



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



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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: χ^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 adverse 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 prove 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 were 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 Distress Thermometer [15], General anxiety (GAD-2) and Depression (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 χ^2 -tests. Model adequacy for REOLC was analyzed with structural equation modelling (SEM), standardized factor loadings, maximum likelihood (ML) method with Satorra-Bentler correction and robust standard errors to confirm factor structure [12]. Goodness of fit was indicated by χ^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 χ^2 statistic supported structural model for relative $\chi^2/df < 2$ [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 χ^2 statistic ($\chi^2(50) = 94.51$, Satorra-Bentler-scaling factor = 1.19, $p < .001$) but good relative χ^2 value ($\chi^2/df = 1.89$). 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

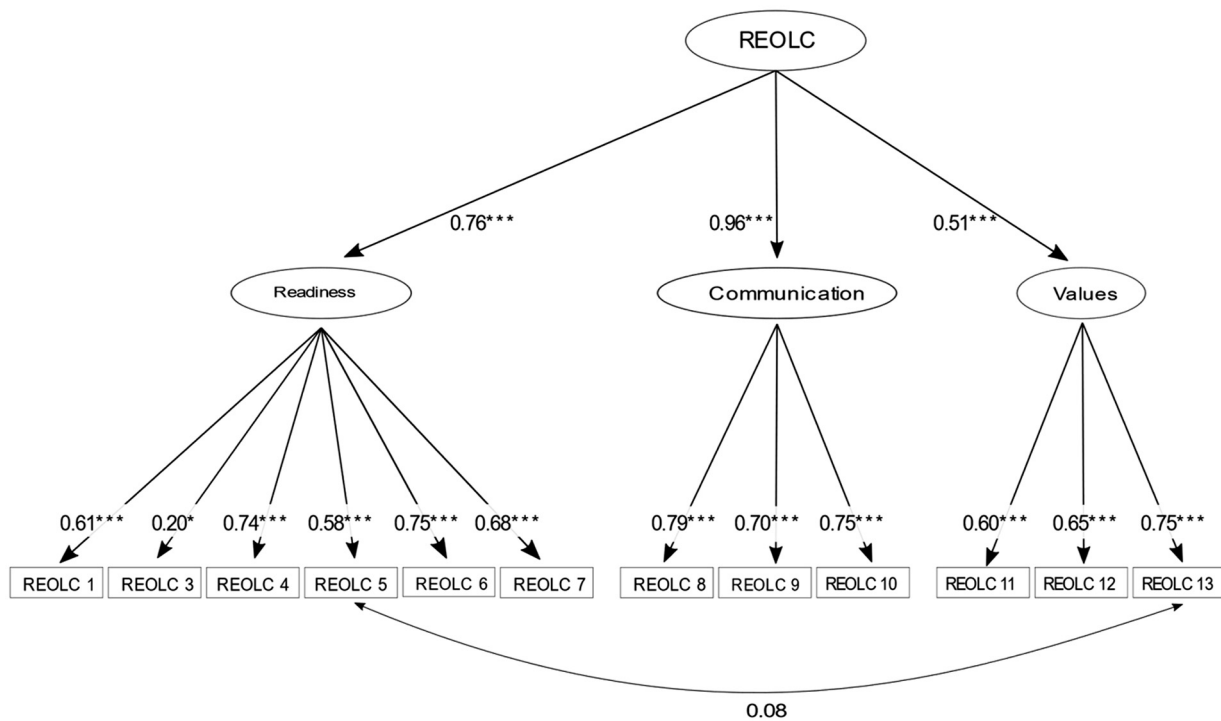


Fig. 1. Structural Equation Model of readiness for end-of life conversations (N = 295). Latent variables in ellipses, items in rectangles, factor loadings represented with significance values and one-headed arrows. Covariances represented with two-headed arrows. *p < .05 ***p < .001.

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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