 25% |

Percentage of distribution to article



**Study IV:** Validation of the Readiness for End-of-Life Conversations (REOLC) scale in a German hospital setting.

| | |
|---|---|
| Berlin, Pia | 75% |
| Seifart, Carola | 10% |
| Von Blanckenburg, Pia | 15% |

**Study V:** Addressing readiness for end-of-life conversations, death anxiety and fear of cancer recurrence in people affected by cancer: A randomized controlled online study.

| | |
|---|---|
| Berlin, Pia | 70% |
| Kloos, Tabea | 10% |
| Von Blanckenburg, Pia | 20% |

Marburg, Juni 2022

Dr. Pia von Blanckenburg

Pia Berlin