Context Sensitive Health Informatics: AI for Social Good
H. Ismaila et al. (Eds.)

doi:10.3233/SHTI250240

The Kübler-Ross Five Stages of Grief Model: A Framework for Human-Centered Health Informatics

Amanda L. JOSEPH[a,b1], Helen MONKMAN[a]
[a] *School of Health Information Science, University of Victoria, Canada*
[b] *Majestic Global Consulting Inc., Canada*
ORCiD ID: Amanda L. Joseph https://orcid.org/0000-0002-5869-037X, Helen Monkman https://orcid.org/0000-0003-0772-9075

Abstract. The Kübler-Ross Five Stages of Grief Model (KR model) is examined in the context of human-centered health informatics. The KR model is positioned as a non-linear set of heuristics which can assist in contextualizing the complexities of human cognitive-emotional processing of distressing events (e.g., organizational change, technology implementation, trauma). Thus, unique perspectives can be provided in each conceptual stage: 1) Denial and Isolation, 2) Anger, 3) Bargaining, 4) Depression, 5) Acceptance. This scoping review sought to: 1) Examine the application of the KR model in the design, evaluation or implementation of healthcare technology, 2) Determine if the KR model has been used to guide context specific user-experience (UX) activities (i.e., persona creation, journey mapping) to understand the patient, physician, nurse or caregiver experiences. The findings underscored that the KR model has various healthcare applications and use, however it remains underutilized as a valuable tool to contextualize human experiences.

Keywords. Elisabeth Kübler-Ross, stages of grief, health informatics, technology

1. Introduction

The Kübler-Ross Five Stages of Grief Model (KR model) was first proposed in 1969, when Swiss psychiatrist Dr. Elisabeth Kübler-Ross published an iconic book entitled "On Death and Dying – What the dying have to teach doctors, nurses, clergy and their own families" [1,2]. Nearly 56 years later, it remains one of the most important humanitarian works on care of the dying. The KR model contributes value in the dialogue between patients and providers discussing the meaning of dying [2], honouring the importance of the patient-provider relationship (and experiences), to inform the design of human-centered healthcare services and delivery. Dr. Kübler-Ross revolutionized global perspectives on hospice care and near-death research by listening to the voices of dying patients, and giving them a public forum [2,3]. She embodied human-centered care perspectives by diligently supporting healthcare providers, patients, and their families [1,2]. Through Kübler-Ross' focused and extensive interviews with terminally ill patients, she noticed a trend in how patients cognitively and emotionally processed their

[1] Corresponding author, Amanda L. Joseph University of Victoria, British Columbia, Canada.
E-mail: amandalynnjoseph@uvic.ca

experiences (i.e., terminal diagnoses, death). Through these observations she proposed the KR model (**Figure 1**) to explain and categorize complicated human experiences into five conceptual stages: 1) Denial and Isolation, 2) Anger, 3) Bargaining, 4) Depression, 5) Acceptance [1,2]. She reiterated that the stage categories (by design) do not appear in order, as individuals may experience them concurrently, sequentially or not at all [1,2]. Therefore the 'five stages' should not be perceived as mandatory or sequential 'steps,' but the model itself should be considered a high-level (and simplified) heuristic framework to classify human experiences [2,45]. The intent of the KR model heuristics (i.e., five stages) was to provide insights into the complexities of the human psyche by fostering empathy, self-reflection, discovery, learning and shared understanding of patient and provider experiences [2,6].

Figure 1. The Kübler-Ross Grief Heuristics adapted from [1,2]

Although not official stages, 'Hope' and 'Anticipatory Grief' are positioned alongside the original stage categories (Figure 1), as complementary cognitive emotive patterns which may be experienced concurrently or iteratively [1,2]. Hence, 'Hope' and 'Anticipatory Grief' are perceivably interwoven into the fabric of the grief construct and can often occur on a spectrum of intensity as do the emotional components associated with each stage [1,2,7]. Beyond the loss of life, grief is a complex response which can arise from a multitude of distressing events (e.g., divorce, financial difficulty, unemployment, organizational change, natural disasters) [2,8,9]. As such, it can occur concurrently, further complicating the grief process, and stifling a person's ability to adapt, heal, and recover from the distressing event [1,2,10].

The KR model is industry agnostic by nature, with diverse potential for application and insight into the human psyche; yet it remains underutilized in human-centered health informatics [7-9,16-19]. Thus, the objectives of this study were to: 1) Examine the application of the KR model in the design, evaluation or implementation of healthcare technology, 2) Determine if the KR model has been used to guide context specific user-experience (UX) activities (i.e., persona creation, journey mapping) to understand patient, physician, nurse or caregiver experiences [11-14].

2. Methods

To begin a scoping review guided by the Arksey O'Malley methodological framework [15], was conducted in the (EBSCOhost)PsycINFO®, PubMed®, and Web of Science®, databases, with variations of the search terms[2] 'kübler ross' OR 'elisabeth kübler-ross' OR 'stages of grief.' The electronic search was performed on January 13, 2025, and included all English peer-reviewed published studies and grey literature that described technology with an application of the original five stages of the KR model in a healthcare

[2] For the comprehensive search strategy please contact the corresponding author.

context:1) Denial and Isolation, 2) Anger, 3) Bargaining, 4) Depression, 5) Acceptance [1,2]. Articles were excluded if they did not meet this criteria, interpretive discord among authors was resolved through discussion and consensus. The study relied on publicly available research which precluded the need for an ethics review. Title and abstract screening of all articles was performed in Covidence®. The subsequent full text review of articles was done and articles were excluded that did not meet the inclusion criteria.

3. Results

A sample of 1,915 articles were initially included in the analysis, of which 180 duplicates removed, leaving 1,735 articles to be reviewed in the first screen. Subsequently, 1,532 articles were then excluded, leaving 203 articles to be assessed in the full text review, of those 196 were excluded. Finally, seven articles met the inclusion criteria, with their data extracted (**Table 1**) into three categories: 1) Technology, 2) Participants, 3) Application and Findings of the KR model.

Table 1. Study Elements and Key Findings

Reference	Technology	Participants	Application (A) and Findings (F) of the KR model
[16]	Social Networking Sites (SNS)	Cancer patients	**A:** Cancer patients use of SNSs for therapeutic support and grief expression was examined in parallel with the five stages of the KR model [16]. **F:** Patients undergoing treatment used SNSs in diverse ways (i.e., emotional, physical support) and express their grief at different stages [16].
[17]	Health Information Technology (HIT); Information Technology (IT)	HIT staff IT staff	**A:** The transition experiences of HIT and IT staff in response to enterprise change was examined using the five stages of the KR model [17]. **F:** During organizational change staff experienced the five stages uniquely regardless of: role, age, discipline, expertise [17]. The stages can be experienced in non-linear cycles, and may be repeated [17].
[8]	Electronic Health Record (EHR)	Physicians Administrators	**A:** EHR implementation was conceptualized through the five stages of the KR model [8]. **F:** Envisioning EHR adoption as loss through the five stages may help organizational change initiatives [8]. This empathetic perspective could increase physician adoption, and improve the overall success of HIT initiatives (e.g., deployment, implementation) [8].
[18]	Virtual Reality (VR) Game	Colleagues Friends Family	**A:** The VR Game had an educational and atmospheric narrative, and was designed based on the five stages of the KR model [18]. **F:** VR Games could provide novel educative experiences for medical students and personnel by providing a deeper understanding about the death process [18].
[7]	Multi Media (MM)	Actress Actor	**A:** The complexities of a mental health disorders (e.g., post-traumatic stress syndrome) was illustrated through film as two actors cognitively processed their own trauma using the five stages of the KR model [7]. **F:** Through relatable, hearth wrenching scenes, MM can portray grief and loss in brutally honest ways [7]. The vivid imagery can foster empathy and understanding of the complexities of trauma, grief and human emotion [7].
[9]	Electronic Medical	Physicians	**A:** The KR model stages were used as a template to examine the emotions of physicians experiencing transformational workflow changes [9].

	Record (EMR)		**F:** The KR model fostered empathy and understanding of physician end-users as EMR implementations are perceived as the demise (i.e., death) of their current service delivery practices, as they must change to a new care model and workflow [9]. The insights of the five stages revealed the challenges and difficulties faced by medical providers in HIT implementations [9].
[19]	Computers Smartphones Servers Network Technologies Software	End-users	**A:** The five stages of the KR model was conceptualized used as a framework, complimented by the Technology Acceptance Model (TAM) to investigate how technology is experience by medical end-users [19]. **F:** Technology acceptance is achieved and experienced by end-users uniquely, as an emotional process [19].

The included articles (i.e., [7-9,16-19]) provided heterogeneous applications of the KR model and technologies: SNS; HIT and IT; EHRs; VR Games; MMs; EMRs, Computers, Smartphones, Servers, Network Technologies, Software. The participants were diverse and provided different perspectives into how the five stages of the KR model could be used in diverse settings and contexts [7-9,16-19].

5. Discussion

This scoping review [15] presented diverse Technologies, Participants, Applications and Findings of the KR model. The first study objective was satisfied in that the application of the KR model in the design, evaluation or implementation of healthcare technology was examined (Table 1). However, the second objective was not met as the included articles did not present examples of context specific UX activities (i.e., personas, journey maps) to understand patient, physician, nurse or caregiver experiences. Furthermore, the findings underscored that the KR model can have various applications and use, however it remains underutilized in human-centered health informatics [7-9,16-19].

Although this was an assessment of publicly available literature, the study design was limited to English articles available electronically. Additionally given the vast criticism and scientific validity of the model; the KR model itself can be considered a limitation. However, the KR model's limitations lie not in its approach or methodology, but rather in how its stages are framed, contextualized, and interpreted by the scientific community. As such the KR model is often misinterpreted as a linear pathway in which an individual must experience each stage (in sequence or chronologically). However, the interview findings revealed that some patients experienced the stages in sequence (others did not), and 'Hope' and 'Anticipatory Grief' were overarching sentiments often experienced across the stages trajectory [1,2]. Therefore the KR model should be viewed (and utilized) as a simple high-level heuristic tool to assist in the understanding of human cognitive-emotional processing during distressing events [1,2]. Notably, despite its healthcare origins, the KR model is translatable across industries and can be used in different contexts (i.e., UX design, technology evaluation, implementation science, organizational change, trauma processing) [7-9,16-19].

6. Conclusion

The findings from this scoping review have revealed that the KR model provides an opportunity to improve the contextualization of human experience when facing distressing events. Moreover, the promise of applying the KR model in a UX context to

guide and inform human-centered health informatics, enhance end-user acceptance, clarify clinical workflows, and improve the delivery of healthcare services are endless [7-9,16-19]. Specifically UX activities such as persona creation, and journey mapping techniques present opportunities to understand healthcare processes, interrelationships, and contexts in service design and delivery [11-14]. Furthermore, the KR model provides a lens in which not only the patient experience can be realized, but it also provides a framework for healthcare providers to recognize their own humanity by reflecting on their feelings and emotions.

References

[1] Kübler-Ross, E. On Death and Dying. New York: MacMillan; 1969.
[2] Kübler-Ross, E. On death and dying (40th ed.). Abingdon, UK: Routledge; 2009.
[3] Kramer K. You Cannot Die Alone: Dr. Elisabeth Kubler-Ross (July 8, 1926-August 24, 2004). Omega: Journal of Death and Dying. 2004;50(2):83–101.
[4] Gigerenzer G, Gaissmaier W. Heuristic decision making. Annu Rev Psychol. 2011;62:451-82. doi: 10.1146/annurev-psych-120709-145346.
[5] Heuristic. Merriam-Webster.com dictionary. [Cited 2025 January 17]. Available from: https://www.merriam-webster.com/dictionary/heuristic.
[6] Dugan DO. Appreciating the legacy of Kubler-Ross: one clinical ethicist's perspective. Am J Bioeth. 2004 Fall;4(4):W24-8. doi: 10.1080/15265160490908112.
[7] Qeis MI, Ihwanny R. The hole in the wall: how the film '27 steps of may' portrays stages of grief and acceptance. Cogent arts & humanities. 2025;12(1).
[8] Shoolin JS. Change Management – Recommendations for Successful Electronic Medical Records Implementation. Applied clinical informatics. 2010;1(3):286–92.
[9] McAlearney AS, Hefner JL, Sieck CJ, Huerta TR. The Journey through Grief: Insights from a Qualitative Study of Electronic Health Record Implementation. Health services research. 2015;50(2):462–88.
[10] Valliani K, Mughal FB. Human emotions during COVID-19: A lens through Kubler-Ross Grief theory. Psychol Trauma. 2022 Feb;14(2):247-249. doi: 10.1037/tra0001064. Epub 2021 Jul 29.
[11] Joseph AL, Kushniruk AW, Borycki EM. Patient journey mapping: Current practices, challenges and future opportunities in healthcare. Knowledge management & e-learning. 2020;12(4):387-404.
[12] Joseph AL, Monkman H, Kushniruk A, Quintana Y. Exploring Patient Journey Mapping and the Learning Health System: Scoping Review. JMIR human factors. 2023;10:e43966–e43966.
[13] Joseph AL, Shah LM, Kushniruk A, Quintana Y. A Human-Centered Physician Journey. Stud Health Technol Inform. 2023 Jun 22;304:76-77. doi: 10.3233/SHTI230374.
[14] Joseph AL, Monkman H, Kushniruk AW. An Evaluation Guide and Decision Support Tool for Journey Maps in Healthcare and Beyond. Stud Health Technol Inform. 2022 Jun 29;295:171-174. doi: 10.3233/SHTI220689.
[15] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol.2005;8(1):19-32.
[16] Hathaway MA. How Cancer Patients Describe Their Experiences of Grief Using Social Networking Sites: A Qualitative Descriptive Study. Grand Canyon University; 2019.
[17] Larry L. A Qualitative Study of the Experience of Individuals Within Information Technology Teams During Transition Using the Kubler-Ross Grief Construct and the Bridges Transition Model. George Washington University;2017
[18] Roth D, von Mammen S, Keil J, Schildknecht M, Latoschik ME. Approaching Difficult Terrain with Sensitivity: A Virtual Reality Game on the Five Stages of Grief. In: 2019 11th International Conference on Virtual Worlds and Games for Serious Applications (VS-Games). IEEE; 2019. p. 1–4.
[19] Sotelo BE. A qualitative case study to investigate the technology acceptance experience outlined in the TAM using the Kübler-Ross stages of grieving and acceptance. Colorado Technical University; 2015.
[20] Dugan DO. Appreciating the legacy of Kubler-Ross: one clinical ethicist's perspective. Am J Bioeth. 2004 Fall;4(4):W24-8. doi: 10.1080/15265160490908112.