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The Potential of the Transformative Storytelling Technique for supporting informal caregiver wellbeing

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I dedicate this work to my grandmother.

Thank you for your stories, love, support, curiosity, humour, advice, and for always believing in me.

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Abstract

In a society where advances and innovations occur daily, the development of digital mental health tools continues at almost uncontrollable rates. Following trends in utilization of storytelling across fields and reflecting on the lack of working models and frameworks for application of storytelling in mental health support, the Transformative Storytelling Technique is designed and developed as a part of this work. This technique represents a new category for creating hybrid content to guide the experience of audiences, starting with the case of informal caregivers.

The aim of this dissertation is to introduce and explore the feasibility of a novel technique – Transformative Storytelling (TST) - in supporting informal caregivers' mental health and wellbeing with designed audio stories. The dissertation is presented in four chapters in line with the objectives and structured according to the research and developmental phases applied in developing this novel technique.

Mixed-method design is used in this work, including qualitative scoping review in first study, narrative inquiry using semi-structured interviews designed following a-priori TST categories of exploration in the second study, and quantitative pre-post interventional study combined with the facial expression tracking in the pilot study. Transformative Storytelling Technique is demonstrated as a potentially successful methodological and digital narrative approach for structuring, thematically synthesizing experiences of target groups, and delivering them via digital narration. This potential was observed in the pilot pre-post assessment, where the technique demonstrated significant reduction of the subjective burden and a significant increase in happiness during the TST story exposure.

In Study 1, the existing digital mental health tools for informal caregivers are being explored, followed by the Study 2 where a potential support solution has been thoroughly discussed and proposed. In line with that, the work continues with Study 3 where the Transformative Storytelling Technique is adapted from the Transformative Video Design and methodological demonstration is being performed. Next, the pilot assessment of the mentioned technique in Study 4 is included to test the feasibility of using the storytelling technique for supporting informal caregivers with TST digital narratives. Finally, limitations and implications for future research are discussed in the final section.

1 GENERAL INTRODUCTION

1.1 THE ROLE OF STORYTELLING IN PSYCHOLOGY AND THERAPY

Following the rapid developments in mental health technology, tools, and approaches for digital health, the scarcity of digital narrative techniques for health and empowerment is noted (De Vecchi et al., 2016). In fact, currently no existing technique for creating digital mental health narratives has been found or has been adapted from the existing therapeutic narrative approaches. Interestingly, although digital storytelling has already been applied in both digital health and science (Rossiter & Garcia, 2010), clear approach or framework guiding the development of such stories does not exist to the best knowledge.

The importance of storytelling in mental health is particularly emphasized for traumatic and stressful experiences that are out of daily experiential scope (Davidson et al., 2021). In fact, in line with narrative identity theory, where life of everyone is internally sublimated as an ever-developing cohesive narrative of lived past and anticipated future experiences, story is crucial for healthy self-identity (McAdams 1987; McAdams, 2011). Therefore, the application of storytelling techniques in supporting mental health throughout individual therapeutic process, but also beyond therapeutic process has been well established.

One of the therapeutic examples of storytelling can be observed in dramatic psychological storytelling (DPS) as part of Expressive Arts therapy which utilizes psycho-theatrics method allowing individuals and groups, guided by the skilled therapist, to design and dramatically express stories (Allen & Krebs, 2007). The client becomes a director or an actor for his own story, gaining full control over the intensity of emotions, story development, peak moments, and even re-creation of potential story resolutions. Such experience can be deeply transformative, provide catharsis, or simple perspective shift that can ultimately allow redefinition of the lived experiences.

In a small cross-sectional study exploring the effects of storytelling in therapy, a sample of 42 females experiencing relationship problems was randomly assigned to either receive a story or psychoeducational information (Parker & Wampler, 2007). The findings revealed that both approaches were equally successful in lowering negative feelings in the relationship and reducing negative affect within participants. Moreover, in the particular case, stories facilitated change in emotional valence, while participants reported sessions running smoothly in both groups.

Storytelling has been successfully implemented up to date in psychotherapy, child and family therapy, medical treatment, counselling, coaching, and supervision (see Hammel, 2018). Furthermore, in a sample of traumatic brain injury survivors, four distinct storytelling categories emerged as intervention approaches to provide support through film, visual arts, written work, and song writing. These categories that are most often used to assist with identity reconstruction in patients, emotional processing, and to support recovery in clinical outcomes such as rehabilitation and executive functioning (Candlish et al., 2022).

Considering current utilization of storytelling and the studies included it can be suggested that this narrative therapeutic approach has been successfully applied in both supporting meaning making and enabling self-identity re-construction. These promising applications expand the potential of storytelling as a psychotherapeutic approach and illuminate the way towards broadening this practice into the digital space. Namely, numerous digital storytelling approaches have already been explored across context, demonstrating excellent results.

For example, Carragher and colleagues (2021) used storytelling approach to support patients who live with aphasia, revealing the therapeutic value of storytelling in improving aspects of language and communication within participants. Another example includes the work of Filoteo and colleagues (2018) who designed digital storytelling to be used in a particular software for patients living with dementia. The utilization of storytelling in this group demonstrated significant improvement in anxiety, stress, and depression after the exposure to storytelling (Filoteo et al., 2018).

Furthermore, Blas and Paolini (2013) explored the value of storytelling beyond therapy, demonstrating excellent results (N=17.000) in knowledge acquisition through storytelling, and the improvement of attitudes and behaviors. Finally, in the example of storytelling for informal caregivers Kajiyama and colleagues (2018) designed a webnovela for Hispanic caregivers providing different types of skills, knowledge, and experiences in each short episode of webnovela, demonstrating excellent findings in knowledge acquisition, development of productive coping skills, and overall improvement in caregiving skills.

The role and the effects of storytelling have been extensively explored throughout literature, particularly elaborating on the neuroscientific background of the storytelling mechanisms and the influence storytelling has on audiences (Grall et al., 2021). Past research has clearly demonstrated that unlike flat narratives, dynamic and structured narratives have an important influence on the behavior and perception of the audience (Grall et al., 2021). However, further work on applying and assessing diverse narrative structures to better understand the influence on the audience emotions and behaviors has not been established.

This dissertation introduces the Transformative Storytelling Technique (TST) as a new methodology for creating and delivering empowering digital mental health narratives for support and potentially large-scale support. The main contribution of this innovative work is in the multifunctionality of the Transformative Storytelling Technique in therapeutic, research, and digital mental health context. First, the technique acts as a qualitative methodological approach for research purpose. Concretely, targeting and structuring stressful and traumatic life experiences into a cohesive narrative providing a pathway to better understanding subjective experiences. Second, the technique can be applied in group therapy guiding the development of empowering group narratives. Third, the technique acts as a structured approach for exploring, designing, and developing empowering digital mental health narratives for large scale support.

The use of narrative and storytelling as a medium for self-expression and self-exploration is a well-known narrative therapy approach (Madigan, 2011). In fact, the inspiration for creating the TST derives from the narrative therapy which acts as a collaborative journey of the client and the therapist in creating and re-authoring problem-saturated narratives into cohesive self-stories. The main distinction between the Transformative Storytelling Technique from the narrative approach in therapy is in the story itself. More specifically, while in narrative therapy the story is shared and built bottom-up by the client and then collaboratively assessed and re-authored with the support of the therapist to obtain final productive narrative, in TST the process is top-down.

In essence, with the TST an improved and more productive story is directly delivered to help manage problematic or difficult experiences, excluding the mediating therapeutic steps that takes place in narrative therapy. Therefore, the TST is immediately distinguished from narrative therapy, emphasizing its practicality in developing and delivering empowering stories, while maintaining the distance from therapeutic approach to acknowledge the value of therapeutic journey and the importance of the therapist in individual therapeutic narrative process.

It must be acknowledged that new and advanced technologies in mental health use storytelling either as a main approach or additional tool, such as VR technologies that inevitably apply some type of storytelling (e.g., linear, non-linear, partial, full, etc.) mobile apps for mental health that rely on storytelling, and video approaches applying narratives (Page & Thomas, 2011). However, vast majority of the existing tools often disregards the role particular narrative structures have in storytelling, which creates further arguments on how well the effects of such tools are understood and on which basis are the support stories developed.

1.2 INFORMAL CAREGIVER

Informal caregiver population is a highly vulnerable population of individuals who join the role of informal caregiver often unexpectedly and unprepared for the task (Avieli et al., 2022). In line with that, the self-identity of these individuals transitions from a family member or close other to a caregiver (Kepic et al., 2019). Inevitably, in line with the caregiving stress model, such transition is considered a stressful and even traumatic experience (Pearlin et al., 1990) which arguably affects the self-identity and how life story is sublimated and joined into the narrative identity of the self (McAdams, 2011).

In fact, informal caregiver population experiences a range of adverse role-related mental health outcomes that are further influenced by the external factors ranging from issues with formal health care systems, to social care system, as well as adverse experiences on a local community level to governmental level (del-Pino-Casado et al., 2019). The combination of these factors with the pre-existing emotional and psychological vulnerability due to the illness or poor health state of the close other who is the care recipient makes informal caregiver population particularly vulnerable and in need of support.

One of the main challenges in informal care sector is managing experienced health consequences due to prolonged care provision, which in turn is motivating and driving modernisation of social infrastructure to incorporate all available resources to provide social support and connectedness for informal caregivers (Power & Hall, 2018). In line with that, there is a growing interest in social media and overall digital platforms to facilitate and strengthen social support for both caregivers and care recipients (Lopez-Gomez et al., 2021). This particular trend drew attention of the research community, which in turn coins the term "caring media technologies" to facilitate better exploration of this novel field of caregiving support (Gibson et al., 2021).

Similarly, to other technoscientific areas that strive to address contemporary social challenges, perpetual innovations in caring media technologies seem to dictate the development of informal care itself and influence the overall sustainability of the informal care future (Lopez-Gomez et l., 2021). Therefore, adopting innovative technological solutions into everyday caregiving practices directly reduces future challenges in welfare systems (Adams et al., 2009; Lopez-Gomez et al., 2021). More specifically, the exploration of new tools and technologies does not necessarily entail novelty, but also existing technologies adapted to informal care context to "repair" and "bricolage" the technologies to better serve informal care (Schwennesen, 2019; Gibson et al., 2019; Lopez-Gomez et al., 2021).

In fact, to reach most vulnerable caregiving population and those at higher risk of social isolation, caring media technologies are promoted as cost-effective solutions that are relatively easy to scale up and deliver. Such technologies are usually avaialbe through designed platforms or the existing community-based and social media platforms that can be used as stand-alone or implemented by healthcare practitioners. Following these argument, informal care population is highly suitable and in

need of digital approaches to further support and facilitate caregiving activities while successfully addressing and assisting with management of personal mental health throughout the role.

1.3 OBJECTIVES

The aim of this dissertation is to (i) design Transformative Storytelling Technique (TST) as a new technique for supporting the empowerment in informal care context; (ii) explore the feasibility and potential effectiveness of this technique in a laboratory setting; and (iii) to provide practical guidelines for its use in various caregiving settings.

The study involved a mixed-methods research design, including both qualitative and quantitative data collection and analysis. The findings of this study provide insights into the potential of the Transformative Storytelling Technique as a support tool for empowering caregivers and highlight the importance of supporting caregivers in their vital caregiving role. The guiding idea is that TST facilitates caregivers to reflect on their role identity, understand how to better share their experiences and challenges with peers, and adopt a more positive perception of their personal experience, leading to more positive response to the complex caregiving role.

In this work I will apply the Transformative Storytelling Technique as a digital tool for informal caregiver mental health support and explore the feasibility of the Transformative Storytelling Technique and its potential in large scale digital audio support. The main objectives of this dissertation are research, development, and application of digital narrative technique for large scale support including:

1)   Analyse state of the art of digital tools for informal caregivers (Study 1)

2)   Design a new methodology (i.e., TST) to create "empowering stories" and deliver them via digital tools that are particularly suited for storytelling dissemination. (Study 2 and Study 3)

3)   Test/validate the feasibility of the TST technique in the domain of caregivers to better understand how context adapted narratives can support informal caregivers (Study 4)

4)   Design a portal/website for sharing empowering TST stories among peers within the target population across Europe.

1.4 METHODOLOGY

Mixed-methods design has been employed for the purpose of this work. Concretely, Study 1 uses qualitative approach to narratively synthesize the state of the art in digital tools for informal caregivers of older adults. These findings then provide a comprehensive pathway to better understand the existing digital mental health tools, their purpose and utilization in informal care as well as possible gaps within that would benefit informal caregivers if properly addressed.

Drawing from these findings, Study 2 proposes a new Transformative Video Design (TVD) approach for supporting informal caregivers through audio and video storytelling. This proposal is then assessed following the design thinking methodology and adapted to the Transformative Storytelling Technique for structuring empowering digital narratives. Method demonstration for this adaptation is then presented in detail in Study 3, and finally assessed in Study 4 using one arm pilot interventional study design.

Research and development flow of the Transformative Storytelling Technique in particular, was executed in six phases (see Figure 1. for the flow of the research development phases) aiming to achieve optimal balance between user-centred design and research development. This balance was obtained by performing extensive literature review in Phase 1 which was then summarized in the scoping review (Study 1) to provide a path to understanding existing types of approaches and technologies that would benefit informal caregivers while maintaining storytelling in mind as a foundation for the potential new tool.

Next, Phase 2 was executed based on the needs and technologies retrieved in phase one, and a new solution incorporating storytelling was proposed (i.e., TVD). Following that in Phase 3 and 4 the proposed solution was assessed against the qualitative needs obtained by involving a sample of informal caregivers (i.e., end-users) in perceived need assessment (user-centered design). Once the better overview was obtained between qualitative needs and the proposed solution, the adaptation to the proposed (i.e., from TVD to TST) solution was made and a step-by-step demonstration has been executed in Phase 5. Finally, in Phase 6 the adapted version in a form of the Transformative Storytelling Technique was assessed (Study 4) and valuable knowledge has been retrieved.

Figure 1. Structured flow of research and development presented in this dissertation

Phase 1	Research on the state of the art in digital tools for informal caregivers
Phase 2	Designing Transformative Video Design (TVD) as a solution based on the Phase 1 and overall storytelling literature
Phase 3	Applying the Design Thinking Methodology to assess the user-value of TVD
Phase 4	Adapting the TVD to Transformative Storytelling Technique post Design Thinking Methodology
Phase 5	Method Demonstration of the Transformative Storytelling Technique in a sample of informal caregivers
Phase 6	Assessing the feasibility of the TST for informal caregivers

1.5 GENERAL FINDINGS

Findings in this work demonstrated in Study 1 that informal caregiver needs range from educational, and information needs to practical and emotional support needs. Moreover, the existing digital tools for informal caregivers have been divided to "mobile based", "web based", and "other" that were more oriented toward new mediums such as virtual reality (VR). The existing tools were shown to successfully support managing range of adverse role-related mental health outcomes such as stress, depression, anxiety, etc. However, it must be noted that these adverse outcomes have been explored quantitatively through literature, while deeper understanding of the potentially underlying or mediating factors for these experiences remains unexplored. The common case is that adverse role-related outcomes are explained directly with the caregiving role itself (i.e., act of providing care). Interestingly, few studies reflected on the expressed meaning-making and identity needs of informal caregivers, with no further reflection and better understanding of internal and personal motives for experiencing those needs.

As demonstrated in Study 3, which applied the TST technique in targeting and sorting informal caregiver needs in a cohesive narrative line, conversely to common practice of attaching the outcomes to caregiving activity, adverse role-related experience are shown as outcomes related to prolonged care provision which is in fact saturated with numerous "triggers" that lead to negative emotional and psychological experiences noted in the Study 1.

In fact, Study 3 shows that structuration of life narratives following the TST methodology provides a linear pathway to better understanding factors that gradually lead to build-up in negative experiences. For example, changes in routine and shift in social connection are noted as important factors in adverse outcomes. These factors are not directly influenced by the care provision itself but rather organization or personal time and lack of support mechanism in the close environment. Moreover, it can be argued that these findings imply potential predictive tendency of TST that allows positioning individual informal caregiver experience in the built TST narrative structure to better understand or even intercept the direction a caregiver is taking in mental health context. The main advantage of such positioning is in the opportunity to locate and prevent adverse outcomes before they reach critical stages (see Study 3, Figure 2). In this aspect, TST acts both as research methodology and preventive approach for practitioners.

However, in the Study 3 the method demonstration has specifically been made for step-by-step development of TST story for support and empowerment of the target population. The pilot feasibility assessment of the TST story developed in Study 3 has been performed in Study 4, demonstrating that exposure to TST audio story significantly lowered informal caregiver burden, while feelings of surprise, followed by happiness gradually and consistently increased throughout the story. Therefore, an important step in the field of digital storytelling for mental health support has been made, demonstrating the role of narrative structure in designing and delivering storytelling.

The TST story delivered to informal caregivers follows a dramatic narrative structure and depicts difficult and challenging circumstances (see Appendix 2), however regardless of the difficult and emotionally charged story, TST structure that supports the story carries important role-related elements that support participants identification. It can be argued that TST supported sense of social connectedness or peer connection, or sense of being understood and in experiential proximity of the story protagonist which ultimately supported positive experience of the dramatic story in this vulnerable and often lonely population.

This dissertation contributes to the field of digital storytelling in mental health a) by demonstrating the important role of underlying narrative structures in storytelling b) while also addressing an important gap in storytelling techniques in mental health, and digital techniques and c) investigating the depth of storytelling as a predictive methodology in mental health (in informal care context). Therefore, it opens new horizons in research methodology, practical application, and digital storytelling creation that inevitably must be acknowledged, considered, and addressed in new digital contents for mental health and support, especially taking into consideration the ongoing new developments such as Metaverse and overall immersive experiences. Furthermore, an important discussion regarding ethics in utilization of the influential storytelling techniques for large scale support and general audiences is also opened to provide better understand the existing gaps systems in place have when overseeing and managing the utilization of such contents.

1.6 OUTLINE OF EACH CHAPTER

Chapter I is an extensive literature review presenting the topic of informal care, challenges, and the existing approaches and tools to support informal caregivers. This chapter draws attention to the topic

of informal care by introducing the definition of informal caregiver, mental health needs and role related outcomes included in the literature. The focus is on the ever-present needs and outcomes throughout multiple illness related context in long term care provision. Better understanding of the informal caregiver needs allows to focus properly on the required help, as well as intercept the adverse role-related outcomes before they manifest psychosomatically. Following that, the discussion is steered towards existing mental health support that is targeting relevant caregiver needs and aims to improve adverse role-related outcomes to better understand what is already available in terms of mental health support for informal caregivers. Finally, Study 1, a scoping review of literature is presented, exploring the existing digital mental health tools for informal caregivers allowing in-depth understanding of the available support mechanisms utilized throughout the digital field. The value of this review is particularly important since it acts as the initial guide to how particular types of storytelling can contribute or improve the existing support.

Chapter II introduces storytelling as a concept and as an approach for therapeutic support. Narrative and storytelling are being discussed in relation to the overall connection to the mental health field, considering the underlying influence of storytelling and the added value of such approach to large scale support. Common applications of the existing storytelling approaches are then demonstrated, leading to the Study 2 which introduces and explores the potential of the newly developed concept of Transformative Video Design for supporting informal caregivers. This concept is based on the theory of narrative identity and adopts the theoretical background of the storytelling mechanisms to incorporate potential support into digital storytelling design.

Chapter III, continuing previous flow of the idea on storytelling, discusses the relevant adaptations of the TVD incorporated to develop final Transformative Storytelling Technique. This chapter is the outcome of three consecutive developmental phases of this project (see Figure 1) relying on assessing the usability of the initial TVD proposal to the relevant informal caregiver needs upon initial user involvement in Phase 3 of the project. Significant adaptations made and final version of the technique is demonstrated step-by-step in the Study 3 which is the Transformative Storytelling Technique method demonstration. Important considerations are included in the discussion section of the Study 3 leading to the Study 4 which is a pilot feasibility assessment of pre-post storytelling exposure in a sample of informal caregivers.

Chapter IV discusses limitations observed in the Study 1, Study 3, and Study 4, but also explores the potential limitations of the Transformative Storytelling Technique itself, as well as potential improvements that can be made across context. Finally, implications for future research are included, taking into consideration isolated components of the technique and overall ethical considerations on applying potent storytelling techniques in health support and health communication.

REFERENCES

Adams, V., Murphy, M., & Clarke, A. E. (2009). Anticipation: Technoscience, life, affect, temporality. Subjectivity, 28(1), 246-265.

Allen, R., & Krebs, N. (2007). Dramatic psychological storytelling. In Dramatic psychological storytelling (pp. 31-41). Palgrave Macmillan, London.

Avieli, H., Band-Winterstein, T., & Zamir, A. (2022). Juggling between caregiving and self-actualization: Older parents' lifelong experience of caring for an adult child with developmental disabilities. *Plos one*, 17(11), e0276779.

Blas, N. D., & Paolini, P. (2013). Digital storytelling and educational benefits: Evidence from a large-scale project. In Transactions on Edutainment X (pp. 83-101). Springer, Berlin, Heidelberg.

Candlish, L., Fadyl, J. K., & D'Cruz, K. (2022). Storytelling as an intervention in traumatic brain injury rehabilitation: a scoping review. *Disability and rehabilitation*, 1-15.

Carragher, M., Steel, G., Talbot, R., Devane, N., Rose, M. L., & Marshall, J. (2021). Adapting therapy for a new world: storytelling therapy in EVA Park. Aphasiology, 35(5), 704-729.

Davidson, T., Moreland, A., Bunnell, B. E., Winkelmann, J., Hamblen, J. L., & Ruggiero, K. J. (2021). Reducing stigma in mental health through digital storytelling. In Research Anthology on Mental Health Stigma, Education, and Treatment (pp. 909-919). IGI Global.

De Vecchi, N., Kenny, A., Dickson-Swift, V., & Kidd, S. (2016). How digital storytelling is used in mental health: A scoping review. *International Journal of Mental Health Nursing*, 25(3), 183-193.

del-Pino-Casado, R., Espinosa-Medina, A., López-Martínez, C., & Orgeta, V. (2019). Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. *Journal of Affective Disorders*, 242, 14-21.

Filoteo, J. V., Cox, E. M., Split, M., Gross, M., Culjat, M., & Keene, D. (2018, July). Evaluation of ReminX as a behavioral intervention for mild to moderate dementia. In 2018 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC) (pp. 3314-3317). IEEE.

Gibson, G., Dickinson, C., Brittain, K., & Robinson, L. (2019). Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. Ageing & Society, 39(11), 2502-2519.

Gibson, M., Hjorth, L., & Choi, J. H. J. (2021). Introduction: Caring media futures. *International Journal of Cultural Studies,* 24(4), 557-566.

Grall, C., Tamborini, R., Weber, R., and Schmälzle, R. (2021). Stories collectively engage listeners' brains: Enhanced intersubject correlations during reception of personal narratives. *Journal of Communication*. 71, 332–355. doi: 10.1093/joc/ jqab004

Hammel, S. (2018). Handbook of therapeutic storytelling: Stories and metaphors in psychotherapy, child and family therapy, medical treatment, coaching and supervision. Routledge.

Kajiyama, B., Fernandez, G., Carter, E. A., Humber, M. B., & Thompson, L. W. (2018). Helping Hispanic dementia caregivers cope with stress using technology-based resources. Clinical gerontologist, 41(3), 209-216.

Kepic M, Randolph A, Hermann-Turner KM (2019) Care for caregivers: Understanding the need for caregiver support. Adultspan Journal 18(1): 40–51.

López-Gómez, D., Beneito-Montagut, R., & García-Santesmases, A. (2021). No future for care without new digital media? Making time (s) for mediated informal care practices in later life. International Journal of Cultural Studies, 24(4), 637-654.

McAdams, D. P. (1987). "A life-story model of identity," in Perspectives in personality. Stamford, CT: JAI Press. p. 15–50.

McAdams, D.P. (2011) Narrative identity. In: Schwartz S, Luyckx K, Vignoles V (eds) Handbook of Identity Theory and Research. New York, NY: Springer, pp.99–115.

Madigan, S. (2011). Narrative therapy. American Psychological Association.

Page, R., & Thomas, B. (Eds.). (2011). New narratives: Stories and storytelling in the digital age. U of Nebraska Press.

Parker, T. S., & Wampler, K. S. (2006). Changing emotion: The use of therapeutic storytelling. Journal of Marital and Family therapy, 32(2), 155-166.

Power, A., & Hall, E. (2018). Placing care in times of austerity. Social & Cultural Geography, 19(3), 303-313.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The gerontologist, 30(5), 583-594.

Rossiter, M., & Garcia, P. A. (2010). Digital storytelling: A new player on the narrative field. New directions for adult and continuing education, 126, 37-48.

Schwennesen, N. (2019). Algorithmic assemblages of care: Imaginaries, epistemologies and repair work. Sociology of Health & Illness, 41, 176-192.

CHAPTER I

2 CHALLENGES, MENTAL HEALTH, AND AVAILABLE TOOLS FOR INFORMAL CAREGIVERS

SUMMARY OF THE CHAPTER

This chapter is a literature background on the topic of informal care and current mental health issues and the existing approaches for informal caregivers. The added value of this chapter is in the amount of literature and depth in addressing past research on mental health and the existing support tools for informal caregivers. This chapter acts as a Phase 1 shown in the general introduction that provides input on the current state of informal care and exploration of the existing needs. Informal caregiving is introduced through the literature on informal caregiving, mental health needs of informal caregivers, and noted adverse role-related experiences. Following that, a reflection on the existing mental health support for informal caregivers is made, Study 1 explores the digital mental health tools for informal caregivers of older adults. This study investigates and narratively synthesizes the retrieved literature, distinguishing among the relevant categories of tools, mental health and practical needs, and overall application of these tools in caregiving context.

2.1 PSYCHOLOGICAL NEEDS OF CAREGIVERS AND DIGITAL TOOLS: STATE OF THE ART

2.2 INFORMAL CAREGIVER NEEDS AND OUTCOMES

Current evidence pertaining to the informal care needs and outcomes varies across the context of illness. Although diverse findings point to a large pool of unmet informal caregiver needs, there is a significant overlap when it comes to education and information needs, communication with health practitioners, and personal mental health needs. For instance, in a systematic review including fifty studies on unmet caregiver and patient needs of people living with cancer, seven unmet needs were identified among informal caregivers (Wang et al., 2018). The identified unmet needs included information about the illness and about the treatments available, and explicitly care related information (Wang et al., 2018).

Similarly, a qualitative analysis of the needs of informal caregivers of recipients living with amyotrophic lateral sclerosis (ALS) indicated that informal caregivers perceived external support and assistance as a need of great value within their role, patient-related factors such as support in communicating the issues and needs with the care recipient, and psychological and emotional support throughout the role – e.g., being understood by others, have the attention and interest regarding personal issues by others, obtaining more alone time and time with significant others (Galvin et al., 2018).

Interesting findings were also reported in a cross-sectional survey of informal caregivers of adult bone-marrow transplant patients where an association between unmet needs of informal caregivers and psychological morbidity was found (Armoogum et al., 2013). In particular, two third of participants reported unmet support care needs, as well as higher psychological morbidity in instances where care recipient also reported higher levels of anxiety and depression.

Another study extensively explored the role of employment in experienced adverse outcomes for informal caregivers. It was noted that informal caregivers who did not have employment during the caregiving role, particularly females, showed lowered psychological wellbeing (Hansen & Slagsvold, 2015). It could be argued that the access to full-time employment has provided another dimension of interaction outside of the caregiving role, allowing informal caregiver to dedicate attention to something beyond caregiving.

Furthermore, a study on the utilization of home health visits by the formal health care personnel noted that 87% of informal caregivers required some sort of assistance within the role (Burgdorf et al., 2021). For instance, caregivers identified the need for training in areas of household chores (e.g., meal preparation, shopping, etc), self-care tasks (e.g., assisting with hygiene needs for care recipient), medication management, and patient supervision to ensure care recipients' safety.

In a hosted online discussion about the caregiver needs in supporting gynaecologic-oncologic patients, a content analysis revealed four main themes (Hand et al., 2018). Not surprisingly, most retrieved themes overlap with previous findings and include accepting help from others, self-care needs, need for information and access to resources, and the communication with the health care professionals. Moreover, barriers in addressing needs were noted such as lack of awareness regarding the needs, adverse emotions, and intrinsic drive to do everything alone.

However, caregiver unmet and perceived needs must not be the only basis for determining the required support for informal care population. Moreover, considering the variations in caregiver needs which are both general and context/illness based, another important factor that must be included in the pursuit of designing and developing support is the caregiving outcome. Concretely, role-related outcomes of prolonged care provision are equally, if not more, important as perceived and unmet caregiver needs. Caregiving role-related outcomes include both physical and psychological outcomes of the prolonged caregiving role, which in short period or through qualitative reflections of informal caregivers might not be realized or recognized.

Studies consistently indicate that caregiving role has negative effects on the psychological health of caregivers, while prolonged exposure to the role leads to an increased risk of experiencing symptoms of anxiety and depression at the clinically significant level (del Pino-Casado et al., 2019). In fact, systematic review indicated that the prevalence rates for depression reach up to 40.2% and around 21.4% for anxiety for informal caregivers of individuals who had stroke, similarly percentage rates for caregivers of individuals living with dementia point to 34.0% for depression and 43.6% for anxiety (Sallim et al., 2015).

The uncertainty about the future of the care recipient and also caregiver himself adds to the experienced role-related burden. Subjective caregiver burden raises from the negative appraisal of the role-related circumstances and has an important position in adverse role related outcomes (del Pino-Casado et al., 2018). Although literature distinguishes subjective caregiver burden from the objective burden, the distinction is not always clearly defined. Objective caregiver burden has been explained through prism of physical, social, and financial outcomes of the role, while subjective burden refers to the emotional and perceived difficulties within the role (Collins & Kishita, 2019).

The prolonged exposure to informal care adds to the negative emotions experienced such as guilt, resentment, sadness, and ever-present fear of losing the loved one the care is provided for (Lindeza et al., 2020). Moreover, a large cross-sectional study with over 560 participants/informal caregivers showed that almost 16% of participants contemplated suicide once or several time in the past twelve months at the time of the study (O'Dwyer et al., 2016). Therefore, potential adverse role-related outcomes do not solely affect psychological or physical state but can in fact lead to serious outcomes for the caregiver.

Early research on adverse caregiving outcomes explored both psychological and physical consequences of prolonged caregiving as well as coping strategies adopted by the caregivers. This type of investigation was later on summed in caregiving stress model which views caregiving as the event that through numerous factors inevitably leads to the experience of personal stress that changes and develops over time (Pearlin et al., 1990). Caregiver wellbeing has been mostly assessed through physical health (Cohen & Syme, 1985; Yates et al., 1999) or mental health (Yates et al., 1999; Gallagher et al., 1989). However, further work on caregiving outcomes noted that the perception of caregivers and meaning attached to the caregiving role had an important influence on the experienced adverse outcome such as stress and anxiety (Gallagher et al., 1989; Lawton et al., 1989).

These findings led to the creation of the caregiving appraisal model which focuses on the objective caregiving circumstances and the subjective caregiver appraisal of the situation. Although the caregiving stress model is more prevalent in research even today, the appraisal model strives to understand the situational aspects that lead to the experience of stress rather than the final health outcome of the caregiving role. In fact, this work includes and discusses numerous studies that utilize the stress model, however this manuscript itself is driven by the appraisal model and draws its inquiry from the perspective of the appraisal model. In such manner, this manuscript proceeds to explore the

existing and potential support for informal caregivers while relying on the importance of distinguishing and reflecting on the situational aspects that lead to the adverse role related experiences.

2.3 THE EXISTING MENTAL HEALTH SUPPORT FOR INFORMAL CAREGIVERS

Numerous psychological interventions for supporting informal caregivers have been developed and adapted throughout the years. A scoping review exploring the effects of the informal caregiver support revealed that the effect of these interventions is small and inconsistent through studies (Lopez-Hartman et al., 2012). However, the existing types of support were shown beneficial in assisting informal caregivers to manage concrete adverse outcomes or gain specific skills or knowledge (e.g., coping ability, education, reducing stress, etc).

For instance, respite services, defined as a type of support provided for informal caregivers that allow temporary break from the caregiving activities, showed positive effect on caregiver burden after 2-3 month's follow-up (Lopez-Hartman et al., 2012; Shaw et al., 2009). These services are organized in diverse ways, but most strive to enable brief break for informal caregivers by providing temporary care-home for the care recipient such as hospice or formal health care worker in home settings. Respite services can span from 1-2 weeks or can also take a form of daycare up to eight hours per day, as well as and night-sitting services. Furthermore, a systematic review and meta-analysis reported a positive effect of respite care on reducing depression (Mason et al., 2007) while the economic value of these services is equivalent to the usual care (e.g., home based formal caregiver).

Another type of support is individual support for informal caregivers in a form of psychosocial support. Such support ranges from individual counselling, skill building, education, to emotional support throughout the role. This type of support aims to provide skills for the caregivers to better manage adverse role related outcomes. The individual support is usually provided through cognitive reframing, psychosocial interventions in person or online, telephone counselling, group support (outside of the individual scope but within psychosocial support scope), art therapy, educational interventions, and meditation-based interventions (Thomas et al., 2017).

An example of individual psychological and psychosocial support can be seen in a Compassion-Focused Therapy and Mindfulness-Based Stress Reduction. These psychotherapeutic approaches are adapted for informal caregivers to support psychosocial needs of informal caregivers, supporting for depression and anxiety in particular, and eventually delay shift from informal care to care home for elderly care recipient (Collins & Kishita, 2019).

However, as argued in the organizing framework for developing and evaluating interventions for informal caregivers (Van Houtven et al., 2011) an intervention might have a positive effect on caregiver outcome but hinder caregiving activities. Furthermore, one of the recommendations provided through this framework is that the interventions should consider a broader set of caregiving role-related outcomes rather than just a narrow adverse mental health outcome (Van Houtven et al., 2011). In line with that, psychosocial support is useful but not sufficient to address wide variety of outcomes.

Interestingly group support interventions have shown to be an important psychosocial-educational support for informal caregivers. This type of support showed promising results in decreasing

depression, anxiety, increase in knowledge about the available resources, as well as an increase in active behavioural coping strategies and seeking social support in support groups (Cassie et al., 2008; Van den Huevel et al., 2002).

Finally, information and communication technology (ICT) enabled an ever-expanding pool of interventions in terms of content and variety of approaches, available on demand in both individual and group settings. Some of the main advantages of ICT support are availability, cost effectiveness, and an opportunity to explore and test numerous available support options. However, ICT support is a vast field that includes not only mental health interventions but also other approaches that do not necessarily provide intervention but also potential treatment or other type of support. Therefore, the first study conducted as a part of this dissertation explored the existing digital tools for informal caregivers of older adults, aiming to provide a synthesis of the existing knowledge, approaches, and tools used for and by informal caregivers to support and address adverse role related outcome. The following section describes the Study 1.

2.4 STUDY 1: DIGITAL MENTAL HEALTH TOOLS FOR CAREGIVERS OF OLDER ADULTS—A SCOPING REVIEW

Petrovic, M., & Gaggioli, A. (2020)

2.4.1 Abstract
Aim: Informal caregivers have an important role in bridging the gap between the assistance care recipients need and what can be provided by the health care systems across Europe. The burden of the caregiving role places a significant threat to caregiver health, and the vast majority of caregiver's report stress and emotional strain, depression, and increased rates of chronic diseases. In line with this, strengthening the caregiver's mental health is one of the main goals for optimal caregiving. Caregivers already struggle with the demand of their role while coping with health problems, social, family, and work obligations. The solution for the caregiver's mental health needs to be accessible, low cost and time-effective. This scoping review investigates digital mental health tools available as a mean of supporting the mental health of caregivers.

Method: Databases searched include Summon search box, the Cochrane Library, and PubMed. Three groups of keywords were combined: relating to digital mental health interventions for caregivers, digital mental health interventions and stress in elderly care, and digital mental health interventions and burden in elderly care.

Results: Caregivers reported that digital mental health tools have an overall positive role in their health. Coping skills, emotion regulation, skill building, and education are found to be important aspects of digital mental health tools. There was a noted lack of digital mental health apps available specifically for the caregiver of older adults. Furthermore, the digital mental health tools, divided into three categories in this review, focused either on building skills or educating caregivers and assisting with the duties rather than the mental health of the caregiver itself. As repeatedly suggested in the

reviewed studies, digital mental health interventions overall contribute to reducing the caregiver burden with a limitation of addressing one aspect of caregiver needs –i.e., specific coping skills or education regarding illnesses such as Alzheimer's disease and Dementia. The lack of all-encompassing, data and theory-driven digital mental health tools for addressing and supporting the caregiver's mental health is evident.

2.4.2   Introduction

The rapid aging of the European population is one of the critical challenges the European social systems are facing today. Current predictions indicate that the number of individuals above 80 years of age will rise from 4.9% in 2016 to 13% in 2070 (Spasova et al., 2018). The predicted rise puts social and health systems in Europe to a severe test and challenges the fiscal sustainability of long-term care while shedding the light on the current demographic changes. Family pattern changes, a higher number of single households, participation of women in the labor market, increased workforce mobility and an increase in retirement age are considered as important factors adding to the anticipated rise (Spasova et al., 2018). Even though the existing health care delivery systems address some of the issues mentioned above, the care gap in the areas such as realigned reimbursement, team-based care, patient and family engagement, and information sharing still remain open (Clarke et al., 2017).

Informal care has been generally defined as unpaid care provided for an older or dependent person with whom the caregiver has a close relationship such as spouse, parent, child, relative, friend or a close neighbour (Triantafillou et al., 2010). The type of help provided by the informal caregiver varies based on the age, illness, and need of the care recipient and can include help with the household chores, running errands, providing transportation to the doctor, social and emotional support, distributing the medication, and providing physical care such as bathing and feeding (Triantafillou et al., 2010; Van Groenou & De Boer, 2016).

According to a study carried out by Piette et al. (2016), care recipients with active and involved caregivers have better self-care and health outcomes than those with less involved caregivers. Moreover, those care recipients accompanied by the caregiver to the physician are more likely to discuss challenging and difficult topics related to their health and issues they are facing (Piette et al, 2016). Informal caregivers have an important role in bridging the gap between what health care systems can provide and the type of assistance and service the care recipient requires.

The burden of caregiving role includes the vast majority of difficulties reported by the caregivers and can be generally divided into physical, psychological and financial hardship (Riffin et al., 2017). It is estimated that the informal caregivers spend on the average 24.4 hours a week providing care, and this doubles to 44.6 hours per week in cases where the care recipient is a spouse or a partner (Grossman et al., 2018). The amount of care provided mostly depends on the care recipient—caregiver relationship—e.g., spouse, parent, sibling, friend—and the living arrangements between the two. Caregiving role comes with diverse challenges, and many of those put caregivers at risk of mental health problems (Grossman et al., 2018; Callan et al., 2016; Ho et al., 2016; Kajiyama et al., 2018) and even increased risk of mortality through the development of severe chronic conditions.

Primary sources of caregiver burden include lack of support network, not using formal and informal services for the caregivers, problem behaviors of the care recipients and insufficient or overwhelmed coping skills (Brown et al., 2016). Stress, depression, and burden overall lead to burnout, which deteriorates the quality of the caregiver's life and might also result in early institutionalization of the care recipient (Wiet et al., 2005). However, the termination of caregiving does not end with the institutionalization of the care recipient into a nursing home. In fact, it has been noted that the

responsibilities often increase since the attention at that point must be given to nursing home staff at ensuring they provide appropriate care in the absence of any family member (Wiet et al., 2005). The caregiving role usually terminates when the care recipient has passed away. It has been suggested that the caregiving cycle might be repeated for the caregiver with another family member or relative (Wiet et al., 2005).

The available interventions for informal caregivers fall into three main categories: respite, psychosocial interventions, and information and communication technology (ICT) support (Lopez-Hartmann et al., 2012). Respite services provide the caregiver with a temporary break from the caregiving role and allow the caregiver time to rest and improve the well-being. The respite care, that temporarily overtakes the caregiving duties, has an overall positive impact on caregivers' burden after 2–3 months follow up (Jardim & Packenham, 2009). The psychosocial support interventions target the caregivers' ability to improve the management of caregiving situations. These interventions can be delivered either individually or as group support and are generally successful at providing caregivers with appropriate coping skills and strategies to deal with the demands of the role (Vandepitte et al., 2019). The final category of interventions is ICT-based options for informal caregivers, such as digital educational platforms, and support services for stress, anxiety, and depression (Cassie et al., 2008).

The ICT support provided for improving health, well-being, and health care are referred to as eHealth (Van Gemert-Pijnen et al., 2018). Although terms such as eHealth, eHealth technology, eHealth interventions, health informatics, and behavior change interventions are used in the field of eHealth interventions, and often interchangeably. In this paper the term eHealth is used to refer to the digital support –i.e., mobile apps, web-based platforms, virtual reality, etc.—that delivers digital interventions or relevant educational content.

eHealth can enhance access to care, the empowerment of the patients and the healthy individuals, the innovation in health care and the new perspective on well-being. In order for an eHealth intervention to be considered successful, besides the theoretical aspect, behavioral modification background, and persuasiveness, it must be available regardless of the time and space, provide empowerment to people by allowing them more control of their healthcare, be a catalyst for innovation in healthcare and maintain the quality of care (Van Gemert-Pijnen et al., 2013).

With respect to the numerous definitions and papers produced up to date, only a few colleagues (Van Gemert Pijnen et al., 2018; Van Gemert-Pijnen et al., 2013) provided a structured categorization of eHealth by offering three different categories:

> • Categorizing eHealth technologies according to the *position they maintain in the healthcare continuum*

> • Categorizing eHealth technologies according to the *characteristics of the technology*

> • Categorizing eHealth technologies according to their *influence on the health-care systems*

The eHealth categorization reveals how broad the field of eHealth is and the range of services and influences it can cover. However, for the purpose of this review the concept of eHealth is framed in terms of digital mental health tools and narrowed down only to the digital tools—i.e., any technological and digital device used to distribute mental help interventions through mobile apps, web-based platforms, virtual reality, etc.—used to provide support and help manage health of the informal caregivers.

An increasing number of systematic reviews support the potential digital mental health tools hold for improving informal caregivers' well-being (Christie et al., 2019). Generally, it is suggested that web and smartphone-based interventions for caregiver populations may offer convenient, low-cost alternatives to visiting mental health professionals in weekly sessions or group settings. Technology-based interventions can be used at any time the caregiver is available. Furthermore, digital mental health tools can be personalized to address multiple issues that caregivers face on a day to day basis.

The purpose of this review is to investigate and thematically synthesize the existing literature, in order to understand the state-of-the-art digital mental health tools for managing burden, stress, and overall adverse mental health outcomes for the informal caregivers. This scoping review is focusing on digital mental health tools available for the informal caregivers of older adults, with the important distinction of excluding caregivers of individuals with cancer. Namely, caregivers of people with cancer face challenges that can be distinguished from other caregiving roles (Northouse et al., 2012).

More specifically, they spend more time in their caregiving role, with care recipients experiencing more variability in symptoms and toxicities from different, multi-modal therapies which might lead to rapid health deterioration during a short period of time. In this sense, the caregivers of individuals with cancer are usually required to monitor the patient's health status frequently and in different ways than other caregivers and use technical and psychosocial skills to promote care recipients' health (Kent et al., 2016). Therefore, digital mental health tools for the caregiver of an individual with cancer, unlike the digital mental health tools for the caregivers in general, must be tailored to provide a combination of specific skills set, coping skills and emotional regulation techniques.

This review does not individually assess the quality of the interventions used in each reviewed study, but rather explores and categorizes digital tools available to deliver the mental health interventions for informal caregivers. Moreover, another important note is that interventions for different health problems will not be explored since the variety of health problems experienced by caregiver's ranges from physical to mental health problems and the number of interventions included would require broadening the research question and the aim of this review.

2.4.3 Materials and Methods

2.4.3.1 *Data Sources and Search Strategy*
The electronic database Summon box (2016–2019) was searched to identify the existing reviews on the topic. The databases, including PubMed (2016–2019), and the Cochrane Library (2016–2019) were searched by combining three groups of keywords in all of the searches (Figure 1). The search focused on relatively new articles published in the last 3 years that contained keywords, for instance, "technology for caregivers AND burden," or "digital mental health interventions AND caregivers" (see Figure 1). Retrieved articles were initially reviewed by the title and the abstract to find potentially relevant papers and exclude irrelevant ones. Relevant articles, that contained the keywords and clearly demonstrated in the abstract that the focus of the paper is on informal caregivers and digital tools available for them, were assessed against the inclusion criteria. Reference lists of relevant articles were reviewed to identify possible additional papers.

Figure 2. Outline of keyword searches used in the scoping review.

> Summon database (20th of May, 2016 - 25th of May, 2019)
>
> ("technology for caregivers" AND "burden" AND "caregivers", "digital mental health interventions" AND
>
> "stress")
>
> PubMed (25th of May, 2016 - 27th of May, 2019)
>
> ("mobile applications and caregivers", "technology and caregivers", "digital mental health interventions
>
> and caregivers" AND "stress")
>
> Cochrane Library (2016 - 2019)
>
> ("technology for caregivers", "digital mental health interventions", "digital tools for caregivers stress",
>
> "mobile applications for caregivers")

2.4.3.2 Study Selection

2.4.3.2.1 Eligibility Criteria

We included (a) randomized controlled trials and observational studies which (b) investigated digital mental health tools available for informal caregivers or informal caregivers-care recipients dyads but offering support for the caregivers delivered via (c) mobile app, website or platform, tablet, virtual reality and mixed approach with web-based interventions combined with telehealth (d) aiming to reduced stress, burden, and adverse mental health outcomes and improve health and well-being of the informal caregiver. The trials and studies must have included (e) an adult population (≥18 years) with a preferable population (≥50 years) since the informal caregivers are statistically population above 50 years of age. We (f) focused on published peer-reviewed articles only, in English.

Digital mental health tools were defined as interventions and educational material provided for informal caregivers via mobile app, computers, tablets, virtual reality, and a mixture of tools such as mobile app and telehealth.

2.4.3.2.2 Inclusion Criteria

Selected papers were assessed against the following inclusion criteria:

(I) studies published in academic and peer-reviewed journals, (II) studies that are either quantitative or qualitative, (III) studies that answer "yes" to three screening questions, and (IV) studies published in English.

Screening questions:

1. Does the study address the use of digital mental health tools?

2. Does the study address digital mental health interventions?

3. Does the study include a caregiver—i.e., formal or informal—or digital mental health tool applicable to the caregiver adverse mental health outcomes –i.e., stress, burden, depression, and coping skills.

2.4.3.2.3   Exclusion Criteria

The following categories of studies excluded:

- articles that did not address digital mental health tools
- articles that did not include digital mental health content and digital mental health support
- articles that included caregiver but maintained a focus on care recipient, without addressing the digital mental health tools for supporting caregiver's health
- articles that included caregiver of children or young people only
- articles including digital mental health tools for the caregiver of individuals with cancer
- duplicate articles and articles not published in English.

2.4.4   Data Extraction and Analysis

The screening of the titles and abstracts performed during the review (Figure 2) aimed to identify the studies that meet the inclusion criteria. Relevant studies were sorted and organized with the Zotero 4.0 software for further review. Full articles were reviewed to extract details about the study population, sample size, type of digital mental health tool, digital mental health intervention, and intervention outcomes (Table 1), conventional and novel findings.

Figure 3. Flow of information through the different phases of a scoping review.

Summon 2016-2019 1692 Citation(s)	PubMed 2016-2019 111 Citation(s)	Cochrane Library 2016-2019 44 Citation(s)

1843 Non-Duplicate Citations Screened

Inclusion/Exclusion Criteria Applied → 1796 Articles Excluded After Title/Abstract Screen

47 Articles Retrieved

Inclusion/Exclusion Criteria Applied → 27 Articles Excluded After Full Text Screen → 4 Articles Excluded During Data Extraction
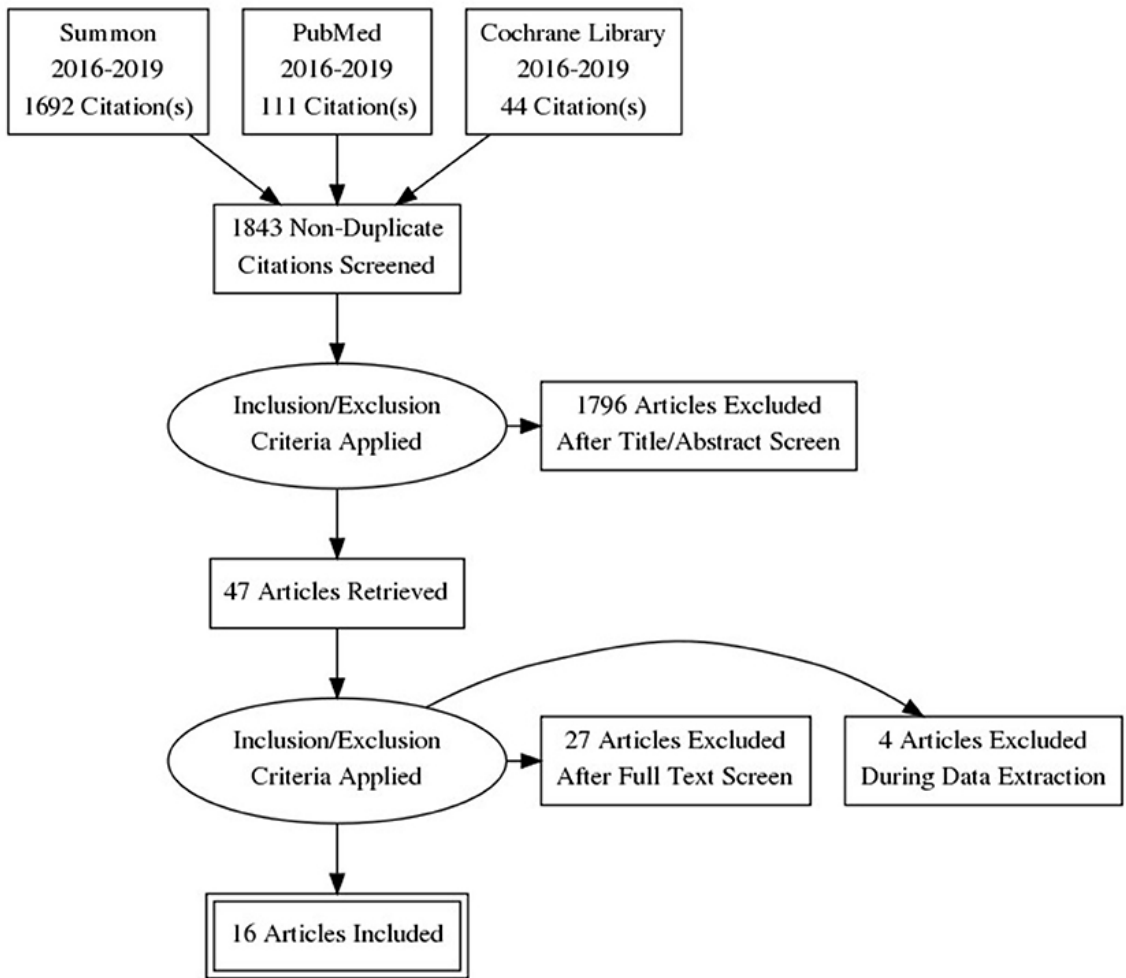
16 Articles Included

Table 1. Summary table of studies included in the present scoping review.

References	Population (sample size)	Intervention	Intervention outcomes
Brown et al. (11)	Caregivers ($n = 11$), case-managers ($n = 6$), and primary care providers ($n = 1$). Mean age caregivers: 56.5 ± 13.5	CareHeroes: Web-based and Android application for caregivers of Alzheimer's and Dementia patients. Implemented in cross-institutional settings over 11 weeks period	50% of caregivers reported feeling more confident in determining solutions in new caregiving situations. 70% of caregivers found the application or web-based platform easy to use regardless of their primary knowledge of technology
Bush et al. (22)	Service veterans ($n = 118$). Mean age: 46 ± 13.5	Virtual Hope Box VHB: smartphone application for improving stress, coping skills, suicidal ideation and perceived reasons for living among patients with elevated risk of suicide	There was an overall decrease in stress and increase in coping skills. Users reported increase in ability to cope with unpleasant emotions and thoughts after using the application for 3-week period. The improvement remained stable entire trial period of 10 weeks
Callan et al. (8)	Primary caregivers ($n = 27$). Mean age: 74 ± 6.52	Adaptive Paced Visual Serial Attention Task (APVSAT): Computer-based cognitive training for the spousal caregivers of the individuals with Dementia	There was a noted increase in performance from the beginning till the end of the 4 week trial, with improve in problem-solving, coping, planning, and persevering with goal directed tasks
Croockston et al. (23)	Users of mental and emotional health applications ($n = 150$). The minimal age for participation: 18	Mindshift, Happify and other self-help applications: Association between theoretical behavioral change mechanisms and the use of self-help applications	Applications increased the overall motivation to be mentally and emotionally healthy. There was an increase in desire to set goals, maintain confidence and control
Frisbee et al. (24)	Caregiver-Veteran dyads ($n = 882$)	Care, RX Refill, Journal, Care4Caregivers, VA Pain Coach, VA PTSD Coach: Applications developed specifically for the study and available only for family caregivers of veterans who suffered severe physical and mental health injuries	Caregivers that experienced most burden, low preparedness, and high strain showed high usage of applications. The applications were used the most when the caregivers needed the assistance with the caregiving tasks
Grossman et al. (7)	200,000 mobile applications reviewed	iTunes, AppStore, and Google Play were searched. 44 applications were shortlisted to provide interventions for caregivers of older adults	36 applications generally addressed one of two categories: information and resources or, caregiver-care recipient interaction, while 8 applications addressed additional categories and provided stress reduction exercises
Ho et al. (9)	Informal caregivers ($n = 20$). Age range: 39–77	Mindfulness-based stress reduction MBSR: Aiming to improve psychological resilience of informal caregivers with a 8 weeks training course with the assessment of the blood gene expression profiles	Significant improvement in psychological resilience of some caregivers was reported. Predictive biomarkers were identified whose expression was associated with the greater benefit from MBSR training
Kajiyama et al. (10)	Latino/Hispanic caregivers ($n = 25$). Mean age: 63	Webnovela Mirela: Culturally adapted Spanish language series designed to educate and train caregivers to cope with care recipients with Dementia. The format was designed to be available without internet access with educational content adopted from "Active Caregiving Empowerment Skills"	There was a significant decrease in the levels of stress and symptoms of depression ($p = 0.045$)
Núñez-Naveira et al. (25)	Informal caregivers ($n = 77$), from Spain, Poland and Denmark	UnderstandAid: effectiveness of application for caregivers of people with Dementia	50% of participants evaluated positively technological and pedagogical specifications. There was a significant decrease of depressive symptoms

References	Participants (sample size)	Intervention	Intervention outcomes
Phongtankuel et al. (26)	Informal caregivers ($n = 80$). Mean age: 57 ± 12	mHealth: exploring the use of mHealth applications, caregivers receptivity and concerns	Informal caregivers reported the needs for: communication, caregiving information, education, updates from professional personnel, and scheduling services, as an important features for mHealth application
Piette et al. (5)	Heart-failure patients-Caregivers dyads ($n = 396$)	CarePartner: Systematic monitoring and interactive voice response calls about care recipients' health condition	Caregivers living away from care recipient who received CarePartner in combination with some mHealth reported lower caregiving strain even 12 months after the trial and significant improvement in depressive symptoms
Poonamallee et al. (27)	University students ($n = 26$)	DarmaLife program: smartphone application aiming to improve emotional intelligence by targeting maladaptive personality traits	DarmaLife had significant positive effect on emotional and social competency
Tam et al. (28)	Caregivers ($n = 43$). Mean age: 64 ± 16.41	Aging Service Technology AST: video educational program aiming to increase knowledge of caregivers about aging services	Younger caregivers (<65 years old) were more open to accepting the AST. Caregivers of the individuals who had fewer domains of functional limitation reported a positive change post-AST program
Tremont et al. (29)	Dementia care recipients and caregivers dyads ($n = 250$)	Telephone delivered interventions for caregivers—Family Intervention Telephone Tracking Caregiver FITT-C	The intervention FITT-C resulted in caregivers using community support services more and health resources less than caregivers in telephone delivered intervention with less Emergency department visits
Wijma et al. (30)	Informal caregivers ($n = 42$). Mean age: 55 ± 11.2	Virtual Reality intervention—Through D'mentia Lens TDL: aiming to improve empathy in informal caregivers	TDL significantly improved empathy, confidence in caring and positive interactions between caregiver and care recipient
Zheng et al. (31)	Study1: Veterans Affairs MC VAMC ($n = 155$). Mean age: 67.78 ± 11.92. Study2: VAMC ($n = 72$). Mean age: 75.42 ± 9.49	Study1: Differences between computer-based and apps intervention usage. Study2: Differences between Telehealth devices and apps intervention usage	Group using computer-based interventions showed improvement in caregiving stress while Telehealth group did not

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The reviewed studies were categorized according to the digital mental health tool used to deliver mental health intervention and support. Three categories included:

- Mobile apps

- Web-based

- Other digital tools

The mobile apps category included all the relevant studies that addressed digital mental health support delivered via mobile app for caregivers or apps addressing general adverse mental health symptoms relevant to caregivers. The web-based category gathered all the studies that included digital mental health support delivered to the caregiver in the form of web-based intervention, web-platform, with or without internet connection needed and web-based video programs or training. The final category of other digital mental health tools contains a study that reviewed virtual reality (VR) training for caregivers and telehealth content for caregiver-care recipient dyads combined with the data tracking by the master's level mental health practitioner.

The study result sections within each category were coded and thematically synthesized in order to gain a better perspective about the aim and purpose of each category and the method or intervention used to address the caregiver's adverse mental health symptoms. The categories were then compared and critically evaluated.

2.4.5 Results

A total of 1,843 relevant non-duplicate records were identified. After applying exclusion criteria, 47 articles were retrieved eligible for full-text screening. Of those, 20 articles met the inclusion criteria, however, four were excluded during the data extraction due to the insufficient description of the study participants resulting in the unclear understanding if the study focused on the caregiver or digital mental health tool that can be used by the caregiver, vague description of procedure or limited report of the results. Out of 16 final articles with four RCT, two were mixed methods, two were qualitative, and thirteen were quantitative studies. Summary of the results, including the authors, population, digital mental health tool or intervention, and the relevant intervention outcomes are provided in Table 1. The reviewed studies providing a comprehensive insight into the digital mental health tools available for the informal caregivers were distinguished by three categories.

The categories included: mobile apps, web-based, and others, and were determined by the device used to support the digital mental health content for the caregivers.

2.4.5.1 Mobile Apps Category

The mobile apps category includes eight reviewed studies with the main focus on mobile-based mental health tools—i.e., mobile apps (Grossman et al., 2018; Brown et al., 2016; Bush et al., 2016; Crookstone et al., 2017; Frisbee, 2016; Núñez-Naveira et al., 2016; Phongtankuel et., 2018; Poonamallee et al., 2018). The thematic analysis of the result sections within the mobile category indicated reappearing topics—e.g., cope, stress, depression, self-regulation, behavior change, self-control—that were further grouped into themes of "coping skills" and "emotional self-regulation." This review suggests that the overall aim of the mobile apps category is centered on building coping and emotional regulation skills of a caregiver as means for dealing with the caregiving burden, stress and adverse emotions in general. The pre-post measurements available in three studies (Bush et al., 2015; Núñez-Naveira et al., 2016, Poonamallee et al., 2018) indicated that the mobile apps helped decreased stress and increased coping skills after only 3 weeks, moreover, there was a reported significant positive impact on decreasing depressive symptoms of the caregivers and significant

positive effect on emotional and social competency. The mobile apps category includes studies reflecting on apps that are designed for the caregivers specifically (e.g., iCare, RX Refill, Journal, Care4Caregivers, UnderstandAid, CareHeroes) and three mobile apps for dealing with adverse mental health symptoms in general, building emotional self-regulation, and the review of self-help apps -VA Pain Coach, VA PTSD Coach, DarmaLife Program, Mindify, Happify (Bush et al., 2016; Croockston 2017; Poonamallee et al., 2018).

2.4.5.2 Web-Based Category

In the web-based category, six studies focused on web-based mental health tools (Calln et al., 2016; Ho et al., 2016; Kajiyama et al., 2018; Brown et al., 2016, Tam et al., 2019, Zheng et al., 2016). The thematic analysis of the result section of the studies indicated recurring topics—e.g., education, information, exercising skills, resilience, training, coping, and distress—merged into more general themes of "education" and "skill building." The thematic synthesis indicated that the reviewed web-based digital mental health tools for caregivers aim to address caregiving burden and adverse mental health outcomes by educating caregivers about specific disorders and training proper skills for specific disorders necessary for the caregiving role. The web-based digital mental health tools were delivered in the form of video-educational programs, webnovela—i.e., intervention delivered through structured episodes in a form of small series similar to sitcoms—providing mindfulness-based stress reduction training via a web-based platform, and attention tasks via websites. One web-based mental health tool, CareHeroes, was an adapted web version of a previously reviewed tool in the mobile app category.

2.4.5.3 Category of "Other" Digital Tools

The third category of "other" includes the final three studies exploring digital mental health tools that could not be classified as mobile apps or web-based mental health tools (Piette et al., 2016; Tremont et al., 2017; Wijma et al., 2018). The mental health tools in question are virtual reality intervention, telephone-delivered intervention for caregiver-care recipient dyads, and combined digital mental health intervention with "CarePartner" systematic monitoring with interactive voice response call for caregivers living outside of the care recipient home.

2.4.6   Discussion

This review aimed to explore the current state of the art digital mental health tools for informal caregivers used as an intervention, support, means of education, and training, that could provide set of skills necessary for an individual to maintain health and well-being while fulfilling the role of a caregiver. The review seeks to understand means by which current digital mental health content available for the informal caregivers is delivered (e.g., via mobile phone, web page, tablet, virtual reality) and purpose these mental health tools are used for (e.g., intervention, training, education, support). The further exploration of the intervention was not performed since the scope of this paper is to review the tools used for distributing the mental health content related to the caregivers.

The thematic synthesis of the data indicated that the digital mental health tools currently available for caregivers could be broadly categorized as mobile apps, web-based, and other digital mental health tools—i.e., digital mental health tools that do not fit the first two categories. It is suggested that each category serves a different purpose.

> • Mobile apps generally address adverse mental health by building skills, such as coping skills and emotional self-regulation, necessary for the caregivers to maintain well-being.

- The web-based mental health tools serve an overall purpose of educating and informing caregivers about the caregiving role and providing skill exercise and training for the caregivers.

- The third category of "other" digital mental health tools includes virtual reality intervention for the caregiver of individuals with Dementia, telephone-delivered intervention combined with digital mental health tool and mental health intervention with systematic monitoring and voice response designed for caregivers living away from the care recipients. This category includes digital mental health tools that address caregiver understanding of the care recipient and caregiver-care recipient communication, and although these digital mental health tools can be useful in improving caregiver's mental health by strengthening the caregiving role, they do not specifically address adverse mental health symptoms.

It can be suggested that the vast majority of mobile apps reviewed provide skill building for caregivers, while the web-based digital mental health tools provide skill training or skills exercising, and education, pointing out that one does not exclude the other, suggesting that they can be used jointly. Therefore, combining the digital tools can lead to creating a useful mixed tool for addressing the caregiver's mental health, burden, and stress at the more general level regardless of the limitations or illness of the care recipient. On the other hand, it can be argued that combining digital mental health tools can be rather overwhelming and burdening for the caregivers in terms of the information exposure and the time amount it would require from the caregiver.

The quality of the therapeutic basis of the mental health interventions provided through mobile apps reviewed in this paper has not been assessed. In fact, brief literature searches for papers assessing the therapeutic quality of the interventions provided through mobile apps has been rather scarce and often requires narrowing the search to a specific mental health issue. Some studies pointed out high-quality scores for mobile app interventions based on engagement, functionality, and aesthetics, as well as the potential to increase access to mental health services (LeBeau et al., 2019; Torous et al., 2018). However, other studies simply provided guidelines and versions of protocols for assessing the quality of mobile app interventions for health care providers (Boudreaux et al., 2014), without clear understanding about the protocols that need to be followed when creating mobile health apps in the first place (Stoyanov et al., 2015).

The summary of the relevant studies in this review suggests general positive outcomes for caregivers after using the digital mental health tool with a reported increase in coping skills or emotional regulation (Callan et al., 2016; Kajiyama et al., 2018, Bush et al., 2016, Poonamallee et al., 2018, Zheng et al., 2016), a decrease in stress, and burden (Grossman et al., 2018; Bush et al., 2016; Zheng et al., 2016) as well as perceived improvements in motivation to care (Crookston et al, 2017). There were no adverse effects of digital mental health tools reported, even in the population that had low familiarity with technology, which might be further argued as a limitation. In line with this, the positive outcomes have been reported cross-sectionally in most studies with no longitudinal data available, pointing out that the positive outcomes might be only temporary.

Digital mental health tools were reported as useful for the caregivers that experienced higher burden and stress and were generally in more distress due to caregiving tasks (Frisbee, 2014). It has been shown that culturally-adapted digital tools are the right approach for educating caregivers, improving coping skills and motivation to care (Kajiyama et al., 2018).

There was an evident lack of digital mental health tools aiming to support the mental health of the caregivers of older care recipients with overall 44 apps promoted on the market as such, while only

eight of these addressed additional categories besides information and resources, communication and caregiver-recipient interaction (Grossman et al., 2018). Furthermore, the majority of digital mental health tools are strongly focused on improving the caregiving role itself, which benefits care-recipients the most.

The digital tools available center on specific limitations or illnesses such as Dementia or Parkinson's disease, without offering the all-encompassing digital mental health tool for caregivers. Namely, a caregiver of an elderly individual without specific limitations or health issues might not benefit from a digital mental health tool designed for the caregiver of the individual with Alzheimer's disease and vice-versa. Most of the digital mental health tools cannot be applied in all-case scenarios. This leaves the caregiver of older people, with physical limitations but not specific mental health difficulty, outside of the research focus.

After using some of the digital mental health tools reviewed in this study, caregivers reported openness and interest in this type of technology (Frisbee, 2014), pointing out the potential interest by the caregivers to expand the knowledge and use the technology. The evident lack of digital interventions for caregivers goes in line with the lack of research data and literature exploring the specific issue. Current literature on caregiving is aiming to improve care recipients' well-being and explore the steps that can be taken by caregivers in order to further improve the quality of life and quality of care for the care recipients. Caregivers, on the other hand, seem to be the disregarded majority.

The reviewed studies reported that the caregivers, when asked to, were able to provide suggestions and describe the digital mental health technology they need in order to improve their well-being. This indicates that there is a clear lack of practical approach in creating digital mental health tools, content, and interventions, by simply involving caregivers in the creation of technology intended for them. In line with this, the development of digital mental health tools such as digital mental health intervention or generally positive technology for dealing with caregiver burden, besides scientific theoretical background, may also include caregiver suggestions and preferences since they have the most experience with caregiving and the mental health needs they develop over a course of role.

The main literature gap in this area of research is mostly centered around the lack of conclusive evidence and clear explanations regarding the effectiveness and therapeutic design in existing digital mental health tools addressing adverse mental health issues caregivers face throughout their role. Out of 16 reviewed papers, only a small portion provided clear therapeutic rationale behind the interventions used. Furthermore, there is an evident gap in the population samples when it comes to the caregivers of older adults. Although informal caregivers of elderly individuals are a rather vast group, faced with similar difficulties of the caregiving role, it can be quite difficult to address numerous negative mental health issues with just one digital mental health tool. As noted during this review as well, studies generally focus on specific limitations or illness of the care recipient rarely including or directly addressing the caregiver. The noted lack of digital mental health interventions available for the caregivers of elderly individuals can also be one of the possible explanations for the literature gap in population samples earlier mentioned.

Even though numerous digital mental health interventions are available on the market, only a small portion can address adverse mental health effects of the caregiving role specifically. There is a grave need for the digital mental health tool designed for caregivers of elderly people that can cover a variety of needs caregivers experience in different stages of their role. In other words, a digital mental health tool for caregivers should provide caregivers with the deeper meaning-making and understanding of the caregiving role regardless if they joined the role voluntarily or were forced to

due to the lack of alternative caregiver. A better understanding of the role effect on the caregiver's life and life adjustments that took place to accommodate the caregiving role must be taken into consideration. The effects of the role should be considered as an important factor that can provide insight and possibly be the predictor of the symptomatology hence could be utilized for the development of the preventive digital mental health tools and content.

The majority of mobile apps, web-based interventions, and other categories of digital mental health tools reviewed, for addressing caregiver stress, are based on the grounds of Cognitive Behavioral Therapy (CBT) or Stress Inoculation Training (SIT). In other words, the delivered digital interventions had a therapeutic background focused on readjusting cognitive patterns related to the adverse mental health effects of the caregiving role. In this way, the interventions were used to shift the emotional well-being of the caregivers or build up stress resilience by preparing the caregivers for adverse mental health effects of the caregiving role through skills training and educational material. The therapeutic background of several reviewed studies was not clearly defined, and it reflects the general literature gap in the therapeutic rationale for digital mental health tools available for the caregivers.

It can be suggested that current digital mental health tools available for caregivers have been somewhat successful at targeting adverse mental health outcomes arising from the caregiving role with noted lack of structure, approach and therapeutic background of interventions. The necessity for a structured digital mental health tool for caregivers with clear theory, protocols, and frameworks is evident in cases where the caregiver is providing care for the recipient that has no specific mental or physical disability.

This scoping review is conducted in order to explore digital mental health tools available for informal caregivers. It is meant to add up to the efforts of other colleagues in filling up the literature gap in informal caregiving and digital mental health research. The results indicated several important points that can be used in further reviews, as well as important points that can guide future digital mental health tools development. These points include important aspects that were successfully included in the digital mental health tools reviewed: coping skills, emotional self-regulation, education, skill-building, and skill training.

In other words, caregivers benefited and showed improved well-being, lowered levels of stress and burden and increased emotional regulation after they were educated about the caregiving role, and they were given certain skills to manage their mental health and well-being while providing care. Teaching caregivers coping skills and emotional self-regulation is an important aspect of the reviewed digital mental health tools and can be argued as an important factor in the overall positive results achieved in the studies reviewed. Another important aspect of digital mental health tools noted in numerous studies reviewed is that they provided a space for caregivers to train or exercise the skills they have acquired, therefore obtaining good mastery over the skills taught. It can be suggested that this allowed caregivers to maintain certain resilience toward stressful events and overall role burden.

2.4.7 Limitations

The lack of clear guidance about the efficacy of the mental health interventions delivered via digital tools explored in this review is considered the main limitation of this review. Namely, the majority of reviewed studies emphasized the effectiveness and success of the digital tool without reflecting on the therapeutic background or rationale for using a specific therapeutic approach for certain mental health issues. Although this review explored the usability of digital mental health tools among caregivers of older adults and the types of digital mental health tools currently available, it cannot provide any definitive conclusion about the efficacy of the interventions distributed through digital

mental health tools as well as the caregivers' preferences when it comes to the type of digital mental health tools available. It could be the case that the interventions that had higher therapeutic potential were delivered in a way that was less convenient for the caregiver or the digital mental health tool used was not the best option for delivering the specific intervention.

Although several studies reported the success of digital mental health tools used, there was no clear checklist followed, and only one study provided follow-up results. Moreover, the comparison between the digital mental health tools available has not been made in any papers, therefore it cannot definitively be concluded that one digital mental health tool or a specific type of technology is more successful than the other. For instance, the educational intervention in a form of Webnovela "Mirella" for Hispanic caregivers was rather successful at providing a set of skills that caregivers reported as useful in their caregiving role. However, there is no clear indication if this intervention could be equally, more, or less successful when delivered via different digital tools such as mobile phones, tablets, web, or even as a VR experience. Finally, the number of papers exploring the digital mental health tools for caregivers is still quite limited which prevents a clear insight into the topic.

Despite its limitations, this review noted numerous positive aspects and suggests that digital mental health tools can be an inexpensive, easily accessible, and time-saving option for addressing the caregiver burden and mental health. There is a need for further improvements and development of commercialized digital mental health tools that will be science-based but caregiver tailored. Moreover, it can be suggested that further development should include pilot testing over different platforms and by using different tools in order to establish the optimal digital tool for each mental health intervention or caregiver-tailored content.

Moreover, according to the results obtained in this review, digital mental health tools for caregivers that provide coping skills, emotional self-regulation skills, education about caregiving, skill-building and skill training in a well-structured approach are the most successful in managing caregiver stress and burden.

Finally, digital mental health tools, including web-based, mobile apps, or virtual reality solutions, have the potential to reshape health care due to its ability to be structured in a therapeutic way, providing interventions for a wide variety of caregivers regardless of their age and personality characteristics, through video, audio, text and interactive content. Due to its affordability, accessibility, adaptability, and ability to deliver structured and therapeutically based interventions, digital mental health tools can be considered as potential next step support for informal caregivers.

REFERENCES

Armoogum, J., Richardson, A., & Armes, J. (2013). A survey of the supportive care needs of informal caregivers of adult bone marrow transplant patients. Supportive Care in Cancer, 21(4), 977-986.

Brown, E. L., Ruggiano, N., Page, T. F., Roberts, L., Hristidis, V., Whiteman, K. L., & Castro, J. (2016). CareHeroes web and Android™ apps for dementia caregivers: a feasibility study. Research in Gerontological Nursing, 9(4), 193-203.

Boudreaux, E. D., Waring, M. E., Hayes, R. B., Sadasivam, R. S., Mullen, S., & Pagoto, S. (2014). Evaluating and selecting mobile health apps: strategies for healthcare providers and healthcare organizations. Translational behavioral medicine, 4(4), 363-371.

Burgdorf, J. G., Stuart, E. A., Arbaje, A. I., & Wolff, J. L. (2021). Family caregiver training needs and medicare home health visit utilization. Medical care, 59(4), 341-347.

Bush, N. E., Smolenski, D. J., Denneson, L. M., Williams, H. B., Thomas, E. K., & Dobscha, S. K. (2017). A virtual hope box: randomized controlled trial of a smartphone app for emotional regulation and coping with distress. Psychiatric Services, 68(4), 330-336.

Callan, J. A., Siegle, G. J., Abebe, K., Black, B., Martire, L., Schulz, R., ... & Hall, M. H. (2016). Feasibility of a pocket-PC based cognitive control intervention in dementia spousal caregivers. Aging & mental health, 20(6), 575-582.

Cassie, K. M., & Sanders, S. (2008). Chapter 12; familial caregivers of older adults. Journal of Gerontological Social Work, 50(S1), 293-320.

Christie, H., Martin, J., Connor, J., Hermans, I., Tange, H. J., & Verhey, F. R. (2019). Which eHealth interventions for caregivers of people with dementia are used in practice. Examining development trajectories and business models Alzheimer's and Dementia. J Alzheimer's Assoc, 15, P511.

Clarke, J. L., Bourn, S., Skoufalos, A., Beck, E. H., & Castillo, D. J. (2017). An innovative approach to health care delivery for patients with chronic conditions. Population health management, 20(1), 23-30.

Cohen, S. E., & Syme, S. I. (1985). Social support and health. Academic Press.

Collins, R. N., & Kishita, N. (2020). Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis. Ageing & Society, 40(11), 2355-2392.

Crookston, B. T., West, J. H., Hall, P. C., Dahle, K. M., Heaton, T. L., Beck, R. N., & Muralidharan, C. (2017). Mental and emotional self-help technology apps: cross-sectional study of theory, technology, and mental health behaviors. JMIR Mental Health, 4(4), e7262.

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & Ramos-

Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. PloS one, 13(1), e0189874.

Frisbee, K. L. (2016). Variations in the use of mHealth tools: the VA mobile health study. JMIR mHealth and uHealth, 4(3), e3726.

Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L. W. (1989). Prevalence of depression in family caregivers. The gerontologist, 29(4), 449-456.

Galvin, M., Carney, S., Corr, B., Mays, I., Pender, N., & Hardiman, O. (2018). Needs of informal caregivers across the caregiving course in amyotrophic lateral sclerosis: a qualitative analysis. BMJ open, 8(1), e018721.

Grossman, M. R., Zak, D. K., & Zelinski, E. M. (2018). Mobile apps for caregivers of older adults: quantitative content analysis. JMIR mHealth and uHealth, 6(7), e9345.

Hand, L. C., Thomas, T. H., Belcher, S., Campbell, G., Lee, Y. J., Roberge, M., ... & Donovan, H. S. (2018). Caregiving is a marathon, not a road race: reenvisioning caregiver support services in gynecologic oncology. International Journal of Gynecologic Cancer, 28(9).

Hansen, T., & Slagsvold, B. (2015). Feeling the squeeze? The effects of combining work and informal caregiving on psychological well-being. European Journal of Ageing, 12(1), 51-60.

Ho, L., Bloom, P. A., Vega, J. G., Yemul, S., Zhao, W., Ward, L., ... & Pasinetti, G. M. (2016). Biomarkers of resilience in stress reduction for caregivers of Alzheimer's patients. Neuromolecular medicine, 18(2), 177-189.

Jardim, C., & Pakenham, K. I. (2009). Pilot investigation of the effectiveness of respite care for carers of an adult with mental illness. Clinical Psychologist, 13(3), 87-93.

Kajiyama, B., Fernandez, G., Carter, E. A., Humber, M. B., & Thompson, L. W. (2018). Helping Hispanic dementia caregivers cope with stress using technology-based resources. Clinical gerontologist, 41(3), 209-216.

Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y. S., Shelburne, N., ... & Huss, K. (2016). Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. Cancer, 122(13), 1987-1995.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of gerontology, 44(3), P61-P71.

LeBeau, K., Huey, L. G., & Hart, M. (2019). Assessing the quality of mobile apps used by occupational therapists: evaluation using the user version of the mobile application rating scale. JMIR mHealth and uHealth, 7(5), e13019.

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on

informal care: a systematic review of family caregivers' perceptions. BMJ Supportive & Palliative Care.

Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. International journal of integrated care, 12.

Mason, A., Weatherly, H., Spilsbury, K., Golder, S., Arksey, H., Adamson, J., & Drummond, M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. Journal of the American Geriatrics Society, 55(2), 290-299.

Northouse, L. L. K at apodi, MC, Schafenacker, AM, & Weiss, D.(2012). In The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *in Seminars in Oncology Nursing* (Vol. 28, pp. 236-245).

Núñez-Naveira, L., Alonso-Búa, B., de Labra, C., Gregersen, R., Maibom, K., Mojs, E., ... & Millán-Calenti, J. C. (2016). UnderstAID, an ICT platform to help informal caregivers of people with dementia: a pilot randomized controlled study. BioMed research international, 2016.

O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2016). Suicidal ideation in family carers of people with dementia. Aging & mental health, 20(2), 222-230.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The gerontologist, 30(5), 583-594.

Phongtankuel, V., Shalev, A., Adelman, R. D., Dewald, R., Dignam, R., Baughn, R., ... & Reid, M. C. (2018). Mobile health technology is here—but are hospice informal caregivers receptive?. American Journal of Hospice and Palliative Medicine®, 35(12), 1547-1552.

Piette, J. D., Striplin, D., Marinec, N., Chen, J., & Aikens, J. E. (2015). A randomized trial of mobile health support for heart failure patients and their informal caregivers: impacts on caregiver-reported outcomes. Medical care, 53(8), 692-699.

Poonamallee, L., Harrington, A. M., Nagpal, M., & Musial, A. (2018). Improving emotional intelligence through personality development: The effect of the smart phone application based Dharma Life Program on emotional intelligence. Frontiers in psychology, 9, 169.

Riffin, C., Van Ness, P. H., Wolff, J. L., & Fried, T. (2017). Family and other unpaid caregivers and older adults with and without dementia and disability. Journal of the American Geriatrics Society, 65(8), 1821-1828.

Sallim, A. B., Sayampanathan, A. A., Cuttilan, A., & Ho, R. C. M. (2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. Journal of the American Medical Directors Association, 16(12), 1034-1041.

Shaw, C., McNamara, R., Abrams, K., Cannings-John, R. L., Hood, K., Longo, M., ... & Williams,

K. (2009). Systematic review of respite care in the frail elderly. Health Technology Assessment, 13(20), 1-246.

Spasova, S., Baeten, R., & Vanhercke, B. (2018). Challenges in long-term care in Europe. Eurohealth, 24(4), 7-12.

Stoyanov, S. R., Hides, L., Kavanagh, D. J., Zelenko, O., Tjondronegoro, D., & Mani, M. (2015). Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR mHealth and uHealth, 3(1), e3422.

Tam, J. W., & Schmitter-Edgecombe, M. (2019). A caregiver educational program: A video program to promote aging services technologies awareness. Geriatric Nursing, 40(1), 78-83.

Thomas, E. W. S., Dalton, J. E., Harden, M., Eastwood, A. J., & Parker, G. M. (2017). Updated meta-review of evidence on support for carers. Health Services and Delivery Research.

Torous, J., Nicholas, J., Larsen, M. E., Firth, J., & Christensen, H. (2018). Clinical review of user engagement with mental health smartphone apps: evidence, theory and improvements. Evidence-based mental health, 21(3), 116-119.

Tremont, G., Davis, J. D., Ott, B. R., Galioto, R., Crook, C., Papandonatos, G. D., ... & Bishop, D. S. (2017). Randomized trial of the family intervention: telephone tracking—caregiver for dementia caregivers: use of community and healthcare resources. Journal of the American Geriatrics Society, 65(5), 924-930.

Triantafillou, J., Naiditch, M., Repkova, K., Stiehr, K., Carretero, S., Emilsson, T., ... & Vlantoni, D. (2010). Informal care in the long-term care system European overview paper.

van Gemert-Pijnen, L. J., Kip, H., Kelders, S. M., & Sanderman, R. (2018). Introducing ehealth. In eHealth research, theory and development (pp. 3-26). Routledge.

Van Gemert-Pijnen, J. E. W. C. (2013). Improving ehealth. O. Peters, & H. C. Ossebaard (Eds.). The Hague: Eleven international publishing.

Van Groenou, M. I., & van Tilburg, T. G. (2016). VU Research Portal.

Van Houtven, C. H., Voils, C. I., & Weinberger, M. (2011). An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. BMC geriatrics, 11(1), 1-18.

Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., & Annemans, L. (2019). Effectiveness of an in-home respite care program to support informal dementia caregivers: A comparative study. International Journal of Geriatric Psychiatry, 34(10), 1534-1544.

Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J. Y. (2018). Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. BMC palliative care, 17(1), 1-29.

Wiet, S. G. (2005). Future of caring for an aging population: trends, technology, and caregiving.

Studies in Health Technology and Informatics, 118(3), 220-230.

Wijma, E. M., Veerbeek, M. A., Prins, M., Pot, A. M., & Willemse, B. M. (2018). A virtual reality intervention to improve the understanding and empathy for people with dementia in informal caregivers: results of a pilot study. Aging & mental health, 22(9), 1121-1129.

Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 54(1), P12-P22.

Zheng, R., Hicken, B. L., Hill, R. D., Luptak, M., Daniel, C. M., Grant, M., & Rupper, R. (2016). Digital technology and caregiver training for older persons: Cognitive and affective perspectives. Educational Gerontology, 42(8), 540-550.

CHAPTER II

3 STORYTELLING BASIS FOR DIGITAL MENTAL HEALTH SUPPORT IN INFORMAL CARE

SUMMARY OF THE CHAPTER

This chapter expands on the storytelling discussion presented in general introduction by exploring deeper mechanisms of storytelling and elaborating on the value of utilizing such mechanisms for mental health support. The chapter introduces the importance of storytelling for support and then divides the discussion of storytelling mechanisms to two distinct but interrelated categories "function of the viewer/listener" and "function of the story". This distinction supports better understanding of the storytelling aspects relevant to story structure itself as well as aspects dependent on the individuals and their personal role in story engagement. Following the introduction on the relevance of storytelling and underlying mechanisms, a Study 2 is added. This chapter however is also crucial in understanding the grounds for developing Transformative Storytelling Technique introduced in Chapter III and the importance of generally expanding the field of narrative psychology in guided structurization for digital mental health stories.

Study 2 proposes new approach for delivering interactive storytelling for informal caregivers as a potential solution to addressing distinct informal caregiver needs beyond the common mental health support needs discussed in the literature. The study reflects on the potential of merging the relevant concepts such as meaning-making, narrative identity, and storytelling into a digital storytelling tool for informal caregivers that has a theoretical potential to serve as a wellbeing and mental health support throughout the role. Study 2 aims to introduce a comprehensive design that will allow for the proposed approach to serve narrative identity support purposes through one concrete design.

Study 2 is a part of Phase 2 which focused on the development of the potential solution based on the existing literature and the findings retrieved from the scoped studies. The added value of Phase 2 is also in the demonstration of the development in digital health context prior to involving the end-users. It is particularly interesting to compare the developmental progress following the Study 3 after the end-user have been involved to provide personal narratives that have been qualitatively evaluated to structure user-needs applying the Transformative Storytelling Technique.

3.1 STORYTELLING MECHANISMS

Stories are immediate and intuitive ways to convey information to an audience. Important value of storytelling is in its ability to enable, facilitate, and accommodate meaning making experience and promote social cohesion. In fact, this adaptive value of storytelling is most evident in unexpected or traumatic circumstances such as natural disasters, where storytelling enables social connection and support (Bietti et al., 2018; Claidiere & Sperber, 2010). It is in these particular cases that groups utilize storytelling to either protect or readjust the existing worldviews to successfully create meaning out of traumatic events. In therapeutic practice, storytelling has multidimensional purpose (Land, 2007) including:

1. Redirecting the attention of the client to include positive aspects or simply quiet the chaotic mind to demonstrate alternative point of view
3. To support reflective mood, allowing the client to rethink and hence train reflection as a coping strategy
4. To serve as a mirror, helping clients recognize themselves in the protagonist
5. To support new and productive ideas and motivation
6. To redefine current perspectives by hearing or sharing story through different perspectives
7. To decrease resistance through the use of metaphors or real and fictional biographies (i.e., "him/her too experienced this but acted like that")
8. To potentially imply rather than instruct solutions.

The audiences' subjective experience of the story, however, has long been considered an outcome or an effect of the story (Grall et al., 2021). Storytelling mechanisms can be divided and explored with two interrelated categories: the function of the listener/viewer and the function of the story.

3.1.1 The function of a listener/viewer

Within the function of a listener/viewer we address the human-related aspects which theoretically support the effectiveness of storytelling. Following Bruner's work (Bruner, 2003) it can be suggested that individuals make sense of the experiences and events by imposing a narrative framework across the information given through the story. This process of narrative thinking to form an understanding of events and information is considered universal and a natural human inclination noted even at the early age when toddlers make sense of their new experiences (Nelson, 2006; Costabile, 2016).

Another related notion is the inner or scripted knowledge of the self that appears as an outcome of the sense-making of outside events that are either perceived through nuclear episodes (McAdams, 1988), memorable events (Pillemer, 1998), self-defining memories (Singer, 1995), or autobiographical memory narratives (Habermas and Bluck, 2000). Interestingly these are nicely synthesized by Singer (2004) with "narrative processing", described as: "storied accounts of past events that range from brief anecdotes to fully developed autobiographies" (Singer, 2004, p. 442).

The aforementioned could also be understood through McAdams's proposal (McAdams, 1987) that "identity is a life story", which consists of lived past, perceived present and imagined future (McAdams, 2011). In other words, lived experiences are turned into inner stories that shape individuals and help them develop meaning and a sense of self. Narrative identity is an all-encompassing term that places the individual meaningfully in a culture, provides cohesion between past, present, and anticipated future, and supports the merging of ongoing narratives into the story of self (McAdams, 2011). Therefore, the ability to establish a linear chronological story sequence of events and experiences builds one's identity (Habermas and Bluck, 2000).

On the other hand, fragmented self-stories or misapplied coherence (e.g., If I were taller, they would like me better) can lead to a series of psychological disorders such as trauma or addiction (Singer, 1996; Habermas and Bluck, 2000). In fact, failure to take a step back and constructively assign meaning to experiences will ultimately result in obsessive thoughts or behaviors (Singer and Conway, 2011).

Furthermore, the attribution theory has an important role in storytelling research. The value of causal attribution in storytelling can be argued at the level of identification and engagement with the story. The process of causal attribution is well summarized in three consecutive steps:

(1) An individual recognizes the behavior observed

(2) Makes dispositional attribution to the behavior

(3) Observes the distinct or unique characteristics of the behavior and adjusts his/her attribution more closely to the actuality of circumstances – i.e., observes the story more openly rather than creating attribution based on internal pre-set knowledge and experience (Walter et al., 2018).

However, bearing in mind that the third step (see above step 3) demands significant cognitive resources to be used, following through requires a certain type of motivation which is in essence closely related to the second category that we named the function of the story (see Petrovic et al., 2022). Concretely, in a meta-analysis (Burger, 1981) on causal attribution for accidents, the observers tended to attribute less responsibility to the perpetrator when they were situationally or personally similar to him/her. This implies that the similarity motivated the observer to engage more complex cognitive processes mentioned in the step three of the causal attribution, to further understand and even justify the perpetrator.

In this manner, the identification is closely supported by the story engagement, which is the function of the story rather than individual function. In fact, it is the structure of a story that determines the engagement of the audience, and it is the identification with the protagonist that maintains it.

3.1.2   The function of the story

Narrative engagement is best explained as story involvement, while identification is more closely related to the involvement with a specific character and is also influenced by the existing empathy of the individual (Cohen, 2001; Walter et al., 2018). Narrative engagement has been recognized as the main mediator between exposure and acceptance of story-consistent beliefs (Bilandzic and Busselle, 2008) suggesting that highly engaging narratives need to lead the audience into considering external factors of the portrayed events to surpass the causal attribution (Walter et al., 2018). Therefore, the story must portray characters that are not socially distant or controversial to the audience (Ritterfeld and Jin, 2006; Slater et al., 2006; Walter et al., 2018).

The power that stories hold in changing recipients' worldviews or attitudes has been attributed to the situational state of being "transported" into the story world (Schreiner et al., 2018). The transportation theory of narrative persuasion poses absorption into a story as a key mechanism of narrative impact (Golding, 2011). However, determinants that might enable "transportation" are still hypothesized.

A neuroimaging finding demonstrated that narrative messages are processed in a hierarchical structure, starting from the auditory sensory processes, analysing the property of the sound, to linguistic processes that separate words from the sentence and assign the meaning (Grall et al., 2021). In fact, non-narrative messages such as short radio commercials are processed in this way. However, more complex engaging narratives which follow the concrete structure and depict emotional events

or relate closely to the life circumstances of the listeners require higher-order cognitive and emotional responses to enable comprehension and social-cognitive inferences (Grall et al., 2021).

Similar to the engagement, which is the function of the story, studies suggest that "transportation" is a function of the story itself but also a stable recipients' disposition (Green and Brock, 2000; Dal Cin et al., 2004; Green, 2004; Schreiner et al., 2018). In this aspect, the action of being "transported into the story world" requires the co-activation of attention, imagery, and emotion (Green, 2004), meaning that the story must be set in such a manner to evoke this activation.

Finally, Slater and colleagues (2006) argue that when identifying with the main character of a story (i.e., being transported into the story world), cognitive responses become more positive since the absorption and identification are incompatible with counterarguing – i.e., sharing the opposite beliefs about the events, reactions, or feelings portrayed in the story (Slater and Rouner, 2002; Slater et al., 2006). Therefore, mastering the craftsmanship of engaging narratives and their interrelated functions (i.e., viewer/listener and story function) is still an ongoing process.

The following study is a part of Phase 2 focused on designing a potential digital solution for informal caregivers that will address the existing informal caregiver needs as discussed in Study 1 while merging storytelling to deliver required narrative support throughout the role.

3.2 STUDY 2: THE POTENTIAL OF TRANSFORMATIVE VIDEO DESIGN FOR IMPROVING CAREGIVER'S WELLBEING

Petrovic, M., & Gaggioli, A. (2021)

3.2.1 Abstract

The existing interventions for informal caregivers assist with managing health outcomes of the role burden. However, the deeper meaning-making needs of informal caregivers have been generally neglected. This paper reflects on the meaning-making needs of informal caregivers, through the theory of narrative identity, and proposes a new approach – the Transformative Video Design technique delivered via video storytelling. Transformative Video Design assists informal caregivers to re-create a cohesive caregiving story and incorporate it into the narrative identity. The technique is used as a stimulus for triggering the self-re-structure within the narrative identity and facilitating role transformation.

Keywords: digital health, informal caregiver, storytelling, stress, video design

3.2.2 Introduction

Financial resource management in rapidly aging societies is one of the main tasks social systems face globally. The ongoing processes of deinstitutionalisation and privatisation across Europe is particularly affecting and reshaping long-term care. As a result, the new model of care emerged in recent years, combining traditional family/informal care with semi-informal help provided by the

migrant workers and partial assistance by the formal care workers (Deusdad et al., 2016). The trend of familiarization and the preference for informal care has been increasingly favoured by the families, as a response to the insufficient resources required for formal care and institutionalisation. Informal caregivers are family members, friends or neighbours that provide unpaid long-term care for the significant other. The European population consists of 10%–25% of informal caregivers, providing up to 60% of the total care (Lilleheie et al., 2020; Zigante, 2018).

Research data persistently point out caregiving as a chronic stress experience, followed by physical and psychological strain in caregivers (Allen et al., 2017; Stall et al., 2019). The prevalence of depressive and anxiety symptoms in informal caregivers, followed by the progressive lack of self-care behaviours, and higher mortality rates through the development of chronic conditions, has been consistently noted in the literature (e.g., Bell et al., 2001; Brimblecombe et al., 2018; Lamura et al., 2008; Schulz et al., 2012).

For instance, the informal caregivers of patients in vegetative states form a belief of being a unique point of reference for care recipient needs, ultimately neglecting themselves throughout their devotion to care recipients (Cipolletta et al., 2016). Nevertheless, caregivers are increasingly expected to assume more demanding roles, including medical care at home, a mediator between health care systems and nursing homes, and be decision-makers for complex health issues (Brimblecombe et al., 2018; Stall et al., 2019).

The burden and the demands of the role underline the increased need for assisting informal caregivers to manage role-related stress and maintain wellbeing. In this paper, upon reflecting on the existing mental health interventions for informal caregivers, we lay out the argument for using Transformative Video Design, as a stimulus for triggering self-structure/restructure of the caregiving role in the narrative identity of the self. Furthermore, we discuss the initial theoretical background of the design and conclude by introducing the methodological workflow of the design.

3.2.2.1 *Psychological interventions to reduce caregiver's burden*
The comprehensive meta-review (Cheng and Zhang, 2020) of systematic reviews and meta-analyses on non-pharmacological interventions for informal dementia caregivers, revealed consistent evidence support across reviews for several types of interventions. The existing classification includes psychoeducation, counselling/psychotherapy, mindfulness-based interventions, occupational therapy interventions and multicomponent interventions. Additionally, respite care was included, however, the closer investigation revealed little benefits and even negative outcomes by arousing the feeling of guilt in caregivers.

Psychoeducation has been shown to reduce depression, enhance mastery and overall quality of life (Cheng and Zhang, 2020). Psychoeducational programs encourage information sharing, emotional, and social support for caregivers, emphasising engagement in pleasure activities to increase emotional wellbeing while providing skill training and support (Frias et al., 2020). However, the literature recognizes common barriers to attendance and participation in these programs, including transportation issues, care costs, insufficient time due to caregiving/or work obligations, personal health issues and the lack of awareness for specific training needs (Abreu et al., 2015).

Interventions based on counselling/psychotherapy demonstrated the effectiveness in reducing depression in caregivers. The evidence points out these interventions receive positive reviews, often when solely assessed and rather vague effectiveness reviews when mixed with psychoeducational interventions (Cheng and Zheng, 2020). Within the counselling relationship, both the practical and emotional needs of the caregiver are being addressed. Caregivers, within the counselling context, are

encouraged to address the grief and the concept of cumulative loss, self-care and the sources of support (Kepic et al., 2019).

Mindfulness-based interventions (MBI) are established on the cognitive-behavioural therapy (CBT) principles, relying on the premise that mental disorders, including psychological distress, are deriving from cognitive factors (Hofmann et al., 2012). Hence focusing on altering the response patterns provides more beneficial outcomes (Akkerman and Ostwald, 2004). MBI has been shown to successfully reduce depression in informal caregivers of people living with dementia (Cheng and Zheng, 2020), often used in a form of mantra repetition, meditation, yoga and mindfulness-based stress reduction.

Occupational therapy was identified as another potent group of interventions that can successfully lower the depression in caregivers. The focus of occupational therapy may range according to the needs of the caregivers, including physical and social environment modifications, activity modification strategies, ambient music and multisensory interventions, as well as exercise-based interventions (Cheng and Zheng, 2020; Piersol et al., 2018).

Finally, multicomponent interventions had beneficial effects on depression and delaying the institutionalisation of the care recipient (Cheng and Zheng, 2020). Additionally, the most effective component of these interventions is psychoeducation, especially valuable when combined with a therapeutic component (Dickinson et al., 2017). Conversely, the data indicate little evidence to support the effectiveness of these interventions on the burden, anxiety and general quality of life. Moreover, it is important to note that the ultimate success of multicomponent interventions depends on the components included and how they match the caregiver's needs (Cheng and Zheng, 2020).

The existing groups of interventions have been successful in assisting caregivers manage adverse role-related outcomes to some extent, with the main advantage of flexible delivery – that is, individual or in group settings. Additionally, many of these interventions can be successfully adapted into digital interventions available via mobile applications, web platforms, in combination with systematic monitoring and virtual reality without the presence of a trained professional required, ultimately lowering the cost and improving the availability of the intervention.

Digital interventions for caregivers, delivered via mobile apps, web-based and VR, promote building skills, emotion-self regulation, education, information about the caregiving role and provide skill training (Petrovic and Gaggioli, 2020). Examples of successful adaptation of psychotherapeutic techniques into digital interventions delivered across platforms include RX Refill, Care, Care4Caregivers, CareHeroes, Mindfulness-Based Stress Reduction (MBSR), UnderstandAid, Webnovela Mirela, Aging Service Technology (AST) and a VR intervention Through D'mentia Lens (Petrovic and Gaggioli, 2020).

3.2.2.2 The limitations of the reviewed interventions

Despite the range and availability of the interventions for informal caregivers, several limitations must be taken into the account. The individuals have distinct levels of personal resources to spend on covering role-related demands (Kayaalp et al., 2020). Coping with the role burden results in unique adverse outcomes on the individual level, ranging from different mental health support needs to respite care. Therefore, recognising caregiving as an idiosyncratic process and acknowledging the uniqueness of each caring situation is one of the principal steps in expanding the forms of assistance available for informal caregivers (Montgomery and Kosloski, 2009). An evident lack of such consideration is present in the reviewed approaches.

Furthermore, the meaning-making needs of the informal caregivers related to the onset of the role (e.g., voluntary or imposed) and the transformation of the role within the relationship have been disregarded in the existing interventions for informal caregivers. The transformation of the role relationship means that the already existing relationship is transforming (e.g. son to the caregiver) rather than being established as a new role added to the spectrum of social roles (Montgomery and Kosloski, 2009). Therefore, the direct consequence this transformation has on an individual is rather an issue of the narrative identity than a tangible problem that can be addressed with an intervention.

The recognized limitations urge for a more concrete approach for supporting caregiver's wellbeing by considering the uniqueness of the experience for each caregiver. The most significant social relationship in the caregiving context is possibly transforming irreversibly (e.g., spouse to the caregiver) as it is the case with dementia caregivers. This implies the loss of a loved one while she/he is still physically present, resulting in a traumatic experience that often lacks structure within the narrative identity of self.

3.2.2.3   The therapeutic value of storytelling

From a therapeutic point of view, storytelling is used to help client reason and behave in new, more productive ways (Crawford et al., 2004). The use of storytelling in therapy provides people with the opportunity to construct better outcomes and plan how to reach them. Storytelling takes the form of a collaborative journey where the therapist and the client create a cohesive story out of the events from the client's life that led to the presented problem, with the clear structure distinguishing beginning, middle and end (Crawford et al., 2004).

Therapists incorporate stories, metaphors and analogies in their practice to challenge unproductive styles of thinking and address maintaining behaviours. The clients become encouraged to re-author their own stories of the past, present and future, shifting from the problem-saturated narratives. Moreover, the collaborative development of the story between the client and the therapist can improve rapport, allow clients to gain a new perspective of their problems, achieving a 'This too will pass' attitude. Stories enhance personal impact through clarity of meaning, and finally help reinforce clients' motivation to affect therapeutic change (Blenkiron, 2005; Rice 2015).

Caldwell (2005) noted that the client's story is the place of the beginning and the result of life review therapy. Specifically, how an individual shapes his perceptions/stories, in turn, shapes the overall experience of life. Techniques such as narrative and expressive arts (e.g., memory books, life maps, self-boxes, time capsules, etc.) allow stepping into the ongoing creative meaning-making process of individuals' life stories.

The therapeutic value of storytelling becomes evident in an example of Beck's (1979) work where together with his colleagues, he developed a cognitive model of depression (Clark et al., 2000). According to the model, individuals living with depression hold a negative view of themselves, others, and the world. Additionally, they consider themselves worthless, leading to the perception of a hopeless future. These types of distortions in thinking cause all the new information to be similarly biased, resulting in generalized conclusions such as 'I am stupid', or 'I am incompetent'.

The distortions in thinking interrupt the formation of healthy rationalisations and any event or thought opposite to the predetermined bias is either contorted to fit the biased conclusion or discarded as incorrect. In line with this, within the general conclusion such as 'I am incompetent', the required perspective shift concerning the existing negative bias is delivered through carefully designed constructive stories. Therapists use this effective strategy to alter the maladaptive assumptions about the self, others, the world and the future (Crawford et al., 2004; Finnbogadóttir and Bernsten, 2014).

Another example of using storytelling in therapy is by creating different metaphors that help a client gain a different perspective. As an illustration, 'The Quicksand' story (Luoma et al., 2007) is included as a metaphor for the distress clients experience in life:

"When we're stuck in quicksand, the immediate impulse is to struggle and fight to get out. But that's exactly what you mustn't do in quicksand – because as you put weight down on one part of your body (your foot), it goes deeper. So the more you struggle, the deeper you sink – and the more you struggle. Very much a no-win situation. With quicksand, there's only one option for survival. Spread the weight of your body over a large surface area – lay down. It goes against all our instincts to lay down and really be with the quicksand, but that's exactly what we have to do. So it is with distress. We struggle and fight against it, but we've perhaps never considered just letting it be, and being with the distressing thoughts and feelings, but if we did, we'd find that we get through it and survive – more effectively than if we'd fought and struggled".

The key advantage of storytelling as a technique in therapy is that the stories are clear and non-mysterious to the clients (Bergner, 2007). In this sense, the story is something that may be created together with the therapist, and the client can immediately utilize (e.g., 'The Quicksand' story) without further learning as compared to the DSM diagnosis. The fundamental benefit of the story over the DSM diagnosis is that the diagnosis is rarely well understood by the clients and requires a certain degree of familiarity with the lexicon of psychiatry and the background in the diagnostics.

The role that the personal stories have and how 'the self' is perceived through these stories has been especially emphasized in recovery and therapy (Angus and Greenberg, 2011). It has been suggested that owning the self-authored record (i.e., personal story) of the event supports the client in recovery by facilitating meaning-making of the experiences and feelings (Nurser et al., 2018). For instance, the recovery from substance abuse, trauma and loss of the significant other, is addressed by the therapist through personal stories of the client, aiming for a narrative shift in the story and improvement in self-perceptions (Angus and Greenberg, 2011).

McAdams and McLean (2013) pinpointed the internalized and evolving life story of a person, integrating the reconstructed past and imagined future into a purposeful concept of self, as a theory of narrative identity. In essence, the stories created from episodic particulars of autobiographical memory construct the story of life, called narrative identity (McAdams and McLean, 2013). The theory argues that through an internalized story, people convey who they were, who they are, and who they might become. Therefore, the importance of creating a positive life story, and constructing positive meaning-making even out of traumatic experiences is crucial for flourishing narrative identity.

3.2.3 The potential of transformative video design for supporting wellbeing

In recent years, the digital interactive story has emerged as a new form of storytelling technique, adopting computer graphics to represent virtual story worlds that allow the direct experience of the narrative itself (De Lima et al., 2018). The interaction is the main distinction between Transformative Video Design (TVD) and the common digital stories that consist of constantly linear overarching plots limiting the interaction. Another important consideration incorporated in the TVD is the agency.

It can be argued that the agency is a crucial part of interactive digital storytelling where participants can interact and change the plot of the story, shaping it any way they like (Stern, 2008).

The rapid progress of digital interactive storytelling has already led to several prototypes (Aljammaz et al., 2020; Aylett et al., 2005; Cavazza et al., 2007; Donikian et al., 2004; Kalmpourtzis et al., 2020; Markouzis and Fessakis, 2016; Mateas and Stern, 2002; Riedl and Young, 2004; Stal et al., 2019; Szilas, 2003; Weiss et al., 2005) centring around narrative control, the duality between the character and plot, and the potential for planning techniques for action generation (Stern, 2008). However, the quality of the interactive content produced in terms of images and motion is still inferior when compared to the live-action film quality (De Lima et al., 2018).

The goal of TVD is to create a narrative immersion. More specifically, to involve the imagination of the participant in the mental construction and contemplation of the story world (Ryan, 2008). Narrative immersion focuses on the influence that the content has on the viewer (Elmezeny et al., 2018). The immersion takes at least three dimensions, including spatial, temporal and emotional (Ryan, 2015). The spatial form is a sense of place and joy experienced from exploring the story world, while the temporal form refers to the curiosity and the desire to know what will happen next. Finally, the emotional form consists of the feelings and reactions to the story and the characters in the story (Ryan, 2008, 2015). Except for the different dimensions of narrative immersion, the design of a good interactive narrative requires a deep understanding of the participants and their stories. Respecting this aspect, one of the first steps in developing TVD includes gathering of the life stories, narrative analysis, and creation of a unified story that provides a detailed overview of the third-person life story participants can relate to.

Researchers, in the field of Artificial Intelligence (AI), are always seeking the development of new algorithms that will allow narrative adaptation and evolution as a function of participants' interaction (Milam et al., 2008). Similarly, in therapy, the therapists are always searching for means of narrative adaptation for general purposes that will further allow the personalisation and evolution of the client's story. Regarding therapy, interactive storytelling is a rather novel approach used in cognitive rehabilitation of adults (Gabele et al., 2019), pediatric oncology patients (Wilson et al., 2015), children with auditory difficulties (Flórez-Aristizábal et al., 2019), and as a tool for facilitating communication with children during counselling (Baceviciute et al., 2012). However, the potential of interactive storytelling for further psychotherapeutic applications is yet to be explored.

The Transformative Video Design draws from the theory of narrative identity (McAdams, 2011; McAdams and McLean, 2013), involving the ability to generate and cultivate both the perception of meaning and purpose in one's existence and the sense of oneness with 'the Self' that pervades the experiences one has throughout life. The structure of the narrative identity is based on the story that the person tells himself and others, progressively becoming the foundation of the narrative identity and at the same time the matrix of successive narratives, in a circular process of development: 'the Self' creates the stories, which create 'the Self'.

We argue three key advantages of Transformative Video Design for maintaining informal caregiver's wellbeing. First, video-based storytelling can act as a stimulus for triggering the self-structure of the personal story, directly addressing the meaning-making needs of caregivers (Cox and McAdams, 2014). Second, the interaction with the content, consisting of branching narratives provides immediate insight into the consequences of choices made within the critical moments in the caregiving role. Finally, the perspective shift facilitates emotion regulation and coping skill acquisition (Chisholm et al., 2014).

3.2.3.1 Transformative video design as a stimulus for self-change

Even though narrative thought, as Bruner (2004) teaches, constitutes a cardinal process of human evolution both on a personal and cultural level, it can also represent a therapeutic tool with great potential that can be profitably integrated into the processes of prevention and treatment of mental disorders. In line with this, McAdams, and other authoritative scholars suggest that storytelling is one of the most powerful tools of personal transformation that humans have ever evolved: not surprisingly, the restructuring of one's life history represents a central element in different forms of psychotherapy. Therefore, mental illness is often the result of a person's inability to tell a 'good story' about their life.

In this perspective, an effective strategy to help people develop 'stories that cure' could therefore be to identify tools capable of promoting an active reflection on the 'turning points' of their existence, or on the stories of those experiences that have helped shape one's identity and guide their choices. Moreover, 'turning points' are also the learning points that brought up the necessary change (i.e., transformation) either because the circumstantial demand exceeded the person's ability to manage the event, or the event has been resurfacing after it has been dealt with consecutively in ineffective ways.

3.2.3.2 Interaction in transformative video design

The interaction within Transformative Video Design refers to the user interaction with the unfolding of the narrative in critical moments of storyline. In essence, the user manages critical points through interaction with the narrative, resulting in the storyline change. The goal of the interaction is to encourage the productive selection of strategies in difficult moments that can be learned (e.g., through trial and error) and adopted as a practical skill within the personal caregiving role. On the other hand, the unproductive strategies lead to further critical issues rising within the story, consequently demonstrating the outcomes of the unproductive coping skills but also increasing the need for the strategy change.

According to the Transformative Experience Design model (Gaggioli, 2015), new media, particularly virtual reality, represents an effective tool for creating 'transformative stories' or rather immersive narrative contents that facilitate the reflection on ones' life story. This enables restructuring, in a positive and adaptive sense, of one's perspective (i.e., worldview). Transformative video design facilitates the creation of 'transformative stories' through the change of perspective (i.e., from third-person to the first-person perspective) and specific narrative structure. The storyline in this context allows the user to interact with the narrative, leading to narrative shifts and resulting in a direct influence on the storyline outcomes. This type of interaction provides an opportunity to learn and experiment with coping and emotion regulation skills, also by taking a cue from the Stress Inoculation Training technique developed by Meichenbaum (2007).

Transformative Video Design for informal caregivers is based on a video story following two main linear story arcs – distinguishing between spousal caregivers and informal caregivers. The story is gender adapted, resulting in the eight final stories – four spousal caregiver stories and four informal caregiver stories (Figure 4). The storytelling begins upon selecting the gender and the type of relation with the care recipient. The linear storyline is constructed following a story of a caregiver, including emotional, physical, social, family, and economic challenges, entwined with daily life. The structure of the story is distinguishing the life before the role, the event leading to the role, the acceptance of the role, and the life during the role gradually leading to the role transformation.

Figure 4. Preview of the initial storytelling structure.
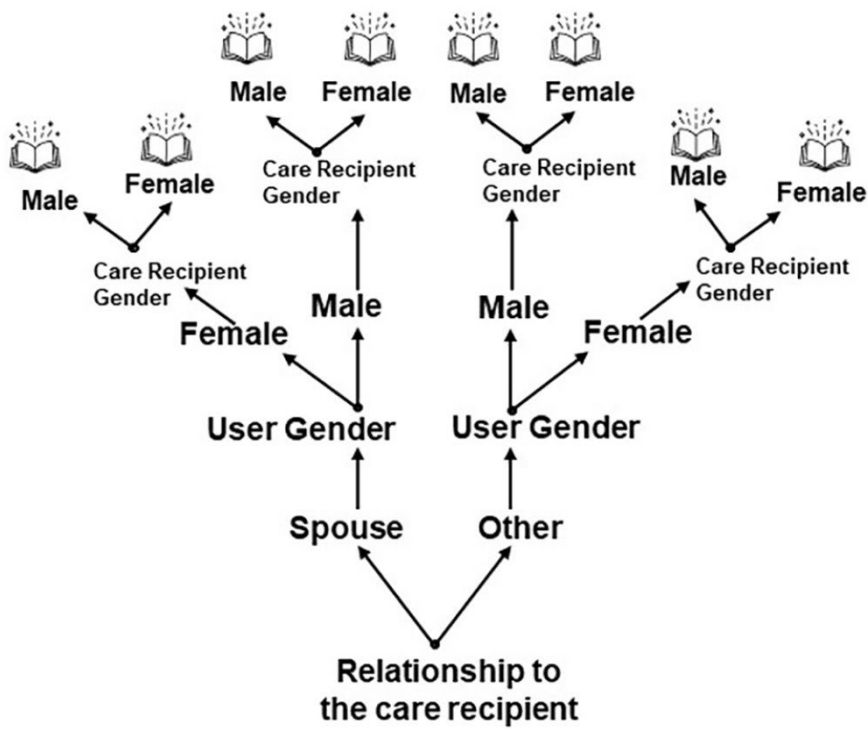
The story arc contains critical points (i.e., interaction points) consisting of a range of outcomes (i.e., an if-then type of scenarios) separating from the linear storyline and spreading into a branching narrative (Figure 5).

Figure 5. The story arc with interaction points.
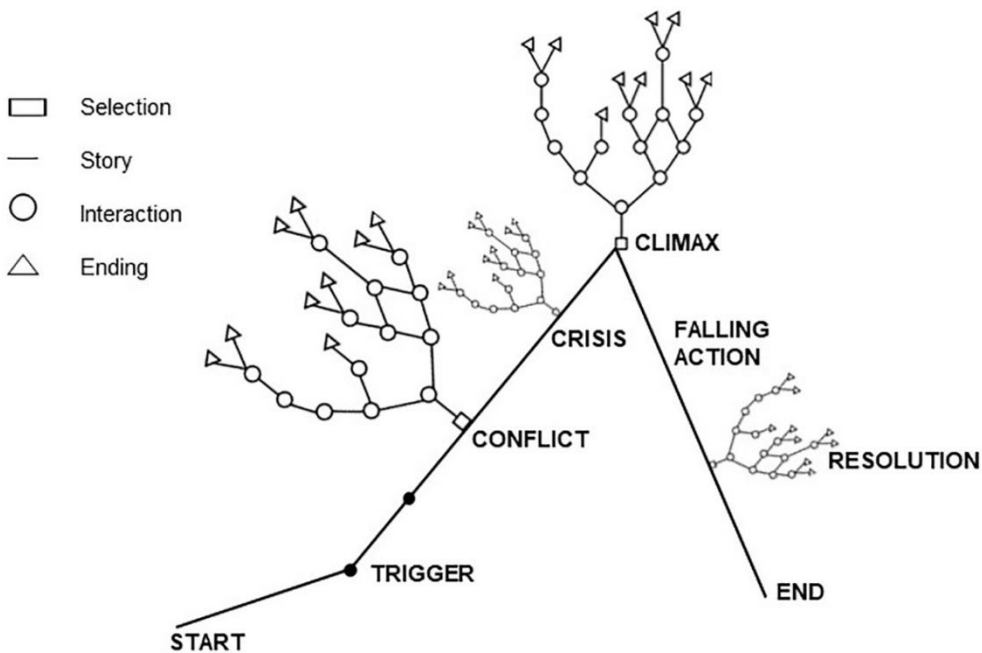
3.2.3.3 *The perspective shift in transformative video design*

The individuals often engage in 'self-talk' as an inner voice guiding moment-to-moment reflection, which has a strong effect on self-control, depending on the language used during the process (Diaz et al., 2014; Kross et al, 2014). Data indicates that using one's name in self-talk rather than the first-person pronoun 'I' is increasing a person's ability of self-control under stress (Moser et al., 2017). Emotion regulation is a form of self-control that heavily relies on cognitive control mechanisms to cover emotional responses. However, Moser et al. (2017) demonstrated that third-person self-talk constructs an effortless form of emotion regulation with no additional cognitive processes. Therefore, the third-person perspective reduces emotional reactivity, allowing an individual to think about the self in a similar way they think about others. In other words, the third-person perspective allows a necessary psychological distance to facilitate self-control.

The healing aspect of the Transformative Video Design relies to the great extent on the perspective shift (e.g., observer to the narrator). Using exemplary stories that fit the clients' circumstances in a third-person perspective, has clear implications about how change can take place, how it can be brought, and what are the beneficial behaviours and actions that can be used to ameliorate adverse mental health issues (Bergner, 2007). At the point of storytelling, clients are not being called upon to reflect on themselves but to see the doings which might be real or fictional, literal, or metaphorical, of other people, allowing them to assume an objective observer stance.

This mode of viewing, which is the externalized mode for an individual or a third-person perspective, results in decreased defensiveness and resistance towards messages passed through the story (Bergner, 2007; De La Torre, 1972) as compared to receiving more direct forms of input about oneself. It has been suggested that the ability to distinguish one's own experiences from the experiences of others is critical for developing self-consciousness, and theory of mind (i.e., learning how to infer the internal states of others). Moreover, these distinct representations between the first-person perspective and third-person perspective have been supported with neuroimaging data, pointing to distinct patterns of neural activity (Chisholm et al., 2014).

As the linear storyline in transformative video design progress in the third-person perspective, the critical points are encountered, shifting into the first-person perspective in a branching narrative with multiple interactions available. Each storyline, both linear and branching, shows a preview of an ongoing story arc (Figure 6) when the video is paused, allowing the understanding of the rising action, critical point, interaction moment and denouement.

Figure 6. Sample of a story arc
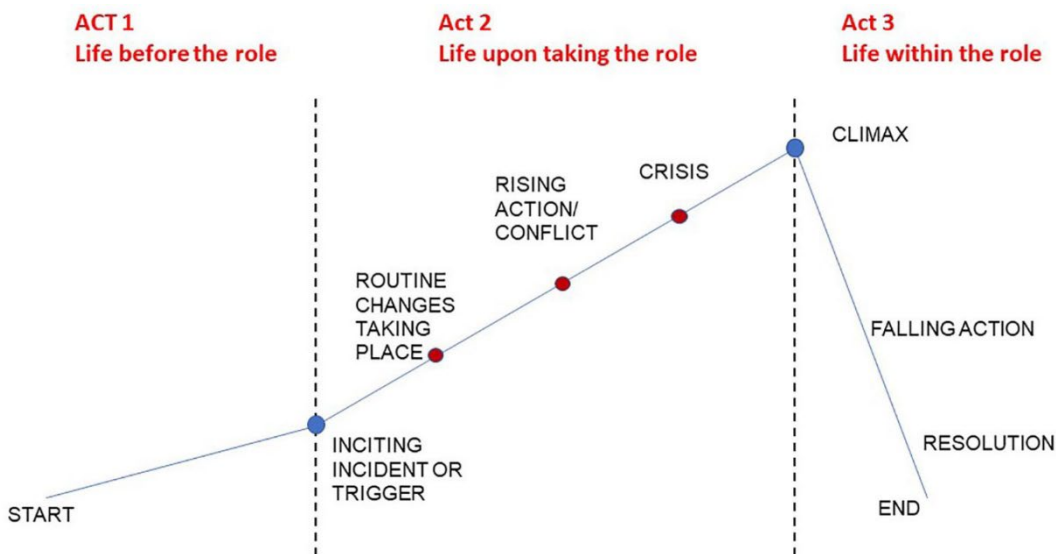
The methodological workflow of the design (Figure 7) consists of the ten consecutive steps distinguishing between user engagement, content formation, storyboard development and video production. Within the workflow, the central point is the user, whose needs are first defined by the literature research, user feedback and then further explored by structured interviews.

Figure 7. The overall design of the methodological workflow
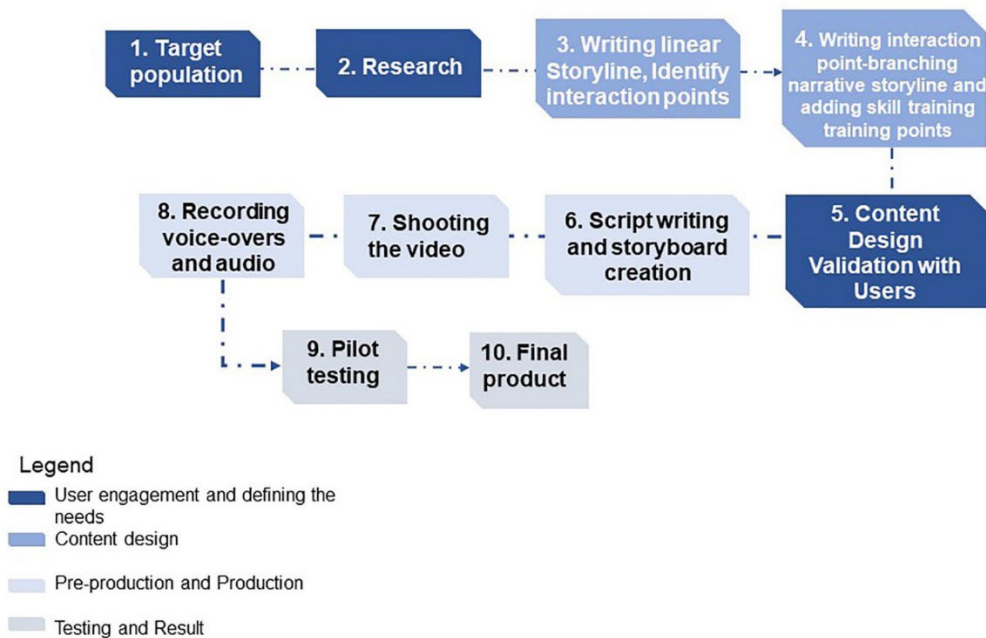
The content and the format of the design are validated with the user's feedback, narrative engagement scale, and emotional responses detected by the facial expression recognition software Noldus FaceReader during the mock trial. Users are engaged in the early steps of the development, allowing the researchers to determine the concrete needs of the users regarding the meaning-making experience. The ultimate design of the story, including the type of video used (i.e., animation vs. live-action), is validated in a mock trial performed before the video production. Finally, the effectiveness of the end-product is tested in a clinical pilot trial applying the same measures used in the content and

format design validation and additionally assessing pre-post measures of stress and anxiety of the participants.

3.2.4 Conclusion

The Transformative Video Design is developed to provide a coherent video structure of the stressful and traumatic experience in a third-person perspective linear storyline, allowing psychological distance from the experience. In other words, it creates a safe space for exploring 'the self' narrative and the outcomes of the individual choices. TVD facilitates the resolution of personal role-related critical points through interactive content, designed in a first-person perspective, within a branching narrative. In this manner, the caregiver can observe the unrolling of caregiving life cohesively, depicting the beginning, the middle and the ongoing situation, while experiencing a perspective shift and exercise response to challenging situations.

The caregiver acts as a protagonist, observer and professional who can distinguish beneficial responses to the critical points, but also a student learning about the possibilities within the interaction leading to facilitated denouement/end in the story. Transformative Video Design builds up video storytelling by potentially serving as a stimulus for triggering the self-structure of the personal narrative leading to the role transformation, while also being the educational tool that provides knowledge about the story arc that can be transferred to the personal story.

Finally, the technique also facilitates coping skill-building and emotion regulation exercise through a perspective shift and challenging interactions available within the storyline. Therefore, we propose the TVD has the potential to stimulate the meaning-making experience for informal caregivers, in turn lowering the need for repetitive mental health interventions. The TVD post technique period is intended for the participants as a period of personal reflection followed by the printed diary-type of the guide dedicated to informal caregivers, facilitating self-structure of the personal story.

We suggest two important future challenges for TVD. The first challenge is to determine the combinatory role of the TVD with existing approaches for informal caregivers. In essence, it needs to be explored if the self-narrative structure provided through TVD facilitates and empowers the success of existing interventions for informal caregivers. The second challenge we suggest for Transformative Video Design lies in future efforts to discover the areas within and beyond mental health applications that could benefit from TVD.

Some of the areas we consider include the health care sector, educational institutions, media and public communication systems involving social policy, urgent/crisis (e.g., COVID-19) response dissemination. For instance, within the healthcare/medical sector, TVD can be used to disseminate the procedure/recovery storytelling for patients.

TVD can provide clear steps of the procedure (e.g., knee replacement), post-procedure steps, and patient expectations during recovery. In essence, the patients would be able to anticipate the recovery and difficult moments of the recovery by exercising coping skills for the proper management of post-procedure outcomes TVD.

The TVD technique for the social policy and urgent crisis response can potentially demonstrate the social benefit of the actions that require urgent implementation. For example, the nationwide impact of the COVID19 vaccination could be addressed through storylines depicting the life of individuals living and experiencing the COVID19 in the environment that has been vaccinated versus an environment that has still not been vaccinated. In this manner, the TVD would provide fast access to

long-term outcomes/outlook of the event in an 'if-then' type of scenarios, allowing fast adoption of the better outcomes into the personal narrative and choices.

REFERENCES

Abreu, M., Silva, A. L., Costa, N., & Abreu, W. (2015). Psychoeducational programs for informal caregivers of dependent older adults: Barriers to participation. Procedia-Social and Behavioral Sciences, 171, 629-634.

Akkerman, R. L., & Ostwald, S. K. (2004). Reducing anxiety in Alzheimer's disease family caregivers: the effectiveness of a nine-week cognitive-behavioral intervention. American Journal of Alzheimer's Disease & Other Dementias®, 19(2), 117-123.

Aljammaz, R., Oliver, E., Whitehead, J., & Mateas, M. (2020, September). Scheherazade's Tavern: A prototype for deeper NPC interactions. In International conference on the foundations of digital games (pp. 1-9).

Allen, A. P., Curran, E. A., Duggan, Á., Cryan, J. F., Chorcoráin, A. N., Dinan, T. G., ... & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience & Biobehavioral Reviews, 73, 123-164.

Angus, L. E., & Greenberg, L. S. (2011). Working with narrative in emotion-focused therapy: Changing stories, healing lives. American Psychological Association.

Aylett, R. S., Louchart, S., Dias, J., Paiva, A., & Vala, M. (2005, September). FearNot!–an experiment in emergent narrative. In International workshop on intelligent virtual agents (pp. 305-316). Springer, Berlin, Heidelberg.

Baceviciute, S., Rützou Albæk, K. R., Arsovski, A., & Bruni, L. E. (2012, November). Digital interactive narrative tools for facilitating communication with children during counseling: A case for audiology. In International conference on interactive digital storytelling (pp. 48-59). Springer, Berlin, Heidelberg.

Beck, A. T. (Ed.). (1979). Cognitive therapy of depression. Guilford press (pp. 143).

Bell, C. M., Araki, S. S., & Neumann, P. J. (2001). The association between caregiver burden and caregiver health-related quality of life in Alzheimer disease. Alzheimer Disease & Associated Disorders, 15(3), 129-136.

Bergner, R. M. (2007). Therapeutic storytelling revisited. American journal of psychotherapy, 61(2), 149-162.

Bietti, L. M., Tilston, O., & Bangerter, A. (2019). Storytelling as adaptive collective sensemaking. Topics in cognitive science, 11(4), 710-732.

Bilandzic, H., & Busselle, R. W. (2008). Transportation and transportability in the cultivation of genre-consistent attitudes and estimates. Journal of Communication, 58(3), 508-529.

Blenkiron, P. (2005). Stories and analogies in cognitive behaviour therapy: A clinical review.

Behavioural and Cognitive Psychotherapy, 33(1), 45-59.

Brimblecombe, N., Fernandez, J. L., Knapp, M., Rehill, A., & Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. Journal of Long-Term Care, (September), 25-40.

Bruner, J. S. (2003). Making stories: Law, literature, life. Harvard University Press.

Bruner, J. (2004). Life as narrative. Social research: An international quarterly, 71(3), 691-710.

Burger, J. M. (1981). Motivational biases in the attribution of responsibility for an accident: A meta-analysis of the defensive-attribution hypothesis. Psychological Bulletin, 90(3), 496.

Caldwell, R. L. (2005). At the confluence of memory and meaning—Life review with older adults and families: Using narrative therapy and the expressive arts to re-member and re-author stories of resilience. The Family Journal, 13(2), 172-175.

Cavazza, M., Lugrin, J. L., Pizzi, D., & Charles, F. (2007, September). Madame bovary on the holodeck: immersive interactive storytelling. In Proceedings of the 15th ACM international conference on Multimedia (pp. 651-660).

Cheng, S. T., & Zhang, F. (2020). A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. BMC geriatrics, 20(1), 1-24.

Chisholm, J. D., Chapman, C. S., Amm, M., Bischof, W. F., Smilek, D., & Kingstone, A. (2014). A cognitive ethology study of first-and third-person perspectives. PloS one, 9(3), e92696.

Cipolletta, S., Pasi, M., & Avesani, R. (2016). Vita tua, mors mea: The experience of family caregivers of patients in a vegetative state. Journal of Health Psychology, 21(7), 1197-1206.

Claidière, N., & Sperber, D. (2010). The natural selection of fidelity in social learning. Communicative & Integrative Biology, 3(4), 350-351.

Clark, D. A., Beck, A. T., Alford, B. A., Bieling, P. J., & Segal, Z. V. (2000). Scientific foundations of cognitive theory and therapy of depression.

Cohen, J. (2001). Defining identification: A theoretical look at the identification of audiences with media characters. Mass communication & society, 4(3), 245-264.

Costabile, K. A. (2016). Narrative construction, social perceptions, and the situation model. Personality and Social Psychology Bulletin, 42(5), 589-602.

Cox, K., & McAdams, D. P. (2014). Meaning making during high and low point life story episodes predicts emotion regulation two years later: How the past informs the future. Journal of Research in Personality, 50, 66-70.

Crawford, R., Brown, B., & Crawford, P. (2004). Storytelling in therapy. Nelson Thornes.

Dal Cin, S., Zanna, M. P., & Fong, G. T. (2004). Narrative persuasion and overcoming resistance.

Resistance and persuasion, 2(175-191), 4.

de la Torre, J. (1972). The therapist tells a story: A technique in brief psychotherapy. Bulletin of the Menninger Clinic, 36(6), 609.

de Lima, E. S., Feijó, B., & Furtado, A. L. (2018). Video-based interactive storytelling using real-time video compositing techniques. Multimedia Tools and Applications, 77(2), 2333-2357..

Deusdad, B. A., Pace, C., & Anttonen, A. (2016). Facing the challenges in the development of long-term care for older people in Europe in the context of an economic crisis. Journal of Social Service Research, 42(2), 144-150.

Diaz, R. (1992). Private speech: From social interaction to self-regulation (pp. 17-53). R. M. Diaz, & L. E. Berk (Eds.). Hillsdale, NJ: L. Erlbaum.

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2017). Psychosocial intervention for carers of people with dementia: what components are most effective and when? A systematic review of systematic reviews. International psychogeriatrics, 29(1), 31-43.

Donikian, S., & Portugal, J. N. (2004, June). Writing interactive fiction scenarii with DraMachina. In International conference on technologies for interactive digital storytelling and entertainment (pp. 101-112). Springer, Berlin, Heidelberg.

Elmezeny, A., Edenhofer, N., & Wimmer, J. (2018). Immersive storytelling in 360-degree videos: An analysis of interplay between narrative and technical immersion. Journal For Virtual Worlds Research, 11(1).

Finnbogadóttir, H., & Berntsen, D. (2014). Looking at life from different angles: Observer perspective during remembering and imagining distinct emotional events. Psychology of Consciousness: Theory, Research, and Practice, 1(4), 387.

Flórez-Aristizábal, L., Cano, S., Collazos, C. A., Benavides, F., Moreira, F., & Fardoun, H. M. (2019). Digital transformation to support literacy teaching to deaf Children: From storytelling to digital interactive storytelling. Telematics and Informatics, 38, 87-99.

Frias, C. E., Risco, E., & Zabalegui, A. (2020). Psychoeducational intervention on burden and emotional well-being addressed to informal caregivers of people with dementia. Psychogeriatrics, 20(6), 900-909.

Gabele, M., Thoms, A., Alpers, J., Hußlein, S., & Hansen, C. (2019, April). Effects of interactive storytelling and quests in cognitive rehabilitation for adults. In GamiFIN (pp. 118-129).

Gaggioli, A. (2016). Transformative experience design. Human computer confluence. Transforming human experience through symbiotic technologies, 96-121.

Golding, L. (2011). Narrative impact of health and occupational safety messages: a comparison across

voice, medium, and topic (Doctoral dissertation, University of Georgia).

Grall, C., Tamborini, R., Weber, R., & Schmälzle, R. (2021). Stories collectively engage listeners' brains: Enhanced intersubject correlations during reception of personal narratives. Journal of Communication, 71(2), 332-355.

Green, M. C. (2004). Transportation into narrative worlds: The role of prior knowledge and perceived realism. Discourse processes, 38(2), 247-266.

Green, M. C., & Brock, T. C. (2000). The role of transportation in the persuasiveness of public narratives. Journal of personality and social psychology, 79(5), 701.

Habermas, T. & Bluck, S.(2000). Getting a life: The emergence of the life story in adolescence. Psychological Bulletin, 126.

Hofmann, S. G., Asnaani, A., Vonk, I. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: A review of meta-analyses. Cognitive therapy and research, 36(5), 427-440.

Kalmpourtzis, G., Ketsiakidis, G., Vrysis, L., & Romero, M. (2020, October). Examining the impact of an interactive storytelling platform on educational contexts through contemporary crowdsourcing methods of audiovisual content publishing. In 2020 15th International Workshop on Semantic and Social Media Adaptation and Personalization (SMA (pp. 1-5). IEEE.

Kayaalp, A., Page, K. J., & Rospenda, K. M. (2021). Caregiver burden, work-family conflict, family-work conflict, and mental health of caregivers: A mediational longitudinal study. Work & Stress, 35(3), 217-240.

Kepic, M., Randolph, A., & Hermann-Turner, K. M. (2019). Care for caregivers: understanding the need for caregiver support. Adultspan Journal, 18(1), 40-51.

Kross, E., Bruehlman-Senecal, E., Park, J., Burson, A., Dougherty, A., Shablack, H., ... & Ayduk, O. (2014). Self-talk as a regulatory mechanism: how you do it matters. Journal of personality and social psychology, 106(2), 304.

Lamura, G., Mnich, E., Nolan, M., Wojszel, B., Krevers, B., Mestheneos, L., & Döhner, H. (2008). Family carers' experiences using support services in Europe: empirical evidence from the EUROFAMCARE study. The Gerontologist, 48(6), 752-771.

Land, K. (2007). Storytelling as therapy: The motives of a counselor. Business Communication Quarterly, 70(3), 377-381.

Lilleheie, I., Debesay, J., Bye, A., & Bergland, A. (2020). Informal caregivers' views on the quality of healthcare services provided to older patients aged 80 or more in the hospital and 30 days after discharge. BMC geriatrics, 20(1), 1-13.

Luoma, J. B., Hayes, S. C., & Walser, R. D. (2007). Learning ACT: An acceptance & commitment therapy skills-training manual for therapists. New Harbinger Publications. pp 37-39.

Markouzis, D., & Fessakis, G. (2016). Rapid prototyping of interactive storytelling and mobile augmented reality applications for learning and entertainment–The case of "k-Knights".

Mateas, M., & Stern, A. (2002). Towards integrating plot and character for interactive drama. In Socially Intelligent Agents (pp. 221-228). Springer, Boston, MA.

McAdams, D. P. (1987). A life-story model of identity. In Perspectives in personality (pp. 15-50). JAI Press.

McAdams, D. P. (2011). Narrative identity. In Handbook of identity theory and research (pp. 99-115). Springer, New York, NY.

McAdams, D.P. & McLean, K.C. (2013). Narrative identity. Current directions in psychological science. SAGE Journals 22(3): 233–238.

Meichenbaum, D. (2007). Stress inoculation training: A preventative and treatment approach. Principles and practice of stress management. University of Waterloo, Ontario, Canada. Chapter to appear in PM Lehrer, RL Woolfolk & WS Sime, Principles and Practice of Stress Management, 497-518.

Milam, D., Seif El-Nasr, M., & Wakkary, R. (2008, November). Looking at the Interactive Narrative Experience through the Eyes of the Participants. In Joint international conference on interactive digital storytelling (pp. 96-107). Springer, Berlin, Heidelberg.

Montgomery, R., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. Generations, 33(1), 47-52.

Moser, J. S., Dougherty, A., Mattson, W. I., Katz, B., Moran, T. P., Guevarra, D., ... & Kross, E. (2017). Third-person self-talk facilitates emotion regulation without engaging cognitive control: Converging evidence from ERP and fMRI. Scientific reports, 7(1), 1-9.

Nelson, K. (Ed.). (2006). Narratives from the crib. Harvard University Press.

Nurser, K. P., Rushworth, I., Shakespeare, T., & Williams, D. (2018). Personal storytelling in mental health recovery. Mental Health Review Journal.

Petrovic, M., & Gaggioli, A. (2020). Digital mental health tools for caregivers of older adults—a scoping review. Frontiers in Public Health, 8, 128.

Petrovic, M., & Gaggioli, A. (2021). The potential of transformative video design for improving caregiver's wellbeing. Health psychology open, 8(1), 20551029211009098.

Piersol, C. V., Jensen, L., Lieberman, D., & Arbesman, M. (2018). Occupational therapy interventions for people with Alzheimer's disease. The American Journal of Occupational Therapy, 72(1), 7201390010p1-7201390010p6.

Pillemer, D. B. (2009). Momentous events, vivid memories. Harvard University Press.

Rice, R. H. (2015). Narrative therapy. The SAGE Encyclopedia of Theory in Counseling and Psychology, 2, 695.

Riedl, M. O., & Young, R. M. (2004, July). An intent-driven planner for multi-agent story generation. In Autonomous Agents and Multiagent Systems, International Joint Conference on (Vol. 2, pp. 186-193). IEEE Computer Society.

Ritterfeld, U., & Jin, S. A. (2006). Addressing media stigma for people experiencing mental illness using an entertainment-education strategy. Journal of health psychology, 11(2), 247-267.

Ryan, M. L. (2008, November). Interactive narrative, plot types, and interpersonal relations. In Joint international conference on interactive digital storytelling (pp. 6-13). Springer, Berlin, Heidelberg.

Ryan, M. L. (2015). Narrative as virtual reality 2: Revisiting immersion and interactivity in literature and electronic media. JHU press.

Schreiner, C., Appel, M., Isberner, M. B., & Richter, T. (2018). Argument strength and the persuasiveness of stories. Discourse Processes, 55(4), 371-386.

Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. Aging & mental health, 16(6), 712-721.

Singer, J. A. (1995). Seeing one's self: Locating narrative memory in a framework of personality. Journal of Personality, 63(3), 429-457.

Singer, J. A. (2004). Narrative identity and meaning making across the adult lifespan: An introduction. Journal of personality, 72(3), 437-460.

Singer, J. A., & Conway, M. A. (2011). Reconsidering therapeutic action: Loewald, cognitive neuroscience and the integration of memory's duality. The International Journal of Psychoanalysis, 92(5), 1183-1207.

Slater, M. D., & Rouner, D. (2002). Entertainment—education and elaboration likelihood: Understanding the processing of narrative persuasion. Communication theory, 12(2), 173-191.

Slater, M. D., Rouner, D., & Long, M. (2006). Television dramas and support for controversial public policies: Effects and mechanisms. Journal of communication, 56(2), 235-252.

Stal, S. T., Catala, A., Theune, M., & Reidsma, D. (2019). Designing a smart toy interactive setting for creating stories. In Interactivity, Game Creation, Design, Learning, and Innovation (pp. 601-610). Springer, Cham.

Stall, N. M., Kim, S. J., Hardacre, K. A., Shah, P. S., Straus, S. E., Bronskill, S. E., ... & Rochon, P.

A. (2019). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: a systematic review. Journal of the American Geriatrics Society, 67(3), 609-617.

Stern, A. (2008, November). Embracing the combinatorial explosion: A brief prescription for interactive story R&D. In Joint international conference on interactive digital storytelling (pp. 1-5). Springer, Berlin, Heidelberg.

Szilas, N. A. (2003). Narrative Engine for Interactive Drama. In Technologies for Interactive Digital Storytelling and Entertainment Conference, Darmstadt, Alemanha.

Walter, N., T. Murphy, S., & Gillig, T. K. (2018). To walk a mile in someone else's shoes: how narratives can change causal attribution through story exploration and character customization. Human Communication Research, 44(1), 31-57.

Weiss, S., Müller, W., Spierling, U., & Steimle, F. (2005, November). Scenejo–an interactive storytelling platform. In International conference on virtual storytelling (pp. 77-80). Springer, Berlin, Heidelberg.

Wilson, D. K., Hutson, S. P., & Wyatt, T. H. (2015). Exploring the role of digital storytelling in pediatric oncology patients' perspectives regarding diagnosis: A literature review. SAGE Open, 5(1), 2158244015572099.

Zigante, V. (2018). Informal care in Europe. Exploring formalisation, availability and quality, EC, 4-38.

CHAPTER III

4 TRANSFORMATIVE STORYTELLING TECHNIQUE: METHODOLOGICAL DESCRIPTION AND FEASIBILITY STUDY

SUMMARY OF THE CHAPTER

This chapter introduces the work performed on developing, adapting, applying, and assessing the Transformative Storytelling Technique as a part of developmental Phase 3, Phase 4, Phase 5, and Phase 6 of this work.

The technique draws from the theoretical premises introduced in the Study 2, followed by the end-user involvement for better understanding subjective experiential aspect of the role-related narratives. The initially proposed TVD approach has then accordingly been adjusted into the TST aiming to better support ease of access, developmental costs, and future utilization and availability of empowering digital narratives for informal caregivers across Europe.

Study 3 included in this chapter thoroughly demonstrates step-by-step application of the storytelling technique drawing originally from the small sample of informal caregivers with included audio story which is attached in a written format in Appendix 2. The narrative structure of TST is used to guide the collection and organization of the narrative building blocks that are then applied to design a fictional caregiver narrative based on the real-life themes of the target population.

Following the end-user involvement in perfecting the development of storytelling approach for digital narratives and the application of TST, the feasibility assessment is included in Study 4 as a part of final Phase 6 of the development of the TST.

4.1 TRANSFORMATIVE STORYTELLING TECHNIQUE (TST)

Transformative Storytelling Technique (TST) derived from the Transformative Video Design (TVD) for informal caregivers is a methodological adaptation of TVD into TST to allow the development of empowering stories with no requirement for digital interaction with the content (Petrovic & Gaggioli, 2021). The basis for the TST is set in narrative therapy approach where problem-saturated narratives are re-authored in collaboration with the therapist and formed in a more objective and productive manner (Madigan, 2011). Following that, the rationale for focusing on the caregiver story as a problem saturated narrative derived from the theory of narrative identity by McAdams (2011) which poses traumatic or stressful events as problematic points within the narration of "the self" which must be re-authored productively in order to be successfully incorporated into the narrative identity of "the self".

In the early introduction of this manuscript, I note two models on caregiving including caregiving stress model and caregiving appraisal model. And although caregiving stress model perceives caregiving as a stressful experience, the second model also addresses subjective appraisal of caregiving that contributes to the perception and experience of stress (Pearlin et al., 1990; Gallagher et al., 1989). Therefore, I here acknowledge caregiving as stressful experience (Pearlin al., 1990) but also reflect on the appraisal by relying on the caregiver's narration that provide excellent insight in the subjective caregiver view of the role. In that manner, in respect to both models, and theory of narrative identity, the TST methodologically allows to explore caregivers' narration and determine the overlapping experiences within group (i.e., consistent experiences), enabling to understand the stressful points (i.e., subjectively experienced) that require re-authoring in order to be productively incorporated into the narrative identity of the self.

This approach, in respect to the narrative therapy, aims to provide top-down experience of narrative therapy which means that instead of re-authoring the problem-saturated narratives in therapeutic settings, the problem saturated narratives are targeted by applying initial steps of the TST (see Study 3) and the story is then re-authored independently of the caregivers to deliver more productive narrative evolution of the story, and then be digitally available on-demand to the target groups (i.e., caregivers; see Study 4).

Drawing from these models, the theory of narrative identity, and relying on the narrative therapy as an approach for improving self-perception and identity of "the self" through narration, I argue that applying the TST technique for creating empowering narratives will improve subjective experience of the informal care. Concretely, the subjective caregiver burden, which is noted in the introduction of this dissertation raises from the negative appraisal of the role related circumstances and has an important function in adverse role-related outcomes (del Pino-Casado et al., 2018). In fact, the exposure to the TST storytelling is expected to influence appraisal of the caregiving role and improve the perception of the role which will be evident in the improvement on the measure of the subjective caregiver burden.

Furthermore, meaning making, which was already discussed in terms of its relevance in the caregiver identity and overall understanding of the caregiver experience is expected to improve. Concretely, TST, through carefully designed narration is expected to improve presence of meaning in caregivers and potentially lower the search for meaning.

The following sections include Study 3 which is a step-by-step method demonstration paper illustrating the application of the Transformative Storytelling Technique to create empowering informal caregiver sample story. However, Study 3 is also a qualitative exploration of informal

caregiver narratives throughout the role. Once the TST is demonstrated, pilot feasibility Study 4 is included, exploring the pre-post output of informal caregivers to TST exposure. The study 4 protocol has been registered in clinicaltrial.org.

4.2 STUDY 3: USING THE TRANSFORMATIVE STORYTELLING TECHNIQUE TO GENERATE EMPOWERING NARRATIVES FOR INFORMAL CAREGIVERS: SEMI-STRUCTURED INTERVIEWS, THEMATIC ANALYSIS, AND METHOD DEMONSTRATION

Petrovic, M., Bonanno, S., Landoni, M., Ionio, C., Hagedoorn, M., & Gaggioli, A. (2022)

4.2.1 Abstract

Background: The transformative storytelling technique is an innovative top-down approach to narrative therapy that aims to provide building blocks for creating flourishing narratives for target groups or populations. This approach acts as a facilitator for implementing the human-centered design in developing digital self-help tools for larger samples or target groups.

Objective: This study applied the transformative storytelling technique, as a new approach in mental health, to develop empowering audio narratives for informal caregivers.

Methods: A narrative inquiry was conducted with 17 informal caregivers (16 women and 1 man) who completed a semistructured interview, "Caregiver Life Story," acquiring information about the beginning of the role, rising action, and critical point of the role. The participants' ages ranged from 41 to 84 years, with all participants providing care for at least a 6-month period. This inquiry was guided by the transformative storytelling technique and aimed to collect data relevant to creating fictional stories based on real-life themes.

Results: Twenty-five overall themes were distinguished across three a priori–set categories, providing narrative building blocks for the informal caregiver life stories. The final empowering caregiver life story was created as an example for this study, demonstrating the application of the transformative storytelling technique in an informal care context.

Conclusions: The creation of empowering stories for populations or target groups in mental health care requires a unified and guided approach that will follow clear guidelines and storytelling principles. The transformative storytelling technique is a first of its kind in the mental health context, representing an initial step in enabling and supporting the creation of meaningful stories and the development of relatable, but productive, narratives. Such narratives have the potential to serve across media and digital platforms for supporting and improving well-being, and potentially triggering self-change in the target group or population.

4.2.2 Introduction

The narrative approach in therapy is a technique grounded in feminist, anthropological, and multicultural theories, offering a collaborative narrative journey and honouring the life experiences

of the client (Madigan, 2011). Following this approach, a narrative therapist assists a client to reauthor the problematic experience into a more constructive personal story by relying on the notion of "multiple truths" within the story rather than the client's subjective stance.

The therapist works with the "problem-saturated" story the client holds about his/her life or some aspect of life, and collaboratively engages in the process of "unpacking" and "reauthoring" the story. This bottom-up approach aims to mutually arrive at the preferred narrative of the story, deconstructing the experience to emphasize the disregarded but helpful aspects and to reconstruct it into a more positive self-story.

Some of the common applications of the narrative approach can be seen in counselling for depression; recovery from abuse; addiction; posttraumatic reactions; and in therapeutic work with couples, adults, and children (Payne, 2006; Ricks et al., 2014; Lowe, 2019). However, a significant limitation of the highly personal nature of narrative therapy is the challenge to implement it for a target group or population. More concretely, a target group or population is here defined as a large group of people sharing a common issue (e.g., alcohol abuse), difficulty, or mental health problem (e.g., posttraumatic stress disorder).

Guided by the idea of expanding narrative therapy principles to the individuals belonging to wider groups and populations, we developed the transformative storytelling technique (TST) (Petrovic & Gaggioli, 2021) as a top-down approach to traditional narrative therapy.

Unlike the bottom-up approach where the clients work on creating a productive self-narrative following various narrative techniques (e.g., narration, journaling, mapping the influence of the problem, outcome questions, counterviewing questions), the top-down approach starts from a ready story to be delivered to a specific group (e.g., informal caregivers).

In this manner, the ready TST narrative acts as a template and a pathway for assisting with self-story restructure for the individual, with no additional knowledge of narrative techniques needed. Concretely, the TST-structured fictional stories act in a 2D manner. The primary dimension is to assist end users (e.g., informal caregivers) to create a more productive self-story within the context (e.g., caregiving) by using the fictional TST story as a template. The second dimension facilitates and enables users to anticipate and intercept the potential role-related issues and prepare appropriate coping strategies.

However, outside of the mental health context, the fundamental of storytelling is both art and craft. While art is an instinct-driven process, the crafting part of storytelling requires a technique in the form of a guided approach that builds the story. Some traditional storytelling techniques include Monomyth, also known as the Hero's Journey; Rags to Riches; The Mountain, or the Freytag pyramid; Nested Loops; Sparklines; In Medias Res; False Start; and Converging Ideas (*Norsensus*, 2022). These techniques provide a cohesive structure for the narrative in literature and allow a writer to set a proper stage for telling the story. For example, the Monomyth, like Joseph Campbell's Hero Journey, sets the storytelling in a circular plot where the protagonist leaves the known and sets out on a journey (*Norsensus*, 2022). Throughout this journey, the protagonists experience difficulties, despair, and lessons, or encounter teachers that help them move on and return to the starting point as a better and improved version of the self (i.e., Hero).

Conversely, the Nested Loops approach enables the core message to be communicated through several narratives delivered within one story. Similarly, the Mountain, which is also known as the Freytag pyramid, allows the storytelling formation in a rising line that marks the dramatic points and resolution of the difficulties (*Norsensus*, 2022). In fact, the Freytag pyramid is one of the oldest and most classic techniques, which is easily utilized and simply structured, allowing even amateur writers to set their story appropriately. Therefore, we adopted this approach in developing our TST.

Unlike the traditional approaches serving the literature structure, the TST provides clear guidelines in creating and structuring empowering digital stories. This technique relies on the narrative approach to therapy and storytelling principles in the narrative, allowing the implementation of narrative therapy principles (e.g., narration, storytelling; nonlinear, linear, or chronological narrative

formation) to larger groups or members of a target population simultaneously through audio or video stories.

Specifically, with the TST, we aim to address the narrative identity needs (i.e., understanding the self in the story) of a group or target population. The TST provides clearly structured digital narratives that act as a cue for triggering self-restructuring within the narrative identity of "the self." In such a manner, with the TST, we strive to empower end users by giving them a tool that will facilitate the adaptation of adverse or unexpected life circumstances (e.g., caregiving) into the productive story of "the self."

The TST facilitates the process of human-centered design in the creation of digital therapeutic narration for larger groups and populations and is currently the only existing technique that provides clear guidelines in creating digital stories for mental health. In line with this concept, the TST differs from the traditional storytelling techniques mentioned above because it focuses on structuring the experiences of target groups to produce building blocks for the creation of productive template stories that trigger self-restructure. Moreover, unlike the real-life accounts of individuals, the TST allows integration of multiple experiences within a given context, resulting in richer and more representative storytelling content.

In this study, we focus on informal caregivers as a target population for developing a healing story guided by the TST. Informal caregivers are considered a backbone of the health care systems across Europe, and we define this population as long-term unpaid primary care providers who assist a family member or a close other in need (e.g., spouse, parent, cousin, in-law, close neighbour) with daily life activities over a course of an illness or chronic condition.

Informal caregivers of older adults and individuals living with dementia have been reported to experience depressive symptoms, anxiety, and increased levels of stress throughout their role when compared to non-caregivers (Amer et al., 2019). Moreover, numerous adverse health outcomes for informal caregivers have been noted across the literature (Verbakel et al., 2014; Gerain & Zech, 2022; Eibich, 2021). Reflecting on the Italian caregiving context, long-term care provision in Italy as well as other Mediterranean countries has been labelled as "familialist" or family-run (Casanova et al., 2020). This type of care regime puts the responsibility of providing long-term care for a loved one in need on the family members, who often reach out for additional support mostly from migrant care workers and less frequently from the social and health systems (Casanova et l., 2020).

A closer look at the existing mental health support and interventions for informal caregivers indicates respite care, psychosocial interventions, and information and communication technology support as the most common therapeutic options used by mental health experts (Petrovic & Gaggioli, 2020). Although numerous studies recognize the existing narrative-identity issues within the caregiving role (Clark & Standard, 1997; Eifert et al., 2015; Hayet et al., 2009; O'Conor, 2007), there is no study available that explored the potential of applying or adapting the narrative approach to accommodate shifts in self-identity of informal caregivers. Informal caregivers often place caregiving activities into primary focus within their lives, while personal life and needs become secondary (Cooper, 2021). In this manner, caregivers take the responsibility of providing care for a loved one in need while negotiating newly formed and unfamiliar roles within the relationship and neglecting other aspects of life (Cooper, 2021).

In fact, this all-consuming nature of caregiving inevitably interferes with social and relational roles, resulting in identity disruptions (Montgomery & Kosloski, 2013). These disruptions mostly occur when personal experiences do not align with the preconceived "self," ultimately causing distress and loss of meaning in life (Montgomery & Kosloski, 2013).

Interestingly, informal caregivers report a loss of self as an outcome of the caregiving role, and as the caregiving role becomes more prominent, informal caregivers require meaning-making in the context of their caregiving identity [Cooper, 2021; Eifert, 2015]. In line with this situation, the ability to

reconcile the discrepancy between self-identity and caregiving identity is detrimental in productive adoption of the caregiving role into the narrative identity of self (Montgomery et al., 2011).

Accordingly, the aim of this study was to provide a step-by-step demonstration of application of the TST for creating a productive and empowering story in the informal care context. Such a story can then be used as a cue for triggering self-restructuring within the narrative identity of an informal caregiver and serve as a guide to facilitate familiarization and understanding of the caregiving experience for the caregivers early in the role.

4.2.3 Methods

4.2.3.1 Overview of the TST

The TST is a top-down approach to traditional narrative therapy that we developed to create ready stories with flourishing narratives for larger groups or target populations. In this study, we used the TST for the creation of audio stories, built through a series of five consecutive steps (see Figure 8), acting as a concrete guideline that we follow in developing the empowering digital story for an informal caregiver sample.

Figure 8. Steps of the transformative storytelling technique.
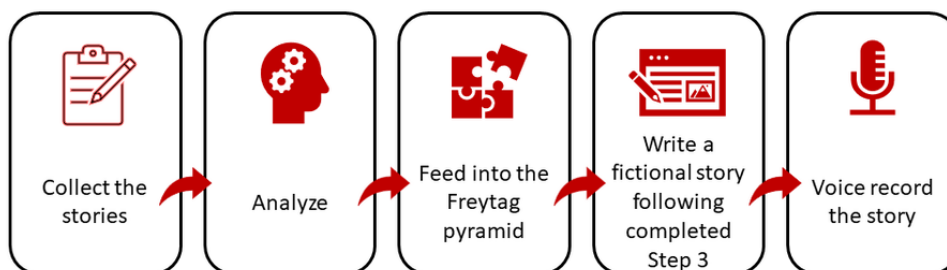
The therapeutic aspect of the TST is based on narrative principles in therapy and draws from the theory of narrative identity (McAdams, 2011), which poses the identity of "the self" as a construct based on an internalized and evolving story required for the meaning-making about the self and others. The storytelling aspect of the TST is based on the Freytag pyramid, which was introduced in 1894 for developing engaging and dramatic story plots in literature (Freytag, 1894). This pyramid is a mountain type of storytelling technique, commonly used in narratives owing to its simplicity, which allows use by individuals who are not experienced writers.

By applying the TST, we (1) collected the stories of the target population (i.e., informal caregivers) through structured interviews; (2) thematically analyzed the stories in search for themes; (3) fed the obtained themes into the Freytag pyramid structure, which enabled visualization of the key elements for (4) writing the fictional story that will be (5) audio-recorded with voice actors, and used as a blueprint of a flourishing narrative and a cue for triggering self-restructuring within the narrative identity of the target population. The fictional story is freely constructed, while strictly following the building blocks retrieved in step 3. Therefore, the obtained story is just a sample of numerous potential fictional stories that can be created following the step-3 building blocks. This paper complies with Standards for Reporting Qualitative Research, as recommended by O'Brien and colleagues (2014).

4.2.3.2 Ethical Statement

The study was approved by the Commissione Etica della Ricerca in Psicologia (CERPS) Ethical Committee of Università Cattolica del Sacro Cuore (UCSC) under protocol number 20-21, and was conducted in compliance with the latest version of the Declaration of Helsinki. Informed consent, provided to the participants in a written version, included a page containing an information sheet

about the study and a page addressing the General Data Protection Regulation, as well as the participant's right to withdraw from the study at any point with no penalties. The informed consent followed the template provided by the CERPS of UCSC and was additionally adapted to include the specific information about the study.

4.2.3.3 *Participants and Procedure*

The participants were long-term primary caregivers (e.g., spouse, daughter, daughter-in-law) of an elderly family member or close other who requires care due to a chronic condition, advanced age, or age-related illness (N=17; 16 women, 1 man). They were recruited on a voluntary basis through a non-profit caregiver association in Italy. The participants had to be providing primary care at the point of recruitment for at least a 6-month period regardless of the living conditions (living with the care recipient or living outside of the care recipient's home). Several recruitment strategies were employed, including posting an information sheet about the study on the information corner in the association, telephone calls to the members of the association who indicated they would like to take part in future studies, and through announcements by the self-help group facilitators who disseminated the study and referred interested caregivers to the information corner where the information sheet was available.

Participants received a link for the online interview through email or during their visit to the caregiving association by the group facilitator or researcher (SB), depending on their presence within the association. The structured interview was available via the Type Form platform, with an average completion time of 10 minutes. Some of the participants who expressed the desire to participate in the study but did not feel comfortable due to the ongoing pandemic or were not sure of how to use the Type Form website were assisted by the researcher in charge of data collection (SB).

Furthermore, due to COVID-19 restrictions at the time of data collection, most caregivers chose to be contacted via telephone to prevent potential contagion of virus transmission to the care recipient. The researcher performed the interview and filled in the data in Type Form on behalf of the participant. The telephone interviews were audio-recorded (at the researcher's request and upon participants approval) and then transcribed into Type Form by the researcher. All participants agreed to be recorded. The duration of the structured interview varied (10-30 minutes) depending on the amount of information shared by the participants, and each participant was interviewed only once.

4.2.3.4 *Interviews*

A structured interview, named "Caregiver Life Story," was created for the purpose of this research. Following the general form suggested by the TST, the interview questions inquired about (1) the beginning of the caregiving role/issue/event, (2) changes that took place, (3) the new routine/outcome, (4) psychological and emotional challenges of the caregiving role/issue/event, and a (5) a critical/climax point of the issue/role/event.

In addition, the interview assessed demographic (i.e., age, gender) and care recipient illness-related (i.e., age and health condition of the care recipient, relationship with the care recipient) information.

4.2.4 Analysis

Thematic analysis was performed following an inductive approach and the six-phase guidelines proposed by Braun and Clarke (2006). The phases included (1) familiarization with the text, (2) initial coding, (3) search for themes, (4) revision of themes, (5) definition of themes, and (6) final output (see Appendix 1). Within the TST, each question acts as an a priori category derived from the Freytag pyramid. In essence, each category collects the data for a specific part of the story plot (deductive) of the Freytag pyramid (see Figure 9). To ensure the extraction of relevant data, we performed the initial coding, which was then refined with more specific and narrowed codes that allowed for an easier

search for themes and definition of themes. The data were analyzed by two researchers independently. Namely, a large amount of interview data contained particularly emotional responses and confessions from the everyday life of informal caregivers that could potentially influence the interpretation. To mitigate the potential effects that highly personal and emotional recollections shared by the participants could have on the objectivity of the analysis, independent analyses were performed by two researchers (MP and ML) and the findings were then jointly compared and discussed until potential disagreements were resolved. The final codes and themes were established by noting and sorting the overlapping codes from the researchers' analysis. The third researcher (GA) supervised this process of distinguishing the themes independently and establishing the final themes jointly. In instances where the researchers disagreed, the points of disagreement within data were marked and blindly validated by the third researcher (GA) without prior knowledge on the specifics of the disagreement.

Figure 9. Themes inserted into the Freytag pyramid serving as building blocks for a story
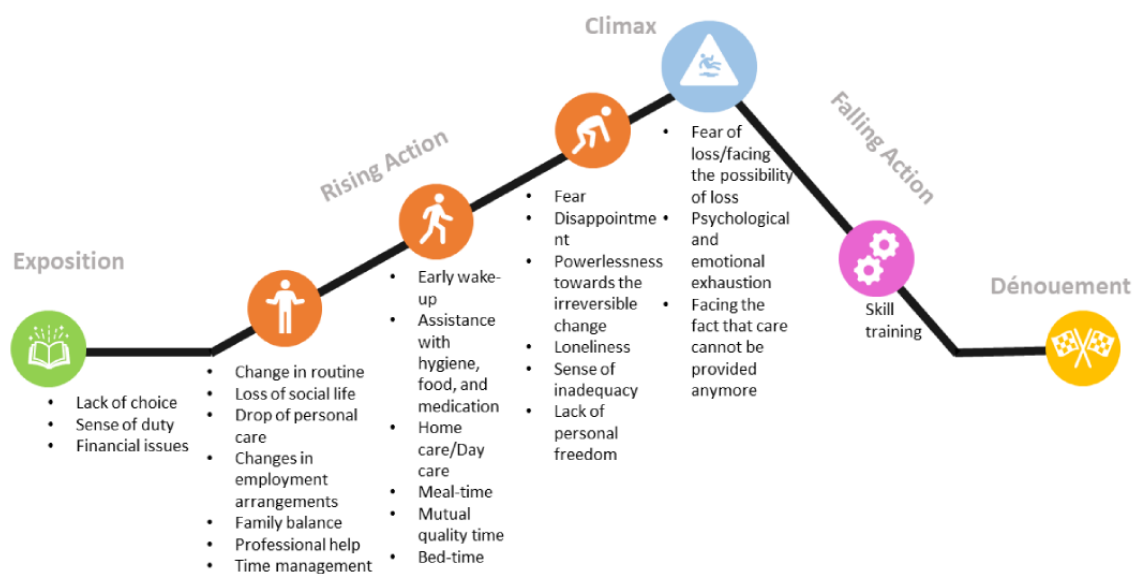
4.2.5 Results

4.2.5.1 Participants

The sample consisted of 16 female informal caregivers and one male informal caregiver (see Table 2). This number generally reflects the unequal gender distribution in informal care, pointing to women as the usual primary caregivers (Bertogg & Strauss, 2018). The most common illness among care recipients was Alzheimer disease, often associated with other chronic conditions. Interestingly, the gender distribution among care recipients was quite homogenous in contrast to the caregivers being predominantly women. Participants provided care mostly for a parent or both parents at once, while there were also some participants providing care for a mother-in-law.

The following results are presented in line with the steps of the TST (see Figure 8 and Appendix 1 for the detailed coding procedure).

Table 2. Characteristics of the study population. [a]

Participant ID	Gender	Age (years)	Gender of the care recipient	Age of the care recipient (years)	Relationship to care recipient
P1	Female	41	Male	70	Father
P2	Female	62	Male	67	Husband
P3	Female	46	Female	82	Husbands' aunt
P4	Female	55	Female	77	Mother-in-law
P5	Female	57	Female	80	Mother-in-law
P6	Female	61	Female	NA[b]	Mother
P7	Female	78	Male	79	Husband
P8	Female	55	Male	81	Father
P9	Female	63	Male	68	Husband
P10	Female	73	Male	78	Husband
P11	Female	47	Male and Female	80 and 80	Parents
P12	Female	64	Female	85	Mother
P13	Male	84	Female	NA	Wife
P14	Female	65	Male and Female	91 and NA	Parents
P15	Female	74	Male	80	Husband
P16	Female	57	Female	84	Mother
P17	Female	59	Female	82	Mother

[a]Illness-related data are removed to respect the privacy of the participants.
[b]NA: not available; information not shared or recipient recently deceased.

4.3 STEP 2: ANALYSIS OF THE STORIES

4.3.1.1 Overview of Themes

The thematic analysis resulted in 25 overall themes. A full list of initial coding, refined coding, and theme formation within each category is available in Appendix 1. The 25 final themes were sorted into a priori categories of the TST. Each interview question collected data for a specific category: (1) the beginning, belonging to the category of exposition/the beginning; (2) life changes, daily life, and psychological and emotional challenges, belonging to the category rising action; and (3) critical point, belonging to the category climax/critical point.

4.3.1.2 Exposition/The Beginning Category

The themes retrieved in the first category reflect the role onset/exposition, which include the lack of choice, sense of duty, and financial issues. The role onset has been marked with a lack of choice in accepting the caregiving duty either due to the living condition (e.g., spouse), or the lack of another caregiver available or willing to provide care (e.g., other siblings denied caregiving, children living across the country), often imposing the caregiving role upon the only available family member.

The sense of duty in providing care was the second noted theme. The sense of duty appeared due to a personal understanding of the relationship, family ties, marital responsibility, or being the only child that is willing to assume care, hence feeling as the last resort available, which is in essence closely related to the first theme of a lack of choice. The caregivers described the sense of duty with statements such as "I have to, she is my mother"; "I am the wife"; or "I am the daughter it's my duty."

The third theme of the first category, financial issues, appeared at the beginning of the role. In line with the theme lack of choice, caregivers also reported that the financial aspect has been an important factor in their decision to become a caregiver. There was a noted lack of financial resources for care

homes as well as in-home formal caregiver support, which also seemed to further add to the prolonged care even when the caregiver was not willing to continue the care provision.

4.3.1.3 Rising Action Category

4.3.1.3.1   Main Category

This category explores the rising action through reported daily changes that occur in individuals' lives due to the caregiving role, average daily life after the changes occurred, and finally psychological and emotional challenges of the role. The category rising action constitutes the following three subcategories.

4.3.1.3.2   Daily Changes Subcategory

Seven themes were noted within the daily-changes subcategory. Caregivers reported that a change in routine took place after the role was assumed, which forced them into giving up numerous habits and adjust to the new way of living. The caregivers expressed this through statements such as "I lost my routine," "the day was organized in the service of her," "I gave up my personal time," and "had to be more present for my parents."

The following theme within the subcategory daily changes was the loss of social life. Caregivers noted this as a relevant aspect of the daily changes that took place through shared statements such as "loss of friends"; "lack of social life"; "gave up my social life"; "all activities we had together stopped, hence our friends drifted apart"; and "my social life doesn't exist anymore."

The third theme, the drop of personal care, was evident through the lack of sleep or sleep disruption, limited sleeping hours, strict waking-up hours, loss of freedom for personal time and activities with family and friends, as well as lack of time to visit the doctor for personal health reasons. This theme was reflected in statements such as "I cannot take care of my own health issue, nor make the time to visit the doctor"; "I have to monitor her during the night because she already fell once"; and "my mother remains my priority."

The fourth theme of the daily-changes subcategory was changes in employment arrangements, which appeared in all cases where employment existed prior to the caregiving role. Some of the statements supporting this theme included "full-time to part-time work," "I had to quit my job," "I was waking up at 4:30 AM going to work and returning home at 8:30 AM."

The fifth theme in the subcategory daily changes was family balance disruptions, which reflects internal family problems that informal caregivers experienced in different contexts due to their role. Disrupted family time or activities were reported among spouses, parents and children, and siblings. The disruptions involved changes in the usual weekend-routine patterns of a family, the amount of time spent together, vacation routine, free time among parents and children, and free time for spouses. Moreover, the family balance was also affected among spousal caregivers reporting that what used to be regular mutual activities have now ended. Additionally, the family balance has also been affected over a course of caregiving due to lack of involvement of other family members who were considered obliged to caretake (e.g., brothers not assisting with caregiving to sister, daughters not assisting with caregiving activities to mother), resulting in the deterioration of the overall family relationship.

The sixth theme, professional help, was noted when caregivers addressed the professional help either in the form of day care or professional/semi-professional caregivers who were hired for in-home assistance. The caregivers who had the financial resources to cover the in-home professional/semi-

professional care expenses hired help regardless of the living arrangements or their full-time presence in the home. Some of the statements the caregivers made regarding professional help included "I paid the woman to help me," "I had to send him to day care against his will so that I can work," and "I had 24-hour home assistance."

The seventh theme of time management within the rising action subcategory of daily changes included all the relevant issues regarding the daily organization of time and changes that took place within the personal schedule. For instance, caregivers reported "all day revolved around the care recipient," "the day was organized in the service of the care recipient," and "I had to give up my personal time."

4.3.1.3.3 Average Day Subcategory

The average day subcategory explores a day in the life of an informal caregiver, including all of the relevant activities concerning care after the initial routine has been shifted and caregiving became a part of life. We noted six emerging themes within this subcategory pointing to early waking hours; assistance with hygiene, food, and medication; daycare center/home; meal-time; mutual quality time; and bed time.

Informal caregivers reported early waking hours as the beginning of each day, followed by assistance with hygiene, food, and medication. These two themes were reported by all caregivers regardless of the living arrangements (e.g., living together or separately). The caregivers reported that the first activity in the morning involved assistance with showering, cleaning, dressing, breakfast, medications, and therapy. This assistance was provided alone or, in a few cases, together with the professional/semi-professional in-home caregiver. Caregivers also noted that the assistance with personal hygiene was the most uncomfortable aspect of the caregiving role and the aspect that was also seen as repulsive in the beginning of the caregiving role.

The third theme was home care/day care. Care recipients either visited the daycare center for a couple of hours, or home care continued with the existing daily routine such as brief walks, grocery shopping, and reading newspapers. Caregivers who had the opportunity to spend some time away from the care recipient noted that they felt good about these hours even though they were still occupied with the caring obligations.

The meal-time theme followed the home care/day care theme. The care recipient would usually return from the daycare center or the late-afternoon home care would continue with early dinner. The mutual quality time theme was noted as a small period existing after dinner where the care recipient and caregiver spent quality time together, such as listening to music, talking, reading, or watching TV. These moments were also marked with the occasional efforts of informal caregivers to reminiscence with the care recipient about the past and good moments lived together.

Bed-time was the final theme within the average daily life subcategory, in which caregivers prepared the care recipient for sleep, distributed the medication, assisted with other care needs, and helped the care recipient go to bed. The caregivers mostly reported going to bed sometime later, after small house chores were complete.

4.3.1.3.4 Psychological and Emotional Challenges Subcategory

Psychological and emotional challenges of the role were identified through six emerging themes, including fear, disappointment, powerlessness, loneliness, sense of inadequacy, and lack of personal freedom.

The theme fear was noted as an important aspect of the subcategory emotional and psychological challenges. Fear experienced by caregivers was related to the care recipients' health and possible deteriorations of their health. In instances where the care recipient was ill, or the condition suddenly worsened, the caregivers reported fearing the possible outcomes and/or that they will not be able to appropriately assess the seriousness of the condition, which might have severe or lethal consequences on the care recipient.

Following the theme of fear, the disappointment theme emerged in the subcategory of emotional and psychological challenges as caregivers described daily events that affected them the most. It was noted that caregivers were disappointed with the disease progression and the outcomes, stating that related events are particularly difficult since they are taking place right in front of the caregivers. Some of the statements portraying these themes include "seeing your mother not recognizing you and not knowing anymore," "becoming a mother of my parents," and "I have always seen my parents as pillars and instead I discovered all their weaknesses."

The powerlessness theme appeared as an outcome of the irreversible change in the disease progression, when, despite the care provided, the condition was still deteriorating/not improving. Caregivers reported "the inability to do something against the disease/the sense of powerlessness caused by the disease weighted the most," "maintain a normal relationship when you are overwhelmed by the suffering that involves seeing the decline due to the disease," and "I feel so angry and I feel lonely."

Loneliness was noted as a fourth theme of the psychological and emotional challenges subcategory, overlapping with the loss of social life theme noted in the subcategory of daily changes. Loneliness was identified by statements such as "I feel lonely," "I find it hard to be the only one who has to follow him," and "she is refusing other caregivers' presence."

Sense of inadequacy was the fifth theme noted when the care recipient condition worsened, or difficult symptoms occurred. Caregivers reported feeling as if they were not sufficiently or adequately prepared to manage caregiving duties, or being in need of time to adapt to new circumstances/worsening of the condition. The examples were noted through a variety of statements such as "the moments of aggression that he had"; "feeling inadequately equipped to provide assistance"; "my movement had to be exactly the same as hers and this cannot happen overnight, you have to adapt"; "she once grabbed my neck"; and "she was waking up at night and ran."

Finally, lack of personal freedom was the sixth theme caregivers repeatedly noted in the subcategory of psychological and emotional challenges. This theme was reflected in planning out private time, going out alone, socializing, organizing weekends with family, or simply managing to spend time with people other than the care recipient. Furthermore, caregivers reported a lack of personal freedom in statements such as "lack of freedom is what oppresses me," "inability to spend time with children," and "sense of guilt for not having the time for everyone."

4.3.1.4 Climax/Critical Point Category

The climax point in the TST is the peak moment where the story begins to unravel since it reached the moment of the greatest tension. The climax/critical point category reflects the peak point for informal caregivers, where the provision of care has reached its peak in terms of difficulty, burden, and negative experiences, and hence must change or terminate. This category explores the themes emerging from the experiences of the most critical moments in the role of caregiving.

The initial theme recognized within the critical point category was the fear of loss/facing the possibility of loss. Caregivers reported that the critical points occurred when they were confronted with the further/serious health deterioration of the care recipient that implied the possibility of a lethal outcome. This theme appeared in the later phases of caregiving and could be potentially related to the following theme of psychological and emotional exhaustion. Concretely, when the caregiver had the resilience and strength to carry the role-related burden, the fear was less present/obvious. Some of the caregivers' statements shedding light on the theme of fear of loss/facing the possibility of loss include "when he gets ill/does not feel well I am scared because I believe it is serious"; "while my father was still having a driving license, since he was a danger to himself and others"; "when he is ill I do not know what the outcome will be"; and "the most critical moment is the last days when you know that nothing else could be done." This fear appeared to surface after the first encounter with the critical situation where the life of a care recipient was jeopardized.

The theme psychological and emotional exhaustion was reflected through numerous examples of negative emotions experienced, tiredness within the role, and the concern about the continuation of the caregiving activity. Furthermore, a few caregivers reported that due to psychological and physical fatigue—which could, in turn, be the consequence of psychological exhaustion—they were concerned if caregiving could last any longer. Caregivers expressed this through statements such as "I have experienced all the feelings of this world, anger, frustration, resentment, loneliness"; "I feel alone and criticized by my siblings while they are not truly aware of the situation"; "yes, there are mornings when I'm more tired and hearing the same things over and over again is heavy"; and "physical fatigue that prevented me from seeing the situation clearly/the worst moment was when I realized I cannot bear the caregiving for much longer."

The final theme noted within the category of climax/critical points was facing the fact that care cannot be provided anymore. It seems that such confrontation with the reality of the situation comes after first experiencing physical, psychological, and emotional exhaustion. Such a conclusion could also be related to the previous argument about the themes of fear, disappointment, and powerlessness, argued as early indicators that imply the caregiver is reaching a critical point within the role.

4.4   STEP 3: ARRANGING THEMES INTO THE FREYTAG PYRAMID

The obtained themes were used as building blocks for development of a fictional story guided by the real-life experiences common to the target population (i.e., informal caregivers). The real-life experiences are reflected in the obtained themes, while the TST is used for incorporating these real-life experiences into a flourishing narrative. Following the third step of the TST, the obtained building blocks/themes were fed into the Freytag pyramid (Figure 9) and used for the creation of numerous stories and different narratives for informal caregivers.

4.5   STEP 4: CREATION OF THE FINAL STORY

The fourth step of the TST consists of writing a fictional story using the obtained figure from step 3 (see Figure 9). The created fictional story provides the viewer/listener an identification with the protagonist who experiences similar challenges throughout the role (i.e., identification is supported by the building blocks/themes) but also an emotional distance that allows taking an objective stance toward the caregiving experience through a third-person perspective (i.e., the narrator telling the story to the caregiver, or the protagonist). A sample of a fictional story created as step 4 of the TST is included in Textbox 1 (see Appendix 2 for the full story).

Once the final step of the TST is completed and the written story is audio-recorded using a voice actor, the audio will be available on the Voice Me Out platform we designed for the informal caregivers (the platform is not yet publicly available; See Chapter IV).

Final fictional caregiver stories created. Words in italics are the retrieved themes incorporated into the fictional story.

- Excerpt from the category "The beginning"

I think I can describe it simply; I *did not have a choice*, but to take her with me that night. *"It is my duty"*—I said to myself—because she is my family. Besides, I *cannot afford anyone* to take care of her. As the days were going by, I had to change so many things in my life, one after another. I had never expected all of it to happen that way. I had to reorganize the space in my house and empty a room for her.

- Excerpt from the category "Rising action"

My entire morning routine had to adapt to her from day one. I had to *change my working hours* and shift to *part-time work* because I couldn't get to work by 9 any longer and stay there until 5. It is difficult sometimes to follow my own schedule.

My spouse often complains, and I do understand him, but I don't see what else I can do. I can't put her into a nursing home. My children didn't seem bothered at the beginning. In fact, they were excited to have Grandma home, but there comes a time when they try to make plans for us to go to the park on the weekend, as we used to, but I can't promise anything because I do not know if she will be in her good mood that weekend and able to leave the house. My *family balance* is completely disturbed.

- Excerpt from the category "Climax/critical point"

Fear, this is how I can describe such moments. I did not know what to do. I was scared for her, for my children. It was fear that didn't let me think for a moment. I felt *powerless* because she wasn't getting any better; she was either the same or getting worse. I couldn't make her get better and I think I was making her worse by not knowing what to do exactly. I was *completely alone*. No one could truly understand what I was going through. I didn't know what to do and I had no one to call. Everyone I knew had already advised me many times to consider a nursing home. I couldn't just take a break to have a *moment for myself* to think. It had been like that for months. I had lost my *personal freedom*. I felt trapped.

I took the phone and called an ambulance.

Textbox 1. Final fictional caregiver stories created. Words in italics are the retrieved themes incorporated into the fictional story.

4.6 DISCUSSION

4.6.1 Principal Findings

This study implemented the TST (Petrovic & Gaggioli, 2021) for developing empowering narratives in an informal care context. We demonstrated how to use the TST to obtain and categorize building blocks of a universal informal caregiver life story to develop an empowering fictional story. The final 25 themes have been distinguished across three a priori categories (i.e., the beginning/exposition, rising action, critical point), covering a wide range of experiential, practical, and emotional changes, along with experiences throughout the role.

Numerous obtained themes (e.g., within the beginning, and psychological and emotional challenges categories/subcategories) are in line with the past literature and reflect the important aspects of the informal care experience. Although some of the themes such as those within the subcategory of daily life constitute a major part of informal caregiver life and activities, they have been rather neglected in the literature to date (see Figure 2). It can be suggested that some of these themes also have an important role in the caregiver burden.

Interestingly, following the TST, we obtained qualitative data that have already been reported in the literature, but never gathered in one study. Namely, the TST enabled an all-encompassing approach to collecting, structuring, and grouping these findings chronologically. In other words, the TST enabled and facilitated gaining a magnified overview of the detailed caregiving experience.

Findings in the beginning/exposition category, which reflects on the early experiences in the role, indicate that informal care is often taken because of personal beliefs about family duties and obligations. This theme is also in line with prior research noting that informal caregivers consistently report this sense of duty across different cultures (Lindahl et al., 2011; Evans et al., 2012; deVugt & Verhey, 2013). Additionally, when several children were available to provide care for a parent, other siblings commonly expected the female child or the oldest child to assume the caregiving role.

Therefore, the sense of duty is arguably not equally present in all potential caregivers, but rather formed by certain expectations for the specific family member to assume care (e.g., the female sibling or the oldest sibling). It could be suggested that the sense of duty or the internal perception of duty is one of the distinctions between those that will assume care in the future and those that will refuse it. However, no current data are available comparing the sense of duty among siblings when more than one child is available to assume the role. Furthermore, it can be added that the existing perception of the feminine nurturing role additionally disadvantages female family members when the caregiving arrangements are being determined (Zygouri et al., 2014).

The financial aspect/lack of resources for formal or institutional care appeared as an important theme in the role assumption. Informal caregivers that had resources to support formal care or financially cover the placement into the nursing home/daycare center reported such actions early in the role. Moreover, caregivers who were able to afford assistance of any kind reported fewer caregiving tasks, ultimately allowing more personal freedom and time for other activities.

In line with this argument, findings from a recent study across 12 European countries assessing existing care policies and health of informal caregivers point to a significantly lower health status of informal caregivers who provide home-based care (Calvo-Perxas et al., 2018). Similarly, our results indicate that in instances where informal caregivers were not able to afford any type of help, the emotional experiences in the subcategory of psychological and emotional challenge within the rising action category were described to a greater extent, with vivid examples and recollections of numerous difficult situations.

Another interesting finding is that caregivers who provide only home care reported more severe emotional responses toward the care recipient and frustration toward the caring situation, which was reflected in the rising action category exploring the psychological and emotional challenges concretely. This insight can also be related to the past literature pointing to psychologically and physically abusive behaviors occurring in the informal caregiving context (Yamamoto et al., 2009; Alves et al., 2019; Riviera-Navarro et al., 2018), suggesting that the type of care (in-home only vs shared care with respite/or a day center) could be related to more severe reactions.

Informal caregivers noted the loss of social life and personal time early in the role, describing these experiences as part of the changes that took place due to the role. A similar theme re-emerged as loneliness in the category of psychological and emotional challenges, described mostly as "lack of friends," "lack of support group," and "lack of people that can serve as a reference point or companion during the difficulties." Interestingly, these findings are consistent with a previous study noting the presence of similar experiences of social isolation and lack of support (Woodford et al., 2018).

The relevance of the theme drop of personal care can also be aligned with the existing literature pointing to the gradual decrease in the physical health of informal caregivers who provide care for a longer period (Lacey et al., 2018). Arguably, the drop of personal care can be attributed to the maladaptation to two other themes, loss of social life and changes in the routine, ultimately occurring as an unconscious process in the caregiver. Moreover, a drop in personal care may act as a potential

mediating factor in the decrease of physical health noted in the literature. The past literature exploring personal self-care in informal caregivers underlines the strong association between self-care and emotional well-being, pain, perceived stress, and general health (Pope et al., 2017).

Changes in employment arrangements is another theme in line with numerous studies, pointing either to the lack of social policy that will provide flexible working hours for informal caregivers or inadequate long-term financial support for the hours missed from work (see Calvo-Perxas et al., 2018; Calvo-Perxas et al., 2021; Plothner et al., 2018).

Caregiver fear, discovered as another theme, has also been noted in the literature in the context of specific illnesses such as pulmonary fibrosis, amyotrophic lateral sclerosis, and heart failure (see Lee et al., 2020; Galvin et al., 2017; Petruzzo et al., 2017), where caregivers did not know how to manage specific illness-related aspects of care. However, the role of an overall fear in informal caregivers about assuming and providing caregiving has been rather neglected.

Another interesting theme discovered in this study is the sense of powerlessness. This theme emerged right before the critical/climax point category. In fact, the themes of fear, disappointment, and powerlessness toward irreversible change could be argued as early indicators that the caregiver is reaching a critical point in adverse experiences within the role, where the care provision either needs to be terminated, restructured, or shared to avoid critical situations.

Sense of loneliness and social abandonment/isolation are present from the early stages of taking up the role and seemed to be most strongly expressed in the emotional and psychological challenges subcategory. These themes are also consistent with the literature, pointing to the reported sense of isolation and abandonment in caregivers (see van Roij et al.,2019; Holkham & Soundy, 2017; Pindus et al., 2018).

The aforementioned themes within the psychological and emotional challenges subcategory could be argued as a set of early indicators leading to the confrontation with the fact that care can no longer be provided, as a part of the critical point category. Following such a perspective, if the early indicators are not appropriately addressed, the critical point follows or can be avoided by perpetual therapeutic work on fear, disappointment, and powerlessness within the role.

Following the categorization of the building blocks (Figure 9) and the creation of the empowering informal caregiver fictional story, these findings demonstrate how the TST can act on two levels. First, the categorization of building blocks with the TST can serve as an informative pathway for further research and interventions. Concretely, building blocks provide a path of the informal caregiver life experience from the beginning of the role until the critical point, and as such, proper steps can be developed to prevent, intercept, or manage problematic experiences in practice.

Second, the value of the created story and the potential effects of this story on informal caregiver well-being need to be assessed in a pilot trial, ensuring that informal caregivers benefit from such stories. The stories serve as a sample of a productive caregiving narrative to be used as a template in self-restructuring of the personal caregiving life stories. If TST stories show positive outcomes for informal caregivers in the currently ongoing pilot testing, we can further explore the development of flourishing gender-adapted narratives through digital health tools. This approach would further facilitate human-centered design in eHealth tools for informal caregivers and provide a new method of exploring adverse experiences while offering a path for creating flourishing and empowering digital narratives.

4.7 LIMITATIONS

Unlike the traditional storytelling approaches, the TST allows for the collection of universal building blocks for target groups or populations rather than individuals. In this sense, the technique enables in-depth exploration of the dominant/repetitive themes in the concrete categories of experience, acting as building blocks of an individual narrative within the target population.

Such collection and representation of the building blocks provide (1) an informative template for research and practice, (2) a pathway in the design and development of tools and interventions, (3) an overview of the narrative of the experience, (4) a blueprint for self-restructuring within the personal story of "the self," and (5) a top-down approach to narrative therapy (i.e., providing ready empowering narratives linked to personal experience).

Several limitations of this study must be considered. Further work on gathering and comparing themes in informal care following the TST is required to verify the universality of the retrieved themes in acting as building blocks for informal care narratives. Therefore, although our focus was on distinguishing universal caregiving experiences through the TST, we cannot assume the generalizability of our findings until the ongoing pilot trial data are retrieved and until the retrieved themes are reproduced by using the TST in further studies.

The majority of our sample was predominantly female informal caregivers, leading to possible perspective bias. The male experiences need to be collected and compared against the obtained themes to ensure the generalization of themes as building blocks for informal care narratives. In this sense, minimizing bias in future studies would strengthen the scientific rigor for obtaining universal themes of the informal care experience.

Another consideration regarding the scientific rigor that must be acknowledged is that all the participants had already taken part in self-help group meetings of the association, which might have prepared them and facilitated their capacity for self-reflection but likely also contributed to preconception of the emotional difficulties. In this sense, some experiences shared with our researcher (SB) might have already been predefined and conceived in self-help groups rather than reflected on for the purpose of our interview. This might ultimately affect the validity of the reported experiences, since they might have been reassessed and adapted in a self-help meeting to better resonate with the support group members rather than resonating with the general informal care experience.

Moreover, it must be noted that this study did not define an upper age limit for informal caregivers, allowing even elderly caregivers to take part in the study. The age difference among informal caregivers raises a question about the universality of the experiences across generations.

Finally, our sample consisted of informal caregivers who provided care for family members with concrete illnesses such as Alzheimer disease, Parkinson disease, or dementia. Therefore, the obtained experiences in this study could be potentially biased or formed by the specific illness presented in the care recipient. A larger sample of informal caregivers including other chronic conditions would be desirable in better exploring and creating universal themes of the informal caregiving experience.

4.8 CONCLUSIONS

The rapid expansion of storytelling applications in mental health calls for structured and tested techniques that will provide consistent narrative structures with clearly defined purpose and goals. The TST is the result of our effort to create a technique for developing structured, meaningful, and empowering narratives for larger groups or populations that can be easily adapted and applied to a digital format. The translation of personal narratives into empowering digital stories is one of our

next goals in implementing the human-centered design in digital health development for informal caregivers, where the value of every individual is recognized in the overall process of the group experience.

4.9 Study 4: The Transformative Storytelling Technique for Developing Guided Digital Narratives in Mental Health Support. Pilot study

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(in-submission)

4.10 Introduction

The combination of the rapid demographic ageing of Europe, supported by the medical advances that sustain prolonged lifespan, as well as shifts in family structures, have contributed to a major challenge for social and health care systems. Namely, the incidence of age-related conditions has increased the need for care provision, whereas current estimates point out that around 80% of the long-term care for the elderly is being delivered by informal caregivers (Spasova et al., 2018). The United Nations Population Division predicts that the population above the age of 60 will rise from 800 million in 2017 to two billion by 2050 (Fuster, 2017) ultimately increasing the demand for informal caregivers and more sustainable care solutions.

However, informal care is a complex role that often leads to adverse physical and emotional outcomes for the caregiver (del-Pino-Cassado et al., 2021). In fact, numerous studies have pointed out that informal caregivers have a higher risk of experiencing psychiatric disorders and adverse psychological outcomes (Sallim et al., 2018; del-Pino-Cassado et al., 2021). An interesting study assessing the short-term and long-term effects of care on female caregivers pointed out that the majority of negative short-term effects gradually fade upon the termination of care (Schmitz & Westphal, 2015) but long-term effects remain present even after five years of care termination.

Nevertheless, the theoretical and empirical work demonstrates that the subjective caregiver burden is the most relevant mediating factor in experienced anxiety, stress, and depression (Lazarus & Folkman, 1984; Gerain & Zech, 2019; Allen et al., 2017). A systematic review and meta-analysis revealed a large positive association between the subjective burden and depressive symptoms in informal caregivers of older individuals (del-Pino-Casado et al., 2019). Moreover, another systematic review and meta-analysis also pointed to a large positive association between the subjective caregiver burden and anxiety (del-Pino-Cassado et al., 2021).

Therefore, it can be argued that targeting subjective caregiver burden can ultimately support the prevention of clinically significant anxiety and depression for informal caregivers. Caregivers also report a constant struggle to balance their own needs against those of the care recipient, which leads to the dilemma of irreversible relationship shift (e.g., from son-mother to caregiver-care recipient), coherence about the provision of care and the meaning of the caregiving role overall (Quinn et al., 2015). Informal caregivers, in fact, report distinct needs throughout the course of caregiving. These needs deviate from the current literature focus which mostly explores the adverse outcomes of informal care and potential means of support.

As an example of distinct needs, in a study exploring the life of informal caregivers following the Transformative Storytelling Technique, the informal caregivers' needs were categorized in a chronological narrative, allowing the preview of the arising issues as the caregiving role progressed (Petrovic et al., 2022). Caregivers reported adverse mental health outcomes later on in the caregiving role, while the dominant issues which gradually led to such outcomes included lack of choice in assuming care, sense of duty, financial issues in enabling formal care, changes in routine, changes in social life, drop of personal care, changes in employment, family balance shift, time management issues, continuous organization of daily life around the care recipients' needs, and in the later phase of the role psychosomatic outcomes of the role (Petrovic et al., 2022).

In the broader health care context, access to support is of critical value in ensuring continuous care. Remote modes of mental health delivery such as eHealth and mHealth can facilitate access to support for a wide population. Storytelling, in a therapeutic context, has an important role in individuals' interactions and personal experiences, enabling individuals to shape the experience and re-assess the weight placed on a certain event - i.e., assessing the events as pleasant or negative experiences (Armstrong & Ulatowska, 2007).

Storytelling interventions use narratives that relate to the target population, aiming to elicit identification and transformation into the story worlds (Petrovic et al., 2022; Wieland et al., 2017). Starting from the narrative principles in therapy (Madigan, 2011), storytelling aims to deliver productive narratives embedded with health messages, skills, education and promoting behavior change. The therapeutic value of stories lies in their ability to create a space for re-affirming or re-creating the identity of "the self" (Carragher et al, 2021). In other words, stories allow the exploration of "the self" in relation to the external world. Moreover, stories of the experiences are not only narratives created to describe "the self" within the stories, but also allow positioning in a sense of temporal continuity for "the self" (McLean, 2008). In essence, temporal continuity is a continuous sense of self through time, space, and events which ensure the integrated existence of the person into "the self" concept. Once this "self" exists in the cohesive line of storied events and experiences of past, present, and imagined future, it is defined as the narrative identity of self (McAdams, 2018).

Disruptions in the self-stories when unexpected and traumatic events take place inevitably influence the integration of such experiences into the narrative identity of the self and potentially lead to a shattered sense of identity and meaning (Crossley, 2000). Therefore, storytelling can also be a powerful approach to rebuilding the sense of self by re-structuring the experience to facilitate its' incorporation into the narrative identity (McAdams et al., 2001). However, in a mental health context, a structured approach for creating empowering and healing digital narratives that can enable such re-structure is still not created.

In our efforts to address this gap, we developed the Transformative Storytelling Technique (TST), as a hybrid method for merging fictional structure and real-life accounts to guide the audiences' experience (see Petrovic et al., 2022). We argue that TST can potentially serve as an essential element of large-scale digital support, education and healing, by combining core elements of the transformative powers of storytelling with the audience's identification of first-hand experiences from others in similar situations with digital means of support. The purpose of this pilot feasibility study was to examine the potential effectiveness of the Transformative Storytelling Technique for supporting and improving wellbeing in the informal care context. The improvement and support of participants' well-being are defined as a significant improvement in at least one of the included variables. These variables in the informal care context include subjective burden, stress, meaning in life, sense of coherence and coping skills. The concrete study questions include:

Is it feasible to use the TST technique for creating audio stories to support informal caregiver wellbeing?

Does TST structured storytelling improve wellbeing, lower subjective caregiver burden, improve meaning in life, sense of coherence, and the use of productive coping strategies?

4.11 MATERIALS AND METHODS

4.11.1 Design and Setting

The present interventional one arm study involved a within-subject design assessing the pre-post outcomes of the gender-adapted caregiver audio narratives created following the Transformative Storytelling Technique (Petrovic & Gaggioli, 2021), facial video recordings during the audio exposure, and qualitative post reflections of the participants (see Figure 10). The study took place in the department of medical rehabilitation of Istituto Auxologico Italiano in Milan where the caregivers were enrolled either as informal caregivers of the patients or outpatients. The institute is an integrated network of hospitals, outpatient, and research facilities with over eighteen offices across different regions of Italy and overall health and administrative personnel of over 2600 people.

Figure 10. Timeframe of the assessment and audio narrative
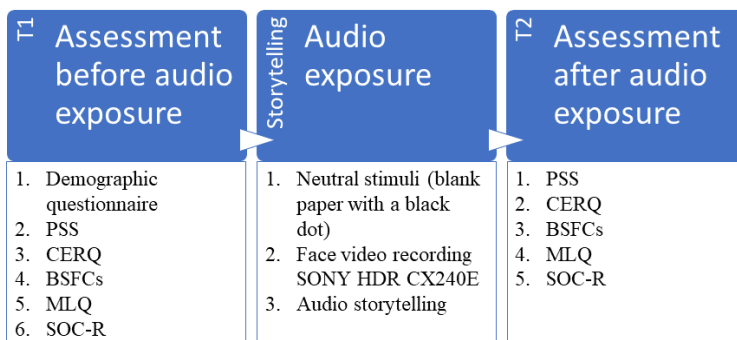
4.11.2 Ethics

The ethical approval for this study has been granted by the ethical committee of the Istituto Auxologico Italiano - Comitato Etico dell' Istituto Auxologico Italiano - in Milan under the code CE 2021072005. The study protocol was registered at Clinical Trials. This study was conducted in compliance with the latest version of the Declaration of Helsinki. Informed consent, provided to the participants in a written version, included a page containing an information sheet about the study and a page addressing the General Data Protection Regulation, as well as the participant's right to withdraw from the study at any point with no penalties.

4.11.3 Participants

The participants of this study were 21 informal caregivers, specifically defined as individuals who provide long-term care for a family member or other loved one in need, free of charge. Adult caregivers (age >18) were welcome, with eligibility criteria focusing on the individuals who provide care for the elderly care recipient. Participants who reported a chronic condition were still considered if they were the main informal caregiver, able and active in care provision (i.e., were not prevented due to the chronic condition).

4.11.4 Procedures

Participants were identified on a weekly basis by the clinical psychologist of the institute involved in the study. The selected people (i.e., those accompanying the care recipient to the medical appointments) received a brief explanation of the study and those interested in part-taking scheduled their participation. The informed consent was signed before the initial data collection.

Following the completion of the T1 baseline questionnaires at the first time point, a video recorder was placed on the desk, and participants were asked to look at the blank paper with a black dot for ten seconds, allowing the establishment of neutral facial expression. The tablet device was then placed in front of the participant, instructing them to press play on the already prepared audio file of the story - adapted to the gender of the participant.

The audio story used in this study is a gender-adapted story developed by the authors following the transformative storytelling technique (TST). Method demonstration and the complete procedure of the story development are described by Petrovic et al., 2022. Following the TST, the informal caregiver life story is developed in a non-linear narrative, describing the beginning of the caregiving role, the changes that took place, emotional and psychological difficulties experienced and the critical/climax point of the story. Upon the critical point, several coping strategies are delivered including positive reappraisal, positive refocusing, refocusing on planning, and putting into perspective. The story is audio recorded by a voice actor (male and female) in Italian. The voice actor delivers the audio story in the first-person perspective, resembling personal recollection. In this study, an audio story is recorded in female and male voices and played according to the participant's gender.

The video recording was active during the exposure to the audio narration until the audio narration was over, and then the video recording was stopped. The participants were asked to quietly reflect on the audio story for five to ten minutes and then the same questionnaires used in the first time point were distributed again for the T2 assessment. However, at this point, the participants were asked to fill in the questionnaire bearing in mind the audio story they just heard.

4.11.5 Materials

The demographic data including nationality, age, employment status, and previous mental health diagnosis were collected using a simple self-report form. The baseline and post-assessment have been conducted for stress, burden, meaning in life, sense of coherence, cognitive emotion regulation strategies, and neutral facial expression.

Perceived Stress Scale – PSS (Cohen, 1994; Mondo et al., 2021) was used for the assessment of stress. The scale contains 10 items assessed on a Likert scale from 0 – "Never" to 4 – "Very Often". The PSS scale is widely used for assessing the perception of stress, which in our study is assessed as a control measure for the overall experimental procedure. The PSS provides insight into the degree to which situations in an individual's life are appraised as stressful, pointing to how unpredictable, uncontrollable, or overloaded participants find their life. The Italian version of PSS -10 is concluded to be a reliable scale for measuring perceived stress in the Italian context (Mondo et al., 2021).

Burden Scale for Family Caregivers short version – BSFCs (Graessel et al., 2014;) is a 10-item instrument for measuring subjective burden in family/informal caregivers. The past validation study examined the internal consistency by obtaining Cronbach's alpha 0.92 for the short version used in this study (Pendergrass et al., 2018). Each item within this scale is formed as a statement rated from 0 – "Strongly Disagree" to 3 – "Strongly Agree". A high degree of agreement in this scale, scored by summing the ratings, indicates a higher subjective burden for the caregivers.

Cognitive Emotion Regulations Questionnaire – CERQ 27- item version (Garnefski et al., 2001; Balzarotti et al., 2016), is a multidimensional questionnaire designed to identify the cognitive coping strategies utilized upon experiencing a negative event. CERQ-27 item version is the adapted version for the Italian population derived from the back translation procedure of the original CERQ-36. After the adjustment for the discrepancies, several items were removed. The obtained internal consistency for all subscales ranged from .61 to .78 (see Balzarotti et al., 2016). CERQ- distinguishes nine different coping strategies assessed via subscales including self-blame, acceptance, rumination, positive refocusing, refocus on planning, positive reappraisal, putting into perspective, catastrophizing, and blaming others. The items in this scale are rated on a Likert scale ranging from 0 – "Almost Never" to 5 – "Almost always".

Meaning in Life Questionnaire – MLQ (Steger et al., 2010; Negri et al., 2020) is used to assess two dimensions of meaning in life - Presence and Search for meaning. The subscale of Presence measures to which extent an individual perceives his/her life as meaningful, while the subscale Search measures to which extent an individual is actively searching for meaning in life. MLQ is a short self-report inventory containing 10 items scored on a 7-point Likert scale ranging from 1- "Absolutely Untrue" to 7- "Absolutely True". MLQ assesses perceived meaning from both cognitive and motivational perspectives (Negri et al., 2020). In the Italian validation of the MLQ factor loading all items clustered on the expected factor, supporting the adequacy of the original model, with Chronbach's alpha values ≥ .86 pointing to good internal consistency.

Sense of Coherence short form– SOC-R (Antonovsky et al., 1993; Chiesi et al., 2020) assesses the coping capacity of individuals in dealing with everyday life events and stressors. SOC-R comprises three dimensions including manageability, balance, and reflection. The questionnaire consists of 13 items formed as statements about life that are scored on a five-point Likert scale ranging from 1 - "Not at all true" to 5 - "Extremely True". The questionnaire is scored by summing the ratings on each item with item 6 being reverse scored. The Italian version of SOC-R obtained an adequate Chronbach's alpha in the overall scale of .70 and the composite reliability for the total scale which was computed by using factor loadings from the first-order three-factor model CFA of .83.

Digital video camera SONY HDR CX240E was used for recording the facial emotion responses during the exposure to the audio narrative.

4.12 ANALYSIS

The demographic data were reported using descriptive statistics. A paired-samples t-test was used to compare the differences between the pre-post scores for perceived stress (PSS), caregiver burden (BSFCs), meaning in life (MLQ), sense of coherence (SOC-R), and cognitive emotion regulation strategies (CERQ). The Kolmogorov-Smirnov test and Shapiro-Wilk's test were used to determine whether the underlying distribution is normal. A sensitivity analysis was performed by running both the paired-sample t-test and Wilcoxon signed-rank test to inspect if the normality violation represents an issue. All analyses were performed using IBM SPSS 27. The value $p < .05$ was considered statistically significant. The facial video recordings were analysed using the facial recognition software FaceReader version 9.2 by Noldus. Emotional facial expressions were analysed by first calculating the average values for each subject for all emotions (happiness, surprise, sadness, fear, anger, disgust). The whole session was then analysed per blocks divided following the TST building blocks aligned with Freytag's pyramid sequence including the beginning of the story, rising action, changes that took place, and climax/critical point of the story. These building blocks that follow the Freytag's sequence were divided per minutes relevant to each sequence. These minutes include the

beginning ranging from 3750 – 4125 (3750 corresponding to 2 minutes and 30 seconds, as the sampling rate of the FaceReader is 25 frames per second), rising action 1 ranging from 4675 to 10650, rising action 2/changes that took place ranging from 12625 to 14150, and critical point/climax 14850 to 15550.

4.13 RESULTS

A total of 21 participants took part in this study, 13 females consisting 61% of the sample and 8 males consisting 39% of the sample. The total sample age ranged from 39 to 86 years with (M=67.10, SD=10.91). Violations in the assumptions were noted, concretely the differences between the scores of the variables were not normally distributed in some subscales (see Table 3), and outliers were present. Mild outliers detected were legitimate observations, and the data analysis was performed while keeping these outliers. Wilcoxon and signed rank test were run in parallel with the paired t-test to determine if the violations reflected on the obtained results. However, no significant difference was revealed for those variables. A paired-sample t-test revealed a significant difference in scores for pre-subjective caregiver burden (M=13.14, SD=5.97) and post-subjective caregiver burden (M=11.66, SD=5.21) conditions; t(20)=2.13, p=0.046 (see Table 4), 95% CI [0.032, 2.920]. These results suggest that the exposure to the audio narrative created following the Transformative Storytelling Technique significantly decreased the subjective caregiver burden of the sample.

Table 3. Kolmogorov-Smirnov and Shapiro Willk's test

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Age	.104	21	.200[*]	.977	21	.869
PSS	.174	21	.098	.923	21	.098
MLQ	.203	21	.024	.809	21	<,001
MLQ presence	.219	21	.010	.887	21	.020
MLQ search	.259	21	<,001	.779	21	<,001
SOC-R	.198	21	.032	.926	21	.113
SOC-R Manageability	.140	21	.200[*]	.970	21	.725
SOC-R Refelction	.218	21	.010	.904	21	.043
SOC-R Balance	.228	21	.006	.910	21	.054
BSFCs	.131	21	.200[*]	.951	21	.358
CERQPositiveReappraisal	.139	21	.200[*]	.950	21	.348
CERQPuttingIntoPrespective	.390	21	<,001	.435	21	<,001
CERQPositiveRefocusing	.219	21	.010	.917	21	.076
CERQAcceptance	.146	21	.200[*]	.948	21	.317
CERQBlamingOthers	.391	21	<,001	.730	21	<,001
CERQSelfBlame	.319	21	<,001	.810	21	<,001
CERQRumination	.205	21	.022	.944	21	.261
diffCERQCatastrophizing	.233	21	.004	.855	21	.005

[*]. This is a lower bound of the true significance.

[a]. Lilliefors Significance Correction

Note 1: Consult the Materials section for abbreviations

Table 4. Paired samples t-test

Paired Samples Test

		Paired Differences							
					95% Confidence Interval of the Difference				
		Mean	Std. Deviation	Std. Error Mean	Lower	Upper	t	df	Sig. (2-tailed)
Pair 1	PSS pre - PSS post	1.38095	3.86622	.84368	-.37893	3.14083	1.637	20	.117
Pair 2	MLQ pre - MLQ post	1.09524	6.64759	1.45062	-1.93071	4.12119	.755	20	.459
Pair 3	MLQ Presence pre - MLQ Presence Post	.33333	2.53640	.55349	-.82122	1.48789	.602	20	.554
Pair 4	MLQ Search pre - MLQ Search post	.57143	5.14365	1.12244	-1.76993	2.91279	.509	20	.616
Pair 5	SOCr pre- SOCr post	-.14286	3.41007	.74414	-1.69510	1.40939	-.192	20	.850
Pair 6	SOCr Manageability pre - SOCr Manageability post	.23810	1.75798	.38362	-.56213	1.03832	.621	20	.542
Pair 7	SOCr Balance pre - SOCr Balance post	-.14286	1.68184	.36701	-.90842	.62271	-.389	20	.701
Pair 8	SOCr Reflection pre - SOCr Reflection post	-.23810	2.16575	.47261	-1.22393	.74774	-.504	20	.620
Pair 9	BSFCs pre - BSFCs post	1.47619	3.17205	.69220	.03229	2.92009	2.133	20	.046
Pair 10	CERQ PositiveReappraisal pre - CERQ PositiveReappraisal post	.04762	1.71686	.37465	-.73389	.82913	.127	20	.900
Pair 11	CERQ Putting Into Perspective pre - CERQ Putting Into Perspective post	-1.61905	8.79475	1.91917	-5.62237	2.38427	-.844	20	.409
Pair 12	CERQ Positive Refocusing pre - CERQ Positive Refocusing post	-.23810	2.18872	.47762	-1.23439	.75820	-.499	20	.624
Pair 13	CERQ Refocus On Planning pre - CERQ Refocus On Planning post	-.19048	1.20909	.26385	-.74085	.35990	-.722	20	.479
Pair 14	CERQ Acceptance pre - CERQ Acceptance post	.28571	2.43193	.53069	-.82129	1.39272	.538	20	.596
Pair 15	CERQ Blaming Others pre - CERQ Blaming Others post	.19048	.92839	.20259	-.23212	.61307	.940	20	.358
Pair 16	CERQ Self Blame pre - CERQ Self Blame post	.09524	.99523	.21718	-.35778	.54826	.439	20	.666
Pair 17	CERQ Rumination pre- CERQ Rumination post	-.04762	1.98686	.43357	-.95203	.85679	-.110	20	.914
Pair 18	CERQ Catastrophizing pre- CERQ Catastrophizing post	.47619	1.50396	.32819	-.20841	1.16079	1.451	20	.162

Note 2: Consult the Materials section for abbreviations.

The FaceReader findings revealed that both happiness and surprise yield significant findings (n=20). The average levels of happiness show that the story has been able to increase over time the number and magnitude of the facial expressions conveying happiness. Statistical analyses between the first

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block of dataset, when participants were exposed to "beginning", and the final block of the dataset, when the same subjects were exposed to the "climax", revealed an increase in happiness of more than the double (from 0.032 up to 0.070 on average). In fact, happiness of the participants systematically increased over time as observed in linear tendency, thus meaning the main effect of the TST experience is improving the reactions of happiness on average during the storytelling (see Figure 11). The statistical difference is 0.047 (two tailed t-test), implies that the story has been able to increase positive emotion in terms of happiness reflected in the participants facial mimicry. Interestingly, when comparing the average levels of surprise in "beginning" and "climax" by applying the two-tailed double t-test there is a significant decrease (p=0.048). This demonstrates that the emotion of surprise was much higher in the beginning p= 0.031 average, than in the climax point p=0.014 (see Figure 3). The systematic decrease of neutral emotional facial expressions reveals that the story is able to increase the number of emotions, regardless of the type of emotions, over time. This finding supports what was already shown during the analyses of happiness where subjects at the starting point of the story did not show many facial expressions (as neutral expression is equal to 62%, the remaining expressional component conveying emotions accounts for 38%). In the final part of the "climax", the drop of percentage arrives to 48% approximately, with a decrease of 14% in terms of neutral face, that's to say with an increase of emotions (no matter what the emotion) of 14% in comparison to the starting point of the story.

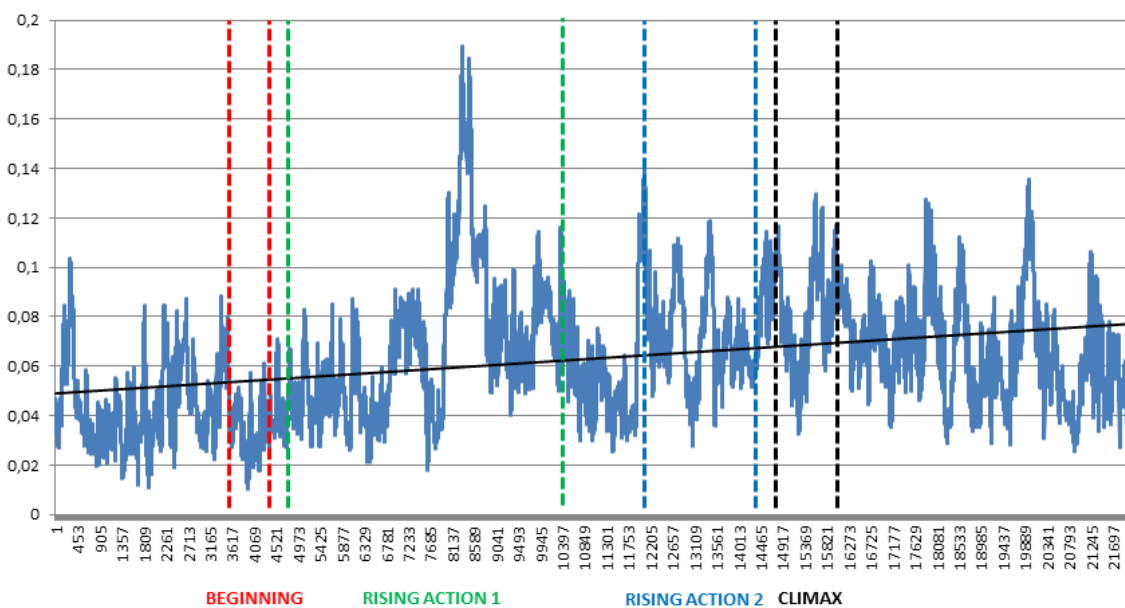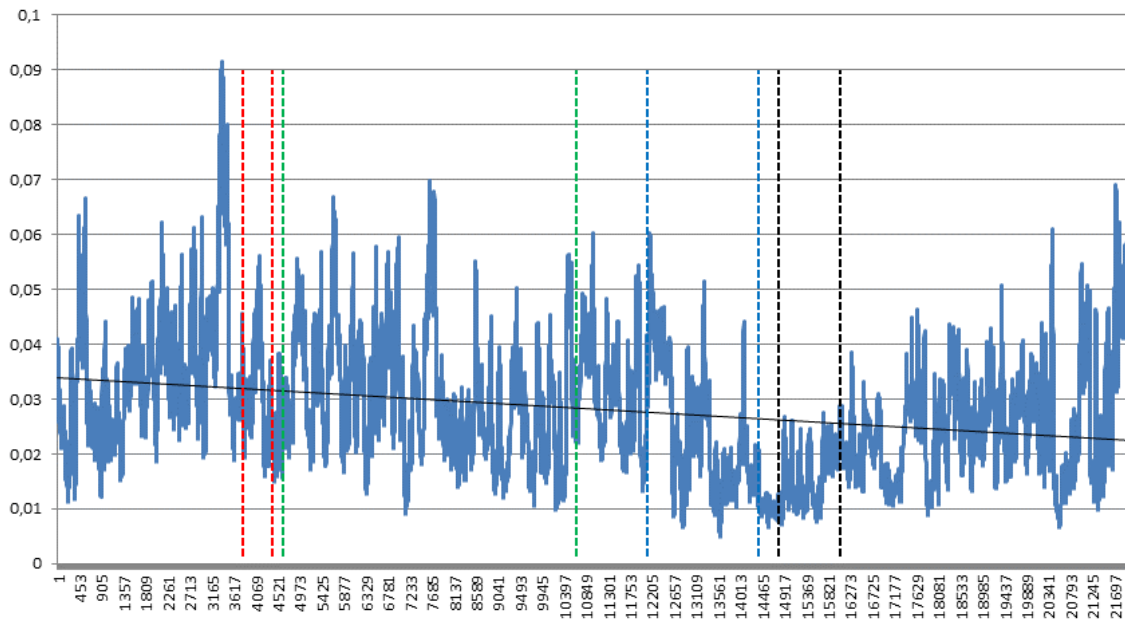*Figure 11. Average happiness level during audio exposure*

Figure 12. Average surprise levels during audio exposure

4.14 DISCUSSION

This study explored the efficacy and the feasibility of the TST technique in the informal care context by assessing the potential changes informal caregivers experience when exposed to the gender-adapted fictional informal caregiver storytelling created by using the TST. The TST technique for empowering digital mental health narratives aims to provide a cohesive path to assembling building blocks of the universal narratives for target populations (e.g., informal caregivers) which can then enable the incorporation of psychoeducation and coping skills to ensure productive fictional outcomes of the story (Petrovic & Gaggioli, 2021). In such a manner, the TST stories act as a template for narrative self-re-structuring within the target population (Petrovic et al., 2022).

Our initial step when assessing the feasibility of TST was to explore if the story structured following our technique can improve subjective caregiver burden, presence of meaning, perceived stress, and sense of coherence in informal caregivers. Positive findings are considered a good indicator for the future inclusion and delivery of other valuable approaches within storytelling such as role-relate skills, education, and psychoeducation and productive coping skills.

Past studies discovered a positive correlation between subjective caregiver burden and depression, anxiety, and burnout (Collins & Kishita, 2019), pointing that as the subjective caregiver burden increases, so does the reported level of depression. Moreover, in a meta-analysis by Collins and Kishita (2019) the findings point out depression in informal caregiver reaches up to 57%, while the estimated range of burden varies from 35.8% to 88.5 %. In line with that, targeting subjective caregiver burden would meaningfully support informal caregivers in managing their wellbeing in relation to experienced depression.

Our findings revealed that participants perceived caregiver burden significantly lower post-audio exposure, while sense of coherence, meaning in life, and cognitive emotion regulation, and perceived stress showed no significant difference post audio exposure. However, emotional facial expression findings revealed that the story was able to induce a significant increase in happiness and observed

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but insignificant increase in sadness coupled with a very small and insignificant increase of disgust. Moreover, the story induced a significant surprise in the beginning of storytelling which could be justified with novelty experience for the participants, and this emotion was significantly reduced by the story over time, due to the predominance of other emotions (such as happiness). Similarly, anger and fear were reduced by the story over time, but no significant differences were found comparing "beginning" with "climax" for these emotions.

The TST audio exposure, as seen in the FaceReader assessment (see Figure 11), was overall pleasant experience that was completed on a positive note or rather stable facial expression of happiness regardless of the incorporation of challenging and even difficult experiential themes within the story. In fact, it must be noted that at the moment of audio exposure the story itself was not promoted as real or fictional to the participants, although the audio narration is recorded with voice actors who were instructed to act out also the "sighs", brief brakes in moments where emotional themes are included, as well as spontaneous moments as having a cup of coffee or drinking water while narrating. Therefore, the experience itself was designed more closely to a confession of a friend or acquaintance about the caregiving rather than storied narration of the story.

Therefore, it can be argued that this impersonation of a caregiver personal confession which included themes that are important, identifiable, similar, and relevant to the experience of the listener himself/herself could be a potential explanation to why participants maintained positive attitude about the story even though dramatic story plot has been delivered, as well as why the family caregiver burden was significantly lowered post audio narration. This finding can be argued as the result of a careful TST structure which provides the sense of social interaction or peer like support which is noted as an important factor in managing and maintain mental health throughout the caregiving role.

It can be suggested that the familiarity of the themes had an important role in surprise decrease during the audio exposure, which could be a potential indicator that the TST can successfully engage target population by delivering engaging and self-identifiable audio experiences which is an important mechanism of the identification and absorption into the story world. It must be noted that in this pilot feasibility assessment, brief audio exposure using the TST technique succeeded in lowering family caregiver subjective burden, which is argued as one of the important factors, but also mediator in further adverse mental health experiences within the role.

On the other hand, we must mention an important limitation within the contextual structure of the audio story itself which could be the potential explanation for insignificant findings in measure for sense of coherence and meaning in life. Concretely, the audio story, as demonstrated in Study 3, was assembled using the themes retrieved from interviews with informal caregiver of individual living with dementia while the sample of our pilot study included informal caregivers across context of illness.

Therefore, an improved sample selection is required for more accurate findings, targeting the participants within the context of the story rather than across the contexts of illness. Furthermore, Perceived Stress Scale (PSS) used is a measure that is assessing the levels of stress perceived across a month period, and although this measure was argued initially as a correct choice considering we aimed to achieve the perspective shift post audio exposure which would reflect in the perceived stress, the future design would benefit from more concrete and even momentary assessments such as biophysiological stress assessment during and post audio exposure.

Nevertheless, considering the past findings on subjective burden that revealed a large positive association between the subjective burden and depressive symptoms in informal caregivers of older

individuals (del-Pino-Casado et al., 2019) and a large positive association between the subjective caregiver burden and anxiety (del-Pino-Cassado et al., 2021), our initial assessment shows promising result for TST storytelling in supporting informal caregivers to manage perceived burden within the role. Indeed, future adjustments in the design and improved sampling procedure are required, to further explore the TST technique in supporting informal caregivers. However, in line with the past findings on storytelling approaches used for supporting mental health across context this assessment encourages deeper exploration of storytelling as a stand-alone or additional tool for independent use among informal caregivers and professional use by the mental health practitioners.

REFERENCES

Allen AP, Curran EA, Duggan Á, et al. (2017) A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience & Biobehavioral Reviews 73: 123–164.

Alves, L. C. D. S., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegrini, L. N. D. C., & Vale, F. A. C. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. Dementia & Neuropsychologia, 13, 415-421.

Amer Nordin, A., Mohd Hairi, F., Choo, W. Y., & Hairi, N. N. (2019). Care recipient multimorbidity and health impacts on informal caregivers: a systematic review. The Gerontologist, 59(5), e611-e628.

Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. Social science & medicine, 36(6), 725-733.

Armstrong, E., & Ulatowska, H. (2007). Making stories: Evaluative language and the aphasia experience. Aphasiology, 21(6-8), 763-774.

Balzarotti, S., Biassoni, F., Villani, D., Prunas, A., & Velotti, P. (2016). Individual differences in cognitive emotion regulation: Implications for subjective and psychological well-being. Journal of Happiness Studies, 17(1), 125-143.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

Bertogg, A., & Strauss, S. (2020). Spousal care-giving arrangements in Europe. The role of gender, socio-economic status and the welfare state. Ageing & Society, 40(4), 735-758.

Calvó-Perxas, L., Vilalta-Franch, J., Litwin, H., Turró-Garriga, O., Mira, P., & Garre-Olmo, J. (2018). What seems to matter in public policy and the health of informal caregivers? A cross-sectional study in 12 European countries. PloS one, 13(3), e0194232.

Calvó-Perxas, L., Vilalta-Franch, J., Litwin, H., Mira, P., & Garre-Olmo, J. (2021). A longitudinal study on public policy and the health of in-house caregivers in Europe. Health Policy, 125(4), 436-441.

Carragher, M., Steel, G., Talbot, R., Devane, N., Rose, M. L., & Marshall, J. (2021). Adapting therapy for a new world: storytelling therapy in EVA Park. Aphasiology, 35(5), 704-729.for a new world: storytelling therapy in EVA Park. Aphasiology, 35(5), 704-729.

Casanova, G., Principi, A., & Lamura, G. (2020). Social innovation in long-term care: Lessons from the Italian case. International Journal of Environmental Research and Public Health, 17(7), 2367.

Chiesi, F., Marunic, G., & Lau, C. (2020). Validation study of an Italian version of the revised Sense

of Coherence Scale (SOC-R). Current Psychology, 1-8.

Clark, M. C., & Standard, P. L. (1997). The caregiving story: how the narrative approach informs caregiving burden. Issues in Mental Health Nursing, 18(2), 87-97.

Cohen, S., Kamarck, T., & Mermelstein, R. (2021). Perceived stress scale. Measuring stress: a guide for health and social scientists. 1994.

Collins, R. N., & Kishita, N. (2020). Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis. Ageing & Society, 40(11), 2355-2392.

Cooper, R. A. (2021). "I Am a Caregiver": Sense-making and Identity Construction through Online Caregiving Narratives. Journal of Family Communication, 21(2), 77-89.

Crossley, M. L. (2000). Narrative psychology, trauma and the study of self/identity. Theory & Psychology, 10(4), 527-546.

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & Ramos- De Vugt, M. E., & Verhey, F. R. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. Progress in neurobiology, 110, 54-62.

del-Pino-Casado, R., Espinosa-Medina, A., López-Martínez, C., & Orgeta, V. (2019). Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. Journal of Affective Disorders, 242, 14-21.

Eibich, P. (2021). Care Or Self-care?: The Impact of Informal Care Provision on Health Behaviour. Max Planck Institute for Demographic Research.

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. American Journal of Health Education, 46(6), 357-367.

Evans, R., Catapano, M., Brooks, D., Goldstein, R., & Avendano, M. (2012). Family caregiver perspectives on caring for ventilator-assisted individuals at home. Canadian respiratory journal, 19(6), 373-379.

Freytag, G. (1894). Freytag's Technique of the Drama. Scott, Foresman.

Fuster, V. (2017). Changing demographics: a new approach to global health care due to the aging

population. Journal of the American College of Cardiology, 69(24), 3002-3005.

Galvin, M., Gaffney, R., Corr, B., Mays, I., & Hardiman, O. (2017). From first symptoms to diagnosis of amyotrophic lateral sclerosis: perspectives of an Irish informal caregiver cohort—a thematic analysis. BMJ open, 7(3), e014985.

Garnefski, N., Kraaij, V., & Spinhoven, P. (2001). Negative life events, cognitive emotion regulation and emotional problems. Personality and Individual differences, 30(8), 1311-1327.

Gérain, P., & Zech, E. (2022). A harmful care: the association of informal caregiver burnout with

depression, subjective health, and violence. Journal of interpersonal violence, 37(11-12), NP9738-NP9762.

Graessel, E., Berth, H., Lichte, T., & Grau, H. (2014). Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. BMC geriatrics, 14(1), 1-9.

Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. Journal of Aging Studies, 23(1), 48-59.

Holkham, L., & Soundy, A. (2018). The experience of informal caregivers of patients with motor neurone disease: a thematic synthesis. Palliative & Supportive Care, 16(4), 487-496.

Lacey, R. E., McMunn, A., & Webb, E. (2019). Informal caregiving patterns and trajectories of psychological distress in the UK Household Longitudinal Study. Psychological medicine, 49(10), 1652-1660.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. Springer publishing company.

Lee, J. Y., Tikellis, G., Corte, T. J., Goh, N. S., Keir, G. J., Spencer, L., ... & Holland, A. E. (2020). The supportive care needs of people living with pulmonary fibrosis and their caregivers: a systematic review. European Respiratory Review, 29(156).

Lindahl, B., Lidén, E., & Lindblad, B. M. (2011). A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings. Journal of clinical nursing, 20(3-4), 454-463.

Lowe, K. (2019). Solution-focused narrative therapy with families. Marriage and family therapy: A practice-oriented approach, 363-380.

McAdams, D. P. (2011). Narrative identity. In Handbook of identity theory and research (pp. 99-115). Springer, New York, NY.

McAdams, D. P., Reynolds, J., Lewis, M., Patten, A. H., & Bowman, P. J. (2001). When bad things turn good and good things turn bad: Sequences of redemption and contamination in life narrative and their relation to psychosocial adaptation in midlife adults and in students. Personality and social psychology bulletin, 27(4), 474-485.

McLean, K. C. (2008). The emergence of narrative identity. Social and Personality Psychology Compass, 2(4), 1685-1702.

Madigan, S. (2011). Narrative therapy. American Psychological Association.

Mondo, M., Sechi, C., & Cabras, C. (2022). Psychometric evaluation of three versions of the Italian Perceived Stress Scale. In Key Topics in Work and Organizational Psychology (pp. 1-9). Springer, Cham.

Montgomery, R. J., Kwak, J., Kosloski, K., & O'Connell Valuch, K. (2011). Effects of the TCARE®

intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 66(5), 640-647.

Montgomery, R. J., & Kosloski, K. D. (2013). Pathways to a caregiver identity and implications for support services. In Caregiving across the lifespan (pp. 131-156). Springer, New York, NY.

Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. PloS one, 13(1), e0189874.

Negri, L., Bassi, M., & Delle Fave, A. (2020). Italian validation of the meaning in life questionnaire: factor structure, reliability, convergent, and discriminant validity. Psychological Reports, 123(2), 578-600.

Norsensu. 8 classic storytelling techniques. Norsensus. URL: https://norsensus.no/storydown/storytelling-techniques/ [accessed 2022-07-17]

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. Academic medicine, 89(9), 1245-1251.

O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. Journal of Aging Studies, 21(2), 165-174.

Payne, M. (2006). Narrative therapy. Narrative Therapy, 1-224.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The gerontologist, 30(5), 583-594.

Petrovic, M., & Gaggioli, A. (2020). Digital mental health tools for caregivers of older adults—a scoping review. Frontiers in Public Health, 8, 128.

Petrovic, M., & Gaggioli, A. (2021). The potential of transformative video design for improving caregiver's wellbeing. Health psychology open, 8(1), 20551029211009098.

Petrovic, M., Bonanno, S., Landoni, M., Ionio, C., Hagedoorn, M., & Gaggioli, A. (2022). Using the Transformative Storytelling Technique to Generate Empowering Narratives for Informal Caregivers: Semistructured Interviews, Thematic Analysis, and Method Demonstration. JMIR formative research, 6(8), e36405.

Petruzzo, A., Paturzo, M., Naletto, M., Cohen, M. Z., Alvaro, R., & Vellone, E. (2017). The lived experience of caregivers of persons with heart failure: A phenomenological study. European Journal of Cardiovascular Nursing, 16(7), 638-645.

Pindus, D. M., Mullis, R., Lim, L., Wellwood, I., Rundell, A. V., Abd Aziz, N. A., & Mant, J. (2018). Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services–a systematic review and meta-ethnography. PloS one, 13(2), e0192533.

Plöthner, M., Schmidt, K., De Jong, L., Zeidler, J., & Damm, K. (2019). Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC geriatrics, 19(1), 1-22.

Pope, N., Giger, J., Lee, J., & Ely, G. (2017). Predicting personal self-care in informal caregivers. Social work in health care, 56(9), 822-839.

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. Dementia, 14(2), 220-237.

Ricks, L., Kitchens, S., Goodrich, T., & Hancock, E. (2014). My story: The use of narrative therapy in individual and group counseling. Journal of Creativity in Mental Health, 9(1), 99-110.

Rivera-Navarro, J., Sepúlveda, R., Contador, I., Fernández-Calvo, B., Ramos, F., Tola-Arribas, M. Á., & Goñi, M. (2018). Detection of maltreatment of people with dementia in Spain: usefulness of the Caregiver Abuse Screen (CASE). European journal of ageing, 15(1), 87-99.

Sallim, A. B., Sayampanathan, A. A., Cuttilan, A., & Ho, R. C. M. (2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. Journal of the American Medical Directors Association, 16(12), 1034-1041.

Schmitz, H., & Westphal, M. (2015). Short-and medium-term effects of informal care provision on female caregivers' health. Journal of health economics, 42, 174-185.

Spasova, S., Baeten, R., & Vanhercke, B. (2018). Challenges in long-term care in Europe. Eurohealth, 4(4), 7-12.

Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: assessing the presence of and search for meaning in life. Journal of counseling psychology, 53(1), 80.

van Roij, J., Brom, L., Soud, Y. E., van de Poll-Franse, L., & Raijmakers, N. J. (2019). Social consequences of advanced cancer in patients and their informal caregivers: a qualitative study. Supportive Care in Cancer, 27(4), 1187-1195.

Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjær, E. L., & Eikemo, T. A. (2017). Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. The European Journal of Public Health, 27(suppl_1), 90-95.

Wieland, M. L., Njeru, J. W., Hanza, M. M., Boehm, D. H., Singh, D., Yawn, B. P., ... & Sia, I. G. (2017). Pilot feasibility study of a digital storytelling intervention for immigrant and refugee adults with diabetes. The Diabetes Educator, 43(4), 349-359.

Woodford, J., Farrand, P., Watkins, E. R., & LLewellyn, D. J. (2018). " I Don't Believe in Leading a

Life of My Own, I Lead His Life": A Qualitative Investigation of Difficulties Experienced by Informal Caregivers of Stroke Survivors Experiencing Depressive and Anxious Symptoms. Clinical Gerontologist, 41(4), 293-307.

Yamamoto, Y., Hayashino, Y., Yamazaki, S., Takegami, M., & Fukuhara, S. (2009). Violent patient behavior is associated with bodily pain and a high burden on informal caregivers. Journal of general internal medicine, 24(10), 1085-1088.

Zygouri, I., Cowdell, F., Ploumis, A., Gouva, M., & Mantzoukas, S. (2021). Gendered experiences of providing informal care for older people: a systematic review and thematic synthesis. BMC health services research, 21(1), 1-15.

CHAPTER IV

5 THE APPLICATION OF TST IN "VOICE ME OUT" WEB PORTAL: OPPORTUNITIES AND CHALLENGES

SUMMARY OF THE CHAPTER

This chapter reflects on the methodological limitations of Study 1 and Study 3, and Study 4. Next, it continues by discussing the implications for future research and further applications in practice. Finally, it includes an introduction and demonstration of front-end concept for the VOICE me OUT web portal designed as the outcomes of the TST technique for informal caregivers. The front-end design of the portal is introduced together with a description of the portal, potential utilization, and the aspect so of the TST that can be further applied in digital context.

5.1 METHODOLOGICAL LIMITATIONS

Several important limitations are noted in this project, considering the studies conducted, procedures followed, and the materials used. Namely, Study I explored digital mental health tools for informal caregivers of older adults, however inclusion criteria did not clearly define the mental health tool itself. In line that, a wider search of the existing tools was enabled, however the quality of the retrieved tools is questionable. For instance, various studies describe mobile applications which are used as a support tool for informal caregivers but do not necessarily constitute mental health tool by its definition. Moreover, the scoping review included variety of methodological approaches including RCT, and qualitative studies. This has been beneficial in retrieving the existing tools in already limited literature; however, the effectiveness of the included digital mental health tools could not be compared by drawing the parallel between the scores obtained across studies. Furthermore, a closer consideration of the existing informal caregiver needs would be beneficial, to better understand and position the focus on the digital tools relevant to the existing caregiver needs.

Following that, Study 3 introduced the Transformative Storytelling Technique as a methodological approach for developing empowering stories. However, the initial steps of data collection for the application of the TST have been hindered by the occurring pandemic at the moment of initiation of data collection. Therefore, it can be suggested that the quality and richness of data retrieved in the conducted telephone interviews varies considerably due to the methodology but also due to the COVID-19 related circumstances. It could be suggested that the intensity of the adverse experiences reported in the interviews is influenced or partially biased by the fears and uncertainty caused by the pandemic itself. This issue certainly reflected on qualitative recollections that were partially defined by the external situation and were potentially intensified due to it. As an outcome, it could be suggested that the retrieved themes (i.e., building blocks of the story) are somehow externally influenced or conditioned and might not reflect the caregiving experience outside of the pandemic.

In line with that, Study 4 which is a pilot assessment of the feasibility of the TST story is performed in a sample of informal caregivers throughout caregiving context. In essence, caregivers were included regardless of the care condition of the care recipient. Although including caregivers across context allowed the assessment of the story in its general application in the informal caregiving population, the story was initially developed as described in the Study 3 using the sample of informal caregivers of individuals living with dementia. In the Chapter II, I address informal caregiving as idiosyncratic process, and continue to discuss in Chapter III the relevance of TST technique in targeting the building blocks of informal care by forming a cluster of data which allows overview of the general caregiving experience rather than individual one. However, I must note that when generalizing caregiving experience, the initial storytelling development must also be performed across context rather than be illness restricted. Therefore, it could be argued that the TST story assessed in the feasibility trial is more appropriate and better accommodate the experience of informal caregivers of individuals with dementia rather than overall experience of informal caregivers. This ultimately could influence the findings of the Study 4 by reflecting in the scale Presence of Meaning scores pre and post storytelling exposure.

5.2 IMPLICATIONS FOR FUTURE RESEARCH

In accordance with the discussed limitations, I distinguish three main implications for future research. First, careful consideration and proper application of TST must be in place in its initial steps when the story building blocks are collected. Second, an additional measure relevant to narrative experience such as Narrative Engagement Questionnaire (NEQ) would be of value. NEQ would allow better

understanding of individual subjective experience of the story. Third, carefully crafted interventional two arm design will allow comparison between flat narrative and TST narrative to understand the value of TST when compared to other types of storytelling currently available or used.

Proper TST application will constitute unbiased building blocks that are target group focused but sub-context free. More concretely, as seen from my example, optimal TST application would constitute collection of the informal caregiver life story as seen in Study 3 by including informal caregivers regardless of the illness of the care recipient, or by assessing the feasibility of the TST by including only informal caregivers of individuals with dementia in Study 4. This implication expands on the potential application of the TST across context which is further demonstrated in VOICE me OUT web portal.

Another important implication I note is the reflection on the narrative engagement of the story. Past researcher indicated that narrative engagement acts as a determinant of absorption into the story world which then affects key cognitive mechanisms in appraisal and counterarguing. Therefore, demonstrating TST narrative engagement in the participants will imply overall potential TST story influence on the participant. In line with that, including Narrative Engagement Questionnaire (NEQ) would allow better understanding of the other outcomes since engagement can act as a mediating factor in story outcomes including meaning making and sense of coherence.

Finally, improved interventional two arm design with flat-narrative story exposure in group 1 and TST story exposure in group 2 would allow better understanding of the effects of the TST on target population. As indicated by past studies (see Petrovic et al., 2022), the influence of the narrative on the audience beliefs and behaviors also depends on the cohesive narrative structure implying that a longitudinal exploration is required to confirm whether methodological steps of TST support the development of influential stories.

6 PROTOTYPING: FIRST APPLICATION OF TRANSFORMATIVE STORYTELLING TECHNIQUE IN VOICE ME OUT WEB PORTAL FOR INFORMAL CAREGIVERS

VOICE me OUT (VO) platform is envisioned as a safe space for informal caregivers to connect, share, and listen to empowering stories. The role of the platform is to act as a two-dimensional medium, where in the first dimension the library of pre-developed empowering stories is available for informal caregivers, while in the second dimension the library of user-recorded personal and role-related stories is available.

In this aspect, VO acts as a tool for TST story empowerment while also serving as a bridge for creating social connection and lowering the sense of isolation and loneliness within the caregiving role. User journey is designed to follow the registration, required selection to better adapt user experience (based on the gender of the user and care recipient, family relation to the care recipient) user account creation, and the adapted library of the pre-recorded stories followed by the library of the uploaded stories. The library can be searched using #selectionofkeywords relevant to the storytelling topic. A following series of figures included aim to demonstrate the front-end design of the platform with the additional explanations.
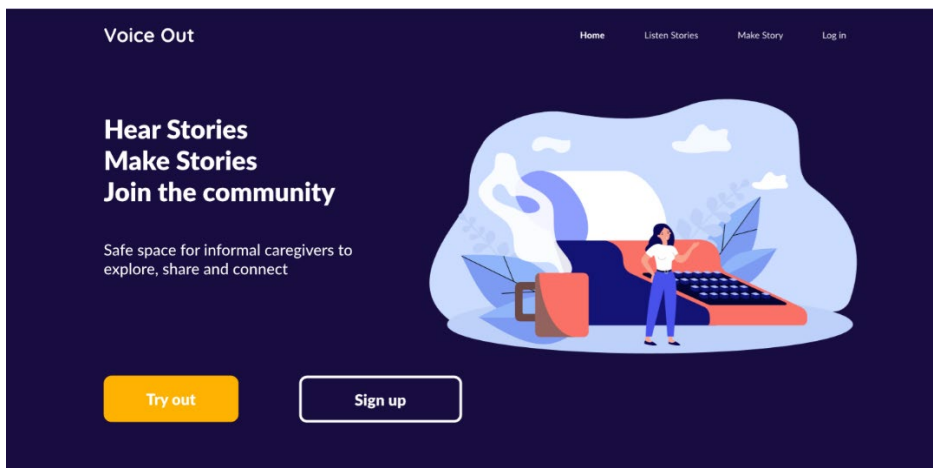
Once the user accesses the landing page (Figure 13) an initial selection can be made between the free trial and registration. Further options of "Listen to Stories" and Make stories" are available, however the option of recording personal stories requires registration while pre-developed library of stories (excluding user-generated stories) is freely available. Following the selection for registration (Figure 14), the user is required to share basic information to generate an account.

Figure 14. Registration page
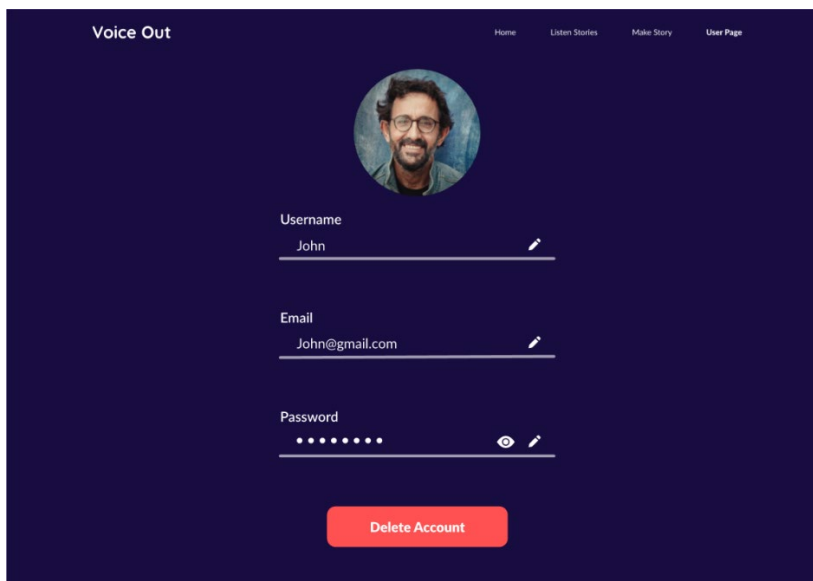
Once the account is generated a series of questions related to the gender of the user, gender of the care recipient, and the relationship to the care recipient are asked to improve user-experience of VO, but also to properly assign the library to the user (Figure 15; Figure 16; Figure 17). For example, if the user is a female caregiver providing long term care for her spouse, the library with generated stories for a male caregiver providing long term care for his father would not be relevant to support identification with the story nor identification with the building blocks (i.e., themes) of the TST, therefore no benefit for the user would be achieved.

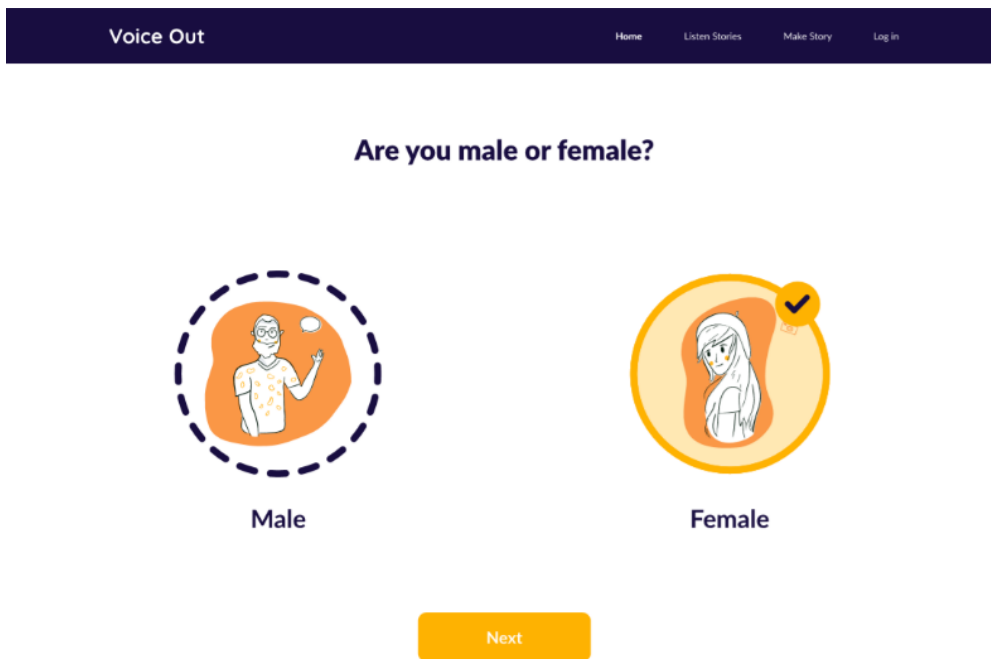*Figure 15. Selection criteria to improve user experience of VO 1/3*

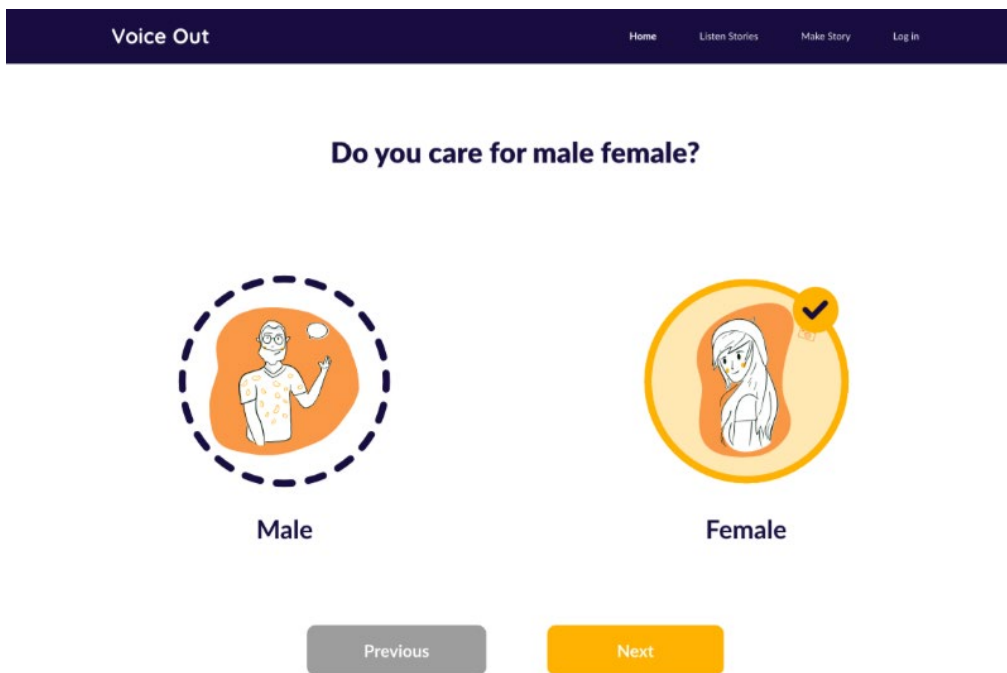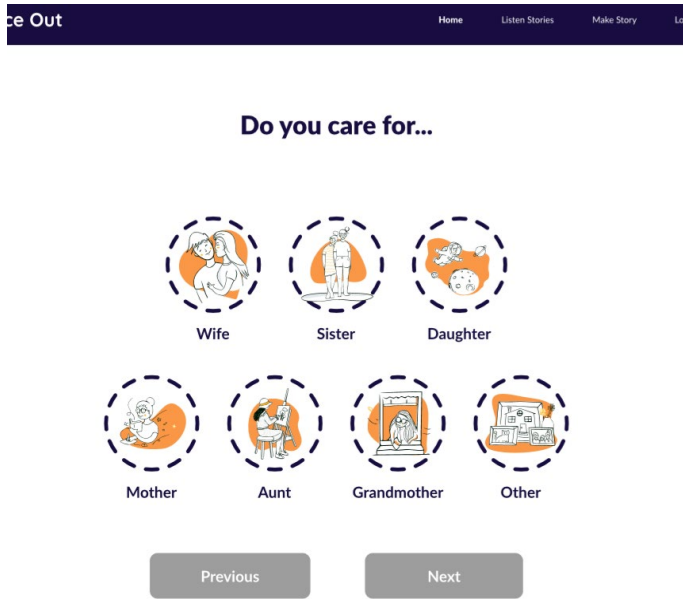*Figure 16. Selection criteria to improve user experience of VO 2/3*

Figure 17. Selection criteria to improve user experience of VO 3/3

After the initial categorization of the user during the registration process the user can access the existing library of pre-developed and user-generated stories, as well as record and share stories (Figure 18).

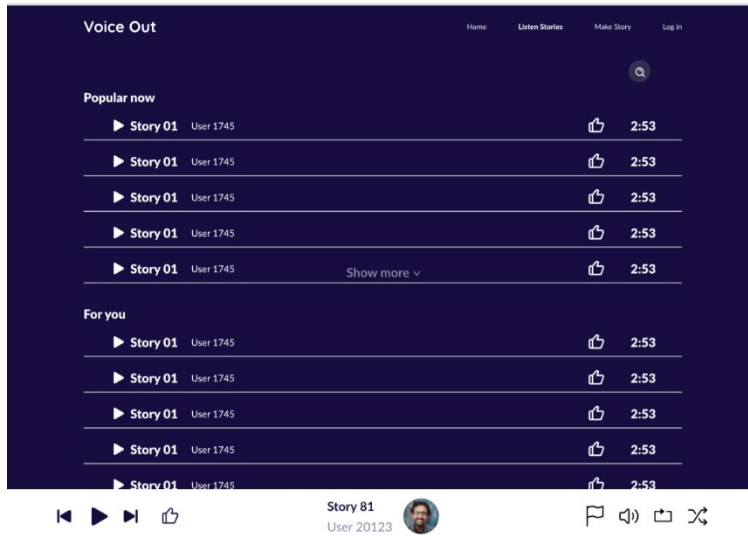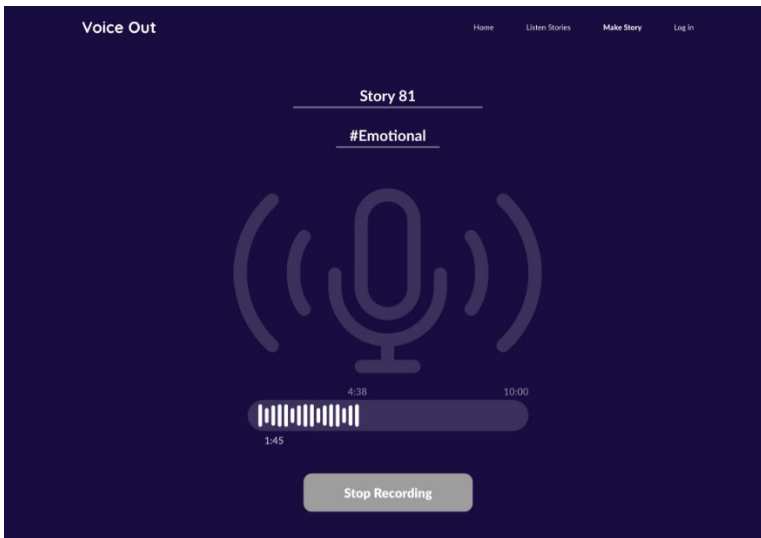*Figure 18. Library of the TST stories and user-generated stories*

Figure 19. User recording personal story

User-recorded stories allow user to record personal caregiving narratives and assign proper #hashtags that then act as filters and position story according to gender, caregiver-care recipient relationship to properly sort user story in the library of generated stories allowing other users with the similar background to locate the story (Figure 19).

Consistent presence on the platform is expected to allow user to highlight stories, create a library of favourite stories, connect with other users by following their libraries, but also store personal recordings that will help user follow his/her own long-term caregiver journey in a form similar to personal audio diary. Longer presence on the platform would be expected to generate user account similar to Figure 20.

Figure 20. User account with highlighted and user-generated stories

VOICE me OUT platform is a prototype version for the envisioned implementation of the Transformative Storytelling Technique for informal caregivers that is aimed to be used as a support

tool. However, in this brief demonstration of the prototype version, it is evident that the technique can be implemented across context for different target populations. TST is designed for large scale support but does not allow generalization of the context, which in essence means that implementation of the technique must be based on a target population such as war veterans, addiction recoveries, PTSD support, marital support, etc. Indeed, further implementation perfecting is possible during the back-end development which could also expand on the number of options and possibilities with TST. Another important point is that such platforms require further administrators and content control to ensure that the platform is used properly and in line with the envisioned purpose.

7 GENERAL CONCLUSIONS

Informal care remains one of the most relevant sources of support for family members and close others in need of long-term support. This type of support enables care recipients to continue independent living and remain in home environment for as long as desired. Although the prevalence and distribution of informal care varies across Europe, the informal caregiver gap is evident in all countries regardless of traditional support preference or formal care services reliance (Spasova et al., 2018). Studies included in this dissertation demonstrated both positive and negative impacts of long-term care provision for informal caregivers. On the positive side, providing informal care can be a rewarding experience that can strengthen relationships and provide a sense of purpose and meaning (Blinka et al., 2022). However, it can also be emotionally and physically demanding, and lead to caregiver burnout and negative impact on caregivers' own health and well-being as consistently demonstrated in past and recent studies (Bell et al., 2001; Kayaalp et al., 2020).

There is an evident need both in theory and practice for policy changes and support system synchronization to help caregivers balance their daily caregiving duties with personal needs while maintaining physical and mental health. These changes include the development and coordination between formal health care system and informal caregivers to access much needed respite care services, financial support, training, and education programs. Furthermore, it is also important to facilitate informal caregivers access to practical care related information and resources that will enable proper daily task execution and overall care for the loved one who receives care. In line with that, the support aspect also extends to support beyond the information, communication, education, and temporary break from care activities to mental health support of the informal caregivers.

As demonstrated in Study 1, digital mental health tools have an overall positive role in supporting informal caregivers' mental health. Moreover, the existing mental health apps for informal caregivers provide range of support such as coping skills, emotion regulation, de-stress techniques through mindfulness approaches, and care skill-building aiming to reduce role-related burden. Similarly, telemedicine and online support groups also serve as tools for enabling social support and peer connection among informal caregivers that were shown as an important aspect of mental health support (Petrovic & Gaggioli, 2020; Cassie et al., 2008; Van den Huevel et al., 2002). Nevertheless, the existing support gap persists and becomes evident when qualitative exploration of informal caregiver daily life and caregiving narratives is conducted. As seen in Study 3, informal caregivers experience extensive and important role-related series of events that overlap between caregivers within the illness context and point to an important gap in addressing these occurrences before the psychological and psychosomatic symptoms appear.

For instance, the TST applied in Study 3 allowed in-depth reflection on life changes, challenges, routine shifts, and emotional and psychological difficulties informal caregivers experience before the symptomatology often addressed with mental health apps and other digital and in-person support appears. Changes in routine explored in Study 3, as well as newly formed daily habits point to a gradual rise in experienced difficulties that are then reflected in emotional challenges which lead to the critical point that is often reflected in depression, anxiety, stress, and overall burden noted in literature (see Figure 2 in Study 3). The retrieved themes in Study 3 can be further considered individually, and the existing support gap can be better targeted and addressed following the TST technique when applied across illness context for informal caregivers. In fact, the overall life narratives and identity shift that occurs upon the assumption of the caregiving role can serve as a

useful path to help future research explore and target informal caregiver mental health needs to better design and understand the support tools required.

Moreover, the added value of the TST technique in supporting informal caregiver wellbeing has also been demonstrated through the Study 4 where informal caregivers experienced significant increase in happiness as demonstrated in the analysis of facial expression, and significant decrease in subjective family caregiver burden in self-report measure. These findings potentially point that the exposure to TST storytelling supported informal caregivers to shift the existing perception of their own caregiving role to more positive one which was then demonstrated in the subjective burden post measure.

Rapidly developing filed of digital health is already utilizing storytelling to support, inform, educate, and treat individuals experiencing vast variety of mental health challenges. However, bearing in mind that prior to TST no existing digital storytelling technique was noted, the question remains if the existing storytelling approaches utilize constructive or potentially destructive narrative structure for the end-users or the audience. In fact, considering the existing neuroscientific findings on the effects of proper narrative structure on influencing audience beliefs and attitudes, as well as the demonstrated role of storytelling in appraisal and attribution, it must be noted that the application of storytelling in mental health must be utilized with caution. Concretely, carefully designed narratives delivered through storytelling and their longitudinal effect needs to be better understood and considered by the research community before future techniques for developing influential mental health content will be created.

Moreover, a simple pilot feasibility testing noted in Study 4 demonstrated that utilization of guided narrative structure can influence the audience even in the brief exposure, as it was case in the Study 4 where informal caregivers listened to TST audio story for fifteen minutes. It must be fully acknowledged that longitudinal effects of repetitive exposure to structured digital narratives are yet to be explored, therefore caution must be applied in further work in both developing and utilizing storytelling techniques for mental health support.

Ethical principles for developing and applying narrative techniques for influencing behavior must be developed and carefully monitored as the field of digital storytelling in mental health prospers. Moreover, it is important to conclude with acknowledging that the existing digital mental health tools and digital narrative as TST can still act as support tool to be utilized by informal caregivers who also have access to mental health experts beyond the digital world. Therefore, digital storytelling can be considered a great addition that can serve for individual and group support to facilitate the assumption of the caregiving role and the development of both practical and mental health skills necessary for the role provision. However, potential concerns, or other issues that can be raised throughout fictional TST stories still require practitioners support and navigation through possible adverse experiences.

We must be prepared to anticipate and intercept the abuse of digital mental health techniques that utilize micro-manipulations or have demonstrated effectiveness in influencing the users/viewer's behaviors, for commercial purposes. Furthermore, vast data-privacy breaches, cybersecurity incidents, and common personal data leaks, also mean that influential digital storytelling techniques can be successfully utilized and delivered without directly involving users which would technically constitute the "beyond influence" use (i.e., abuse). Such use would define deliberate abuse of potent narrative techniques for financial benefit, guiding public opinion or opinion of an individual according to the subjective goals of groups, organizations, or other individuals. In fact, all abuse of narrative techniques that in some way can cause potential damage to the end user should be considered as "beyond influence". A transdisciplinary approach to ethical guidelines and rules is truly required

considering the future use of guided digital storytelling techniques, their transparency, labelling and safety.

REFERENCES

Bell CM, Araki SS, Neumann PJ (2001) The association between caregiver burden and caregiver health-related quality of life in Alzheimer disease. Alzheimer Disease & Associated Disorders 15(3): 129–136.

Blinka, M. D., Liu, C., Sheehan, O. C., Rhodes, J. D., & Roth, D. L. (2022). Family caregivers emphasise patience and personal growth: a qualitative analysis from the Caregiving Transitions Study. Age and Ageing, 51(2), afab266.

Cassie, K. M., & Sanders, S. (2008). Chapter 12; familial caregivers of older adults. Journal of Gerontological Social Work, 50(S1), 293-320.

Petrovic, M., & Gaggioli, A. (2020). Digital mental health tools for caregivers of older adults—a scoping review. Frontiers in Public Health, 8, 128.

Kayaalp, A., Page, K. J., & Rospenda, K. M. (2021). Caregiver burden, work-family conflict, family-work conflict, and mental health of caregivers: A mediational longitudinal study. Work & Stress, 35(3), 217-240.

Spasova, S., Baeten, R., & Vanhercke, B. (2018). Challenges in long-term care in Europe. Eurohealth, 24(4), 7-12.

Van Den Heuvel, E. T., de Witte, L. P., Stewart, R. E., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2002). Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: which caregivers benefit the most?. Patient education and counseling, 47(4), 291-299.

LIST OF PUBLICATIONS RELATED TO THE DISSERTATION

1. Petrovic, M., & Gaggioli, A. (2020). Digital mental health tools for caregivers of older adults—a scoping review. Frontiers in Public Health, 8, 128.
2. Petrovic, M., & Gaggioli, A. (2020). The potential of transformative interactive video storytelling for improving caregivers' mental wellbeing: a research protocol. Annu. Rev. Cyberther. Telemed, 275, 2020.
3. Petrovic, M., & Gaggioli, A. (2021). The potential of transformative video design for improving caregiver's wellbeing. Health psychology open, 8(1), 20551029211009098.
4. Petrovic, M., Gaggioli, A., Landoni, M., & Ionio, C. (2021, November). Building-up Self-Re-Structure of Personal Life Story within Informal Care. In International Journal in Qualitative Methods (Vol. 20, pp. 33-33). 2455 Teller RD, Thousand Oaks CA 91320 USA: SAGE Publications Inc.
5. Petrovic, M., Bonanno, S., Landoni, M., Ionio, C., Hagedoorn, M., & Gaggioli, A. (2022). Using the Transformative Storytelling Technique to Generate Empowering Narratives for Informal Caregivers: Semistructured Interviews, Thematic Analysis, and Method Demonstration. JMIR formative research, 6(8), e36405.
6. Petrovic, M., Liedgren, J., & Gaggioli, A. (2022). Beyond Influence: Contextualization and Optimization for new narrative techniques and story-formats. Perspective paper. Frontiers in Communication, 245.

REFERENCES

Abreu, M., Silva, A. L., Costa, N., & Abreu, W. (2015). Psychoeducational programs for informal caregivers of dependent older adults: Barriers to participation. Procedia-Social and Behavioral Sciences, 171, 629-634.

Adams, V., Murphy, M., & Clarke, A. E. (2009). Anticipation: Technoscience, life, affect, temporality. Subjectivity, 28(1), 246-265.

Akkerman, R. L., & Ostwald, S. K. (2004). Reducing anxiety in Alzheimer's disease family caregivers: the effectiveness of a nine-week cognitive-behavioral intervention. American Journal of Alzheimer's Disease & Other Dementias®, 19(2), 117-123.

Aljammaz, R., Oliver, E., Whitehead, J., & Mateas, M. (2020, September). Scheherazade's Tavern: A prototype for deeper NPC interactions. In International conference on the foundations of digital games (pp. 1-9).

Allen, A. P., Curran, E. A., Duggan, Á., Cryan, J. F., Chorcoráin, A. N., Dinan, T. G., ... & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience & Biobehavioral Reviews, 73, 123-164.

Allen, R., & Krebs, N. (2007). Dramatic psychological storytelling. In Dramatic psychological storytelling (pp. 31-41). Palgrave Macmillan, London.

Alves, L. C. D. S., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegrini, L. N. D. C., & Vale, F. A. C. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. Dementia & Neuropsychologia, 13, 415-421.

Amer Nordin, A., Mohd Hairi, F., Choo, W. Y., & Hairi, N. N. (2019). Care recipient multimorbidity and health impacts on informal caregivers: a systematic review. The Gerontologist, 59(5), e611-e628.

Angus, L. E., & Greenberg, L. S. (2011). Working with narrative in emotion-focused therapy: Changing stories, healing lives. American Psychological Association.

Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. Social science & medicine, 36(6), 725-733.

Armoogum, J., Richardson, A., & Armes, J. (2013). A survey of the supportive care needs of informal caregivers of adult bone marrow transplant patients. Supportive Care in Cancer, 21(4), 977-986.

Armstrong, E., & Ulatowska, H. (2007). Making stories: Evaluative language and the aphasia experience. Aphasiology, 21(6-8), 763-774.

Avieli, H., Band-Winterstein, T., & Zamir, A. (2022). Juggling between caregiving and self-actualization: Older parents' lifelong experience of caring for an adult child with developmental disabilities. *Plos one*, 17(11), e0276779.

Aylett, R. S., Louchart, S., Dias, J., Paiva, A., & Vala, M. (2005, September). FearNot!–an experiment in emergent narrative. In International workshop on intelligent virtual agents (pp. 305-316). Springer, Berlin, Heidelberg.

Baceviciute, S., Rützou Albæk, K. R., Arsovski, A., & Bruni, L. E. (2012, November). Digital interactive narrative tools for facilitating communication with children during counseling: A case for audiology. In International conference on interactive digital storytelling (pp. 48-59). Springer, Berlin, Heidelberg.

Balzarotti, S., Biassoni, F., Villani, D., Prunas, A., & Velotti, P. (2016). Individual differences in cognitive emotion regulation: Implications for subjective and psychological well-being. Journal of Happiness Studies, 17(1), 125-143.

Beck, A. T. (Ed.). (1979). Cognitive therapy of depression. Guilford press (pp. 143).

Bell CM, Araki SS, Neumann PJ (2001) The association between caregiver burden and caregiver health-related quality of life in Alzheimer disease. Alzheimer Disease & Associated Disorders 15(3): 129–136.

Bergner, R. M. (2007). Therapeutic storytelling revisited. American journal of psychotherapy, 61(2), 149-162.

Bertogg, A., & Strauss, S. (2020). Spousal care-giving arrangements in Europe. The role of gender, socio-economic status and the welfare state. Ageing & Society, 40(4), 735-758.

Bietti, L. M., Tilston, O., & Bangerter, A. (2019). Storytelling as adaptive collective sensemaking. Topics in cognitive science, 11(4), 710-732.

Bilandzic, H., & Busselle, R. W. (2008). Transportation and transportability in the cultivation of genre-consistent attitudes and estimates. Journal of Communication, 58(3), 508-529.

Blas, N. D., & Paolini, P. (2013). Digital storytelling and educational benefits: Evidence from a large-scale project. In Transactions on Edutainment X (pp. 83-101). Springer, Berlin, Heidelberg.

Blinka, M. D., Liu, C., Sheehan, O. C., Rhodes, J. D., & Roth, D. L. (2022). Family caregivers emphasise patience and personal growth: a qualitative analysis from the Caregiving Transitions Study. Age and Ageing, 51(2), afab266.

Blenkiron, P. (2005). Stories and analogies in cognitive behaviour therapy: A clinical review. Behavioural and Cognitive Psychotherapy, 33(1), 45-59.

Boudreaux, E. D., Waring, M. E., Hayes, R. B., Sadasivam, R. S., Mullen, S., & Pagoto, S. (2014).

Evaluating and selecting mobile health apps: strategies for healthcare providers and healthcare organizations. Translational behavioral medicine, 4(4), 363-371.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

Brimblecombe, N., Fernandez, J. L., Knapp, M., Rehill, A., & Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. Journal of Long-Term Care, (September), 25-40.

Bruner, J. S. (2003). Making stories: Law, literature, life. Harvard University Press.

Bruner, J. (2004). Life as narrative. Social research: An international quarterly, 71(3), 691-710.

Brown, E. L., Ruggiano, N., Page, T. F., Roberts, L., Hristidis, V., Whiteman, K. L., & Castro, J. (2016). CareHeroes web and Android™ apps for dementia caregivers: a feasibility study. Research in Gerontological Nursing, 9(4), 193-203.

Burgdorf, J. G., Stuart, E. A., Arbaje, A. I., & Wolff, J. L. (2021). Family caregiver training needs and medicare home health visit utilization. Medical care, 59(4), 341-347.

Burger, J. M. (1981). Motivational biases in the attribution of responsibility for an accident: A meta-analysis of the defensive-attribution hypothesis. Psychological Bulletin, 90(3), 496.

Bush, N. E., Smolenski, D. J., Denneson, L. M., Williams, H. B., Thomas, E. K., & Dobscha, S. K. (2017). A virtual hope box: randomized controlled trial of a smartphone app for emotional regulation and coping with distress. Psychiatric Services, 68(4), 330-336.

Caldwell, R. L. (2005). At the confluence of memory and meaning—Life review with older adults and families: Using narrative therapy and the expressive arts to re-member and re-author stories of resilience. The Family Journal, 13(2), 172-175.

Callan, J. A., Siegle, G. J., Abebe, K., Black, B., Martire, L., Schulz, R., ... & Hall, M. H. (2016). Feasibility of a pocket-PC based cognitive control intervention in dementia spousal caregivers. Aging & mental health, 20(6), 575-582.

Calvó-Perxas, L., Vilalta-Franch, J., Litwin, H., Turró-Garriga, O., Mira, P., & Garre-Olmo, J. (2018). What seems to matter in public policy and the health of informal caregivers? A cross-sectional study in 12 European countries. PloS one, 13(3), e0194232.

Calvó-Perxas, L., Vilalta-Franch, J., Litwin, H., Mira, P., & Garre-Olmo, J. (2021). A longitudinal study on public policy and the health of in-house caregivers in Europe. Health Policy, 125(4), 436-441.

Candlish, L., Fadyl, J. K., & D'Cruz, K. (2022). Storytelling as an intervention in traumatic brain injury rehabilitation: a scoping review. Disability and rehabilitation, 1-15.

Carragher, M., Steel, G., Talbot, R., Devane, N., Rose, M. L., & Marshall, J. (2021). Adapting therapy

for a new world: storytelling therapy in EVA Park. Aphasiology, 35(5), 704-729.

Casanova, G., Principi, A., & Lamura, G. (2020). Social innovation in long-term care: Lessons from the Italian case. International Journal of Environmental Research and Public Health, 17(7), 2367.

Cassie, K. M., & Sanders, S. (2008). Chapter 12; familial caregivers of older adults. Journal of Gerontological Social Work, 50(S1), 293-320.

Cavazza, M., Lugrin, J. L., Pizzi, D., & Charles, F. (2007, September). Madame bovary on the holodeck: immersive interactive storytelling. In Proceedings of the 15th ACM international conference on Multimedia (pp. 651-660).

Cheng, S. T., & Zhang, F. (2020). A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. BMC geriatrics, 20(1), 1-24.

Chiesi, F., Marunic, G., & Lau, C. (2020). Validation study of an Italian version of the revised Sense of Coherence Scale (SOC-R). Current Psychology, 1-8.

Christie, H., Martin, J., Connor, J., Hermans, I., Tange, H. J., & Verhey, F. R. (2019). Which eHealth interventions for caregivers of people with dementia are used in practice. Examining development trajectories and business models Alzheimer's and Dementia. J Alzheimer's Assoc, 15, P511.

Chisholm, J. D., Chapman, C. S., Amm, M., Bischof, W. F., Smilek, D., & Kingstone, A. (2014). A cognitive ethology study of first-and third-person perspectives. PloS one, 9(3), e92696.

Cipolletta, S., Pasi, M., & Avesani, R. (2016). Vita tua, mors mea: The experience of family caregivers of patients in a vegetative state. Journal of Health Psychology, 21(7), 1197-1206.

Claidière, N., & Sperber, D. (2010). The natural selection of fidelity in social learning. Communicative & Integrative Biology, 3(4), 350-351.

Clark, D. A., Beck, A. T., Alford, B. A., Bieling, P. J., & Segal, Z. V. (2000). Scientific foundations of cognitive theory and therapy of depression.

Clarke, J. L., Bourn, S., Skoufalos, A., Beck, E. H., & Castillo, D. J. (2017). An innovative approach to health care delivery for patients with chronic conditions. Population health management, 20(1), 23-30.

Clark, M. C., & Standard, P. L. (1997). The caregiving story: how the narrative approach informs caregiving burden. Issues in Mental Health Nursing, 18(2), 87-97.

Cohen, J. (2001). Defining identification: A theoretical look at the identification of audiences with media characters. Mass communication & society, 4(3), 245-264.

Cohen, S. E., & Syme, S. I. (1985). Social support and health. Academic Press.

Cohen, S., Kamarck, T., & Mermelstein, R. (2021). Perceived stress scale. Measuring stress: a guide for health and social scientists. 1994.

Costabile, K. A. (2016). Narrative construction, social perceptions, and the situation model. Personality and Social Psychology Bulletin, 42(5), 589-602.

Cox, K., & McAdams, D. P. (2014). Meaning making during high and low point life story episodes predicts emotion regulation two years later: How the past informs the future. Journal of Research in Personality, 50, 66-70.

Crawford, R., Brown, B., & Crawford, P. (2004). Storytelling in therapy. Nelson Thornes.

Collins, R. N., & Kishita, N. (2020). Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis. Ageing & Society, 40(11), 2355-2392.

Cooper, R. A. (2021). "I Am a Caregiver": Sense-making and Identity Construction through Online Caregiving Narratives. Journal of Family Communication, 21(2), 77-89.

Crookston, B. T., West, J. H., Hall, P. C., Dahle, K. M., Heaton, T. L., Beck, R. N., & Muralidharan, C. (2017). Mental and emotional self-help technology apps: cross-sectional study of theory, technology, and mental health behaviors. JMIR Mental Health, 4(4), e7262.

Crossley, M. L. (2000). Narrative psychology, trauma and the study of self/identity. Theory & Psychology, 10(4), 527-546.

Dal Cin, S., Zanna, M. P., & Fong, G. T. (2004). Narrative persuasion and overcoming resistance. Resistance and persuasion, 2(175-191), 4.

Davidson, T., Moreland, A., Bunnell, B. E., Winkelmann, J., Hamblen, J. L., & Ruggiero, K. J. (2021). Reducing stigma in mental health through digital storytelling. In Research Anthology on Mental Health Stigma, Education, and Treatment (pp. 909-919). IGI Global.

de la Torre, J. (1972). The therapist tells a story: A technique in brief psychotherapy. Bulletin of the Menninger Clinic, 36(6), 609.

de Lima, E. S., Feijó, B., & Furtado, A. L. (2018). Video-based interactive storytelling using real-time video compositing techniques. Multimedia Tools and Applications, 77(2), 2333-2357.

del-Pino-Casado, R., Espinosa-Medina, A., López-Martínez, C., & Orgeta, V. (2019). Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. *Journal of Affective Disorders*, 242, 14-21.

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & Ramos- De Vugt, M. E., & Verhey, F. R. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. Progress in neurobiology, 110, 54-62.

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & Ramos-

Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. PloS one, 13(1), e0189874.

De Vecchi, N., Kenny, A., Dickson-Swift, V., & Kidd, S. (2016). How digital storytelling is used in mental health: A scoping review. *International Journal of Mental Health Nursing*, 25(3), 183-193.

Deusdad, B. A., Pace, C., & Anttonen, A. (2016). Facing the challenges in the development of long-term care for older people in Europe in the context of an economic crisis. Journal of Social Service Research, 42(2), 144-150.

Diaz, R. (1992). Private speech: From social interaction to self-regulation (pp. 17-53). R. M. Diaz, & L. E. Berk (Eds.). Hillsdale, NJ: L. Erlbaum.

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2017). Psychosocial intervention for carers of people with dementia: what components are most effective and when? A systematic review of systematic reviews. International psychogeriatrics, 29(1), 31-43.

Donikian, S., & Portugal, J. N. (2004, June). Writing interactive fiction scenarii with DraMachina. In International conference on technologies for interactive digital storytelling and entertainment (pp. 101-112). Springer, Berlin, Heidelberg.

Eibich, P. (2021). Care Or Self-care?: The Impact of Informal Care Provision on Health Behaviour. Max Planck Institute for Demographic Research.

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. American Journal of Health Education, 46(6), 357-367.

Elmezeny, A., Edenhofer, N., & Wimmer, J. (2018). Immersive storytelling in 360-degree videos: An analysis of interplay between narrative and technical immersion. Journal For Virtual Worlds Research, 11(1).

Evans, R., Catapano, M., Brooks, D., Goldstein, R., & Avendano, M. (2012). Family caregiver perspectives on caring for ventilator-assisted individuals at home. Canadian respiratory journal, 19(6), 373-379.

Filoteo, J. V., Cox, E. M., Split, M., Gross, M., Culjat, M., & Keene, D. (2018, July). Evaluation of ReminX as a behavioral intervention for mild to moderate dementia. In 2018 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC) (pp. 3314-3317). IEEE.

Finnbogadóttir, H., & Berntsen, D. (2014). Looking at life from different angles: Observer perspective during remembering and imagining distinct emotional events. Psychology of Consciousness: Theory, Research, and Practice, 1(4), 387.

Flórez-Aristizábal, L., Cano, S., Collazos, C. A., Benavides, F., Moreira, F., & Fardoun, H. M. (2019). Digital transformation to support literacy teaching to deaf Children: From storytelling to digital interactive storytelling. Telematics and Informatics, 38, 87-99.

Freytag, G. (1894). Freytag's Technique of the Drama. Scott, Foresman.

Frias, C. E., Risco, E., & Zabalegui, A. (2020). Psychoeducational intervention on burden and emotional well-being addressed to informal caregivers of people with dementia. Psychogeriatrics, 20(6), 900-909.

Frisbee, K. L. (2016). Variations in the use of mHealth tools: the VA mobile health study. JMIR mHealth and uHealth, 4(3), e3726.

Fuster, V. (2017). Changing demographics: a new approach to global health care due to the aging population. Journal of the American College of Cardiology, 69(24), 3002-3005

Gabele, M., Thoms, A., Alpers, J., Hußlein, S., & Hansen, C. (2019, April). Effects of interactive storytelling and quests in cognitive rehabilitation for adults. In GamiFIN (pp. 118-129).

Gaggioli, A. (2016). Transformative experience design. Human computer confluence. Transforming human experience through symbiotic technologies, 96-121.

Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L. W. (1989). Prevalence of depression in family caregivers. The gerontologist, 29(4), 449-456.

Galvin, M., Gaffney, R., Corr, B., Mays, I., & Hardiman, O. (2017). From first symptoms to diagnosis of amyotrophic lateral sclerosis: perspectives of an Irish informal caregiver cohort—a thematic analysis. BMJ open, 7(3), e014985.

Galvin, M., Carney, S., Corr, B., Mays, I., Pender, N., & Hardiman, O. (2018). Needs of informal caregivers across the caregiving course in amyotrophic lateral sclerosis: a qualitative analysis. BMJ open, 8(1), e018721.

Garnefski, N., Kraaij, V., & Spinhoven, P. (2001). Negative life events, cognitive emotion regulation and emotional problems. Personality and Individual differences, 30(8), 1311-1327.

Gérain, P., & Zech, E. (2022). A harmful care: the association of informal caregiver burnout with depression, subjective health, and violence. Journal of interpersonal violence, 37(11-12), NP9738-NP9762.

Gibson, G., Dickinson, C., Brittain, K., & Robinson, L. (2019). Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. Ageing & Society, 39(11), 2502-2519.

Gibson, M., Hjorth, L., & Choi, J. H. J. (2021). Introduction: Caring media futures. *International Journal of Cultural Studies,* 24(4), 557-566.

Golding, L. (2011). Narrative impact of health and occupational safety messages: a comparison across

voice, medium, and topic (Doctoral dissertation, University of Georgia).

Graessel, E., Berth, H., Lichte, T., & Grau, H. (2014). Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. BMC geriatrics, 14(1), 1-9.

Grall, C., Tamborini, R., Weber, R., & Schmälzle, R. (2021). Stories collectively engage listeners' brains: Enhanced intersubject correlations during reception of personal narratives. Journal of Communication, 71(2), 332-355.

Green, M. C. (2004). Transportation into narrative worlds: The role of prior knowledge and perceived realism. Discourse processes, 38(2), 247-266.

Green, M. C., & Brock, T. C. (2000). The role of transportation in the persuasiveness of public narratives. Journal of personality and social psychology, 79(5), 701.

Grossman, M. R., Zak, D. K., & Zelinski, E. M. (2018). Mobile apps for caregivers of older adults: quantitative content analysis. JMIR mHealth and uHealth, 6(7), e9345.

Habermas, T. & Bluck, S.(2000). Getting a life: The emergence of the life story in adolescence. Psychological Bulletin, 126.

Hand, L. C., Thomas, T. H., Belcher, S., Campbell, G., Lee, Y. J., Roberge, M., ... & Donovan, H. S. (2018). Caregiving is a marathon, not a road race: reenvisioning caregiver support services in gynecologic oncology. International Journal of Gynecologic Cancer, 28(9).

Hammel, S. (2018). Handbook of therapeutic storytelling: Stories and metaphors in psychotherapy, child and family therapy, medical treatment, coaching and supervision. Routledge.

Hansen, T., & Slagsvold, B. (2015). Feeling the squeeze? The effects of combining work and informal caregiving on psychological well-being. European Journal of Ageing, 12(1), 51-60.

Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. Journal of Aging Studies, 23(1), 48-59.

Ho, L., Bloom, P. A., Vega, J. G., Yemul, S., Zhao, W., Ward, L., ... & Pasinetti, G. M. (2016). Biomarkers of resilience in stress reduction for caregivers of Alzheimer's patients. Neuromolecular medicine, 18(2), 177-189.

Hofmann, S. G., Asnaani, A., Vonk, I. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: A review of meta-analyses. Cognitive therapy and research, 36(5), 427-440.

Holkham, L., & Soundy, A. (2018). The experience of informal caregivers of patients with motor neurone disease: a thematic synthesis. Palliative & Supportive Care, 16(4), 487-496.

Jardim, C., & Pakenham, K. I. (2009). Pilot investigation of the effectiveness of respite care for carers of an adult with mental illness. Clinical Psychologist, 13(3), 87-93.

Kajiyama, B., Fernandez, G., Carter, E. A., Humber, M. B., & Thompson, L. W. (2018). Helping Hispanic dementia caregivers cope with stress using technology-based resources. Clinical gerontologist, 41(3), 209-216.

Kalmpourtzis, G., Ketsiakidis, G., Vrysis, L., & Romero, M. (2020, October). Examining the impact of an interactive storytelling platform on educational contexts through contemporary crowdsourcing methods of audiovisual content publishing. In 2020 15th International Workshop on Semantic and Social Media Adaptation and Personalization (SMA (pp. 1-5). IEEE.

Kayaalp, A., Page, K. J., & Rospenda, K. M. (2021). Caregiver burden, work-family conflict, family-work conflict, and mental health of caregivers: A mediational longitudinal study. Work & Stress, 35(3), 217-240.

Kepic, M., Randolph, A., & Hermann-Turner, K. M. (2019). Care for caregivers: understanding the need for caregiver support. Adultspan Journal, 18(1), 40-51.

Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y. S., Shelburne, N., ... & Huss, K. (2016). Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. Cancer, 122(13), 1987-1995.

Kross, E., Bruehlman-Senecal, E., Park, J., Burson, A., Dougherty, A., Shablack, H., ... & Ayduk, O. (2014). Self-talk as a regulatory mechanism: how you do it matters. Journal of personality and social psychology, 106(2), 304.

Lacey, R. E., McMunn, A., & Webb, E. (2019). Informal caregiving patterns and trajectories of psychological distress in the UK Household Longitudinal Study. Psychological medicine, 49(10), 1652-1660.

Lamura, G., Mnich, E., Nolan, M., Wojszel, B., Krevers, B., Mestheneos, L., & Döhner, H. (2008). Family carers' experiences using support services in Europe: empirical evidence from the EUROFAMCARE study. The Gerontologist, 48(6), 752-771.

Land, K. (2007). Storytelling as therapy: The motives of a counselor. Business Communication Quarterly, 70(3), 377-381.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. Springer publishing company.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of gerontology, 44(3), P61-P71.

LeBeau, K., Huey, L. G., & Hart, M. (2019). Assessing the quality of mobile apps used by occupational therapists: evaluation using the user version of the mobile application rating scale. JMIR mHealth and uHealth, 7(5), e13019.

Lee, J. Y., Tikellis, G., Corte, T. J., Goh, N. S., Keir, G. J., Spencer, L., ... & Holland, A. E. (2020). The supportive care needs of people living with pulmonary fibrosis and their caregivers: a systematic review. European Respiratory Review, 29(156).

Lilleheie, I., Debesay, J., Bye, A., & Bergland, A. (2020). Informal caregivers' views on the quality of healthcare services provided to older patients aged 80 or more in the hospital and 30 days after discharge. BMC geriatrics, 20(1), 1-13.

Lindahl, B., Lidén, E., & Lindblad, B. M. (2011). A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings. Journal of clinical nursing, 20(3-4), 454-463.

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: a systematic review of family caregivers' perceptions. BMJ Supportive & Palliative Care.

López-Gómez, D., Beneito-Montagut, R., & García-Santesmases, A. (2021). No future for care without new digital media? Making time (s) for mediated informal care practices in later life. International Journal of Cultural Studies, 24(4), 637-654.

Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. International journal of integrated care, 12.

Lowe, K. (2019). Solution-focused narrative therapy with families. Marriage and family therapy: A practice-oriented approach, 363-380.

Luoma, J. B., Hayes, S. C., & Walser, R. D. (2007). Learning ACT: An acceptance & commitment therapy skills-training manual for therapists. New Harbinger Publications. pp 37-39.

McAdams, D. P. (1987). "A life-story model of identity," in Perspectives in personality. Stamford, CT: JAI Press. p. 15–50.

McAdams, D.P. (2011) Narrative identity. In: Schwartz S, Luyckx K, Vignoles V (eds) Handbook of Identity Theory and Research. New York, NY: Springer, pp.99–115.

McAdams, D. P., Reynolds, J., Lewis, M., Patten, A. H., & Bowman, P. J. (2001). When bad things turn good and good things turn bad: Sequences of redemption and contamination in life narrative and their relation to psychosocial adaptation in midlife adults and in students. Personality and social psychology bulletin, 27(4), 474-485.

McAdams, D.P. & McLean, K.C. (2013). Narrative identity. Current directions in psychological science. SAGE Journals 22(3): 233–238.

Madigan, S. (2011). Narrative therapy. American Psychological Association.

McLean, K. C. (2008). The emergence of narrative identity. Social and Personality Psychology

Compass, 2(4), 1685-1702.

Markouzis, D., & Fessakis, G. (2016). Rapid prototyping of interactive storytelling and mobile augmented reality applications for learning and entertainment–The case of "k-Knights".

Mason, A., Weatherly, H., Spilsbury, K., Golder, S., Arksey, H., Adamson, J., & Drummond, M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. Journal of the American Geriatrics Society, 55(2), 290-299.

Mateas, M., & Stern, A. (2002). Towards integrating plot and character for interactive drama. In Socially Intelligent Agents (pp. 221-228). Springer, Boston, MA.

Meichenbaum, D. (2007). Stress inoculation training: A preventative and treatment approach. Principles and practice of stress management. University of Waterloo, Ontario, Canada. Chapter to appear in PM Lehrer, RL Woolfolk & WS Sime, Principles and Practice of Stress Management, 497-518.

Milam, D., Seif El-Nasr, M., & Wakkary, R. (2008, November). Looking at the Interactive Narrative Experience through the Eyes of the Participants. In Joint international conference on interactive digital storytelling (pp. 96-107). Springer, Berlin, Heidelberg.

Mondo, M., Sechi, C., & Cabras, C. (2022). Psychometric evaluation of three versions of the Italian Perceived Stress Scale. In Key Topics in Work and Organizational Psychology (pp. 1-9). Springer, Cham.

Montgomery, R., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. Generations, 33(1), 47-52.

Montgomery, R. J., & Kosloski, K. D. (2013). Pathways to a caregiver identity and implications for support services. In Caregiving across the lifespan (pp. 131-156). Springer, New York, NY.

Montgomery, R. J., Kwak, J., Kosloski, K., & O'Connell Valuch, K. (2011). Effects of the TCARE® intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 66(5), 640-647.

Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. PloS one, 13(1), e0189874.

Moser, J. S., Dougherty, A., Mattson, W. I., Katz, B., Moran, T. P., Guevarra, D., ... & Kross, E. (2017). Third-person self-talk facilitates emotion regulation without engaging cognitive control: Converging evidence from ERP and fMRI. Scientific reports, 7(1), 1-9.

Negri, L., Bassi, M., & Delle Fave, A. (2020). Italian validation of the meaning in life questionnaire: factor structure, reliability, convergent, and discriminant validity. Psychological Reports, 123(2), 578-600.

Nelson, K. (Ed.). (2006). Narratives from the crib. Harvard University Press.

Norsensus. 8 classic storytelling techniques. Norsensus. URL: https://norsensus.no/storydown/storytelling-techniques/ [accessed 2022-07-17]

Northouse, L. L. K at apodi, MC, Schafenacker, AM, & Weiss, D.(2012). In The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *in Seminars in Oncology Nursing* (Vol. 28, pp. 236-245).

Núñez-Naveira, L., Alonso-Búa, B., de Labra, C., Gregersen, R., Maibom, K., Mojs, E., ... & Millán-Calenti, J. C. (2016). UnderstAID, an ICT platform to help informal caregivers of people with dementia: a pilot randomized controlled study. BioMed research international, 2016.

Nurser, K. P., Rushworth, I., Shakespeare, T., & Williams, D. (2018). Personal storytelling in mental health recovery. Mental Health Review Journal.

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. Academic medicine, 89(9), 1245-1251.

O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. Journal of Aging Studies, 21(2), 165-174.

O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2016). Suicidal ideation in family carers of people with dementia. Aging & mental health, 20(2), 222-230.

Page, R., & Thomas, B. (Eds.). (2011). New narratives: Stories and storytelling in the digital age. U of Nebraska Press.

Parker, T. S., & Wampler, K. S. (2006). Changing emotion: The use of therapeutic storytelling. Journal of Marital and Family therapy, 32(2), 155-166.

Payne, M. (2006). Narrative therapy. Narrative Therapy, 1-224.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The gerontologist, 30(5), 583-594.

Petrovic, M., Bonanno, S., Landoni, M., Ionio, C., Hagedoorn, M., & Gaggioli, A. (2022). Using the Transformative Storytelling Technique to Generate Empowering Narratives for Informal Caregivers: Semistructured Interviews, Thematic Analysis, and Method Demonstration. JMIR formative research, 6(8), e36405.

Petrovic, M., & Gaggioli, A. (2020). Digital mental health tools for caregivers of older adults—a scoping review. Frontiers in Public Health, 8, 128.

Petrovic, M., & Gaggioli, A. (2021). The potential of transformative video design for improving caregiver's wellbeing. Health psychology open, 8(1), 20551029211009098.

Petruzzo, A., Paturzo, M., Naletto, M., Cohen, M. Z., Alvaro, R., & Vellone, E. (2017). The lived

experience of caregivers of persons with heart failure: A phenomenological study. European Journal of Cardiovascular Nursing, 16(7), 638-645.

Phongtankuel, V., Shalev, A., Adelman, R. D., Dewald, R., Dignam, R., Baughn, R., ... & Reid, M. B. (2018). Mobile health technology is here—but are hospice informal caregivers receptive?. American Journal of Hospice and Palliative Medicine®, 35(12), 1547-1552.

Piersol, C. V., Jensen, L., Lieberman, D., & Arbesman, M. (2018). Occupational therapy interventions for people with Alzheimer's disease. The American Journal of Occupational Therapy, 72(1), 7201390010p1-7201390010p6.

Piette, J. D., Striplin, D., Marinec, N., Chen, J., & Aikens, J. E. (2015). A randomized trial of mobile health support for heart failure patients and their informal caregivers: impacts on caregiver-reported outcomes. Medical care, 53(8), 692-699.

Pillemer, D. B. (2009). Momentous events, vivid memories. Harvard University Press.

Pindus, D. M., Mullis, R., Lim, L., Wellwood, I., Rundell, A. V., Abd Aziz, N. A., & Mant, J. (2018). Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services–a systematic review and meta-ethnography. PloS one, 13(2), e0192533.

Plöthner, M., Schmidt, K., De Jong, L., Zeidler, J., & Damm, K. (2019). Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC geriatrics, 19(1), 1-22.

Poonamallee, L., Harrington, A. M., Nagpal, M., & Musial, A. (2018). Improving emotional intelligence through personality development: The effect of the smart phone application-based Dharma Life Program on emotional intelligence. Frontiers in psychology, 9, 169.

Pope, N., Giger, J., Lee, J., & Ely, G. (2017). Predicting personal self-care in informal caregivers. Social work in health care, 56(9), 822-839.

Power, A., & Hall, E. (2018). Placing care in times of austerity. Social & Cultural Geography, 19(3), 303-313.

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. Dementia, 14(2), 220-237.

Rice, R. H. (2015). Narrative therapy. The SAGE Encyclopedia of Theory in Counseling and Psychology, 2, 695.

Ricks, L., Kitchens, S., Goodrich, T., & Hancock, E. (2014). My story: The use of narrative therapy in individual and group counseling. Journal of Creativity in Mental Health, 9(1), 99-110.

Riedl, M. O., & Young, R. M. (2004, July). An intent-driven planner for multi-agent story generation.

In Autonomous Agents and Multiagent Systems, International Joint Conference on (Vol. 2, pp. 186-193). IEEE Computer Society.

Riffin, C., Van Ness, P. H., Wolff, J. L., & Fried, T. (2017). Family and other unpaid caregivers and older adults with and without dementia and disability. Journal of the American Geriatrics Society, 65(8), 1821-1828.

Ritterfeld, U., & Jin, S. A. (2006). Addressing media stigma for people experiencing mental illness using an entertainment-education strategy. Journal of health psychology, 11(2), 247-267.

Rivera-Navarro, J., Sepúlveda, R., Contador, I., Fernández-Calvo, B., Ramos, F., Tola-Arribas, M. Á., & Goñi, M. (2018). Detection of maltreatment of people with dementia in Spain: usefulness of the Caregiver Abuse Screen (CASE). European journal of ageing, 15(1), 87-99.

Rossiter, M., & Garcia, P. A. (2010). Digital storytelling: A new player on the narrative field. New directions for adult and continuing education, 126, 37-48.

Ryan, M. L. (2008, November). Interactive narrative, plot types, and interpersonal relations. In Joint international conference on interactive digital storytelling (pp. 6-13). Springer, Berlin, Heidelberg.

Ryan, M. L. (2015). Narrative as virtual reality 2: Revisiting immersion and interactivity in literature and electronic media. JHU press.

Sallim, A. B., Sayampanathan, A. A., Cuttilan, A., & Ho, R. C. M. (2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. Journal of the American Medical Directors Association, 16(12), 1034-1041.

Schmitz, H., & Westphal, M. (2015). Short-and medium-term effects of informal care provision on female caregivers' health. Journal of health economics, 42, 174-185.

Schreiner, C., Appel, M., Isberner, M. B., & Richter, T. (2018). Argument strength and the persuasiveness of stories. Discourse Processes, 55(4), 371-386.

Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. Aging & mental health, 16(6), 712-721.

Schwennesen, N. (2019). Algorithmic assemblages of care: Imaginaries, epistemologies and repair work. Sociology of Health & Illness, 41, 176-192.

Shaw, C., McNamara, R., Abrams, K., Cannings-John, R. L., Hood, K., Longo, M., ... & Williams, K. (2009). Systematic review of respite care in the frail elderly. Health Technology Assessment, 13(20), 1-246.

Singer, J. A. (1995). Seeing one's self: Locating narrative memory in a framework of personality. Journal of Personality, 63(3), 429-457.

Singer, J. A. (2004). Narrative identity and meaning making across the adult lifespan: An introduction. Journal of personality, 72(3), 437-460.

Singer, J. A., & Conway, M. A. (2011). Reconsidering therapeutic action: Loewald, cognitive neuroscience and the integration of memory's duality. The International Journal of Psychoanalysis, 92(5), 1183-1207.

Slater, M. D., & Rouner, D. (2002). Entertainment—education and elaboration likelihood: Understanding the processing of narrative persuasion. Communication theory, 12(2), 173-191.

Slater, M. D., Rouner, D., & Long, M. (2006). Television dramas and support for controversial public policies: Effects and mechanisms. Journal of communication, 56(2), 235-252.

Spasova, S., Baeten, R., & Vanhercke, B. (2018). Challenges in long-term care in Europe. Eurohealth, 4(4), 7-12.

Stal, S. T., Catala, A., Theune, M., & Reidsma, D. (2019). Designing a smart toy interactive setting for creating stories. In Interactivity, Game Creation, Design, Learning, and Innovation (pp. 601-610). Springer, Cham.

Stall, N. M., Kim, S. J., Hardacre, K. A., Shah, P. S., Straus, S. E., Bronskill, S. E., ... & Rochon, P. A. (2019). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: a systematic review. Journal of the American Geriatrics Society, 67(3), 609-617.

Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: assessing the presence of and search for meaning in life. Journal of counseling psychology, 53(1), 80.

Stern, A. (2008, November). Embracing the combinatorial explosion: A brief prescription for interactive story R&D. In Joint international conference on interactive digital storytelling (pp. 1-5). Springer, Berlin, Heidelberg.

Stoyanov, S. R., Hides, L., Kavanagh, D. J., Zelenko, O., Tjondronegoro, D., & Mani, M. (2015). Mobile app rating scale: a new tool for assessing the quality of health mobile apps. JMIR mHealth and uHealth, 3(1), e3422.

Szilas, N. A. (2003). Narrative Engine for Interactive Drama. In Technologies for Interactive Digital Storytelling and Entertainment Conference, Darmstadt, Alemanha.

Tam, J. W., & Schmitter-Edgecombe, M. (2019). A caregiver educational program: A video program to promote aging services technologies awareness. Geriatric Nursing, 40(1), 78-83.

Thomas, E. W. S., Dalton, J. E., Harden, M., Eastwood, A. J., & Parker, G. M. (2017). Updated meta-review of evidence on support for carers. Health Services and Delivery Research.

Torous, J., Nicholas, J., Larsen, M. E., Firth, J., & Christensen, H. (2018). Clinical review of user

engagement with mental health smartphone apps: evidence, theory and improvements. Evidence-based mental health, 21(3), 116-119.

Tremont, G., Davis, J. D., Ott, B. R., Galioto, R., Crook, C., Papandonatos, G. D., ... & Bishop, D. S. (2017). Randomized trial of the family intervention: telephone tracking—caregiver for dementia caregivers: use of community and healthcare resources. Journal of the American Geriatrics Society, 65(5), 924-930.

Triantafillou, J., Naiditch, M., Repkova, K., Stiehr, K., Carretero, S., Emilsson, T., ... & Vlantoni, D. (2010). Informal care in the long-term care system European overview paper.

Van Den Heuvel, E. T., de Witte, L. P., Stewart, R. E., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2002). Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: which caregivers benefit the most?. Patient education and counseling, 47(4), 291-299.

van Gemert-Pijnen, L. J., Kip, H., Kelders, S. M., & Sanderman, R. (2018). Introducing ehealth. In eHealth research, theory and development (pp. 3-26). Routledge.

Van Gemert-Pijnen, J. E. W. C. (2013). Improving ehealth. O. Peters, & H. C. Ossebaard (Eds.). The Hague: Eleven international publishing.

Van Groenou, M. I., & van Tilburg, T. G. (2016). VU Research Portal.

Van Houtven, C. H., Voils, C. I., & Weinberger, M. (2011). An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. BMC geriatrics, 11(1), 1-18.

van Roij, J., Brom, L., Soud, Y. E., van de Poll-Franse, L., & Raijmakers, N. J. (2019). Social consequences of advanced cancer in patients and their informal caregivers: a qualitative study. Supportive Care in Cancer, 27(4), 1187-1195.

Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., & Annemans, L. (2019). Effectiveness of an in-home respite care program to support informal dementia caregivers: A comparative study. International Journal of Geriatric Psychiatry, 34(10), 1534-1544.

Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjær, E. L., & Eikemo, T. A. (2017). Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. The European Journal of Public Health, 27(suppl_1), 90-95.

Walter, N., T. Murphy, S., & Gillig, T. K. (2018). To walk a mile in someone else's shoes: how narratives can change causal attribution through story exploration and character customization. Human Communication Research, 44(1), 31-57.

Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J. Y. (2018). Unmet care needs of advanced

cancer patients and their informal caregivers: a systematic review. BMC palliative care, 17(1), 1-29.

Weiss, S., Müller, W., Spierling, U., & Steimle, F. (2005, November). Scenejo–an interactive storytelling platform. In International conference on virtual storytelling (pp. 77-80). Springer, Berlin, Heidelberg.

Wieland, M. L., Njeru, J. W., Hanza, M. M., Boehm, D. H., Singh, D., Yawn, B. P., ... & Sia, I. G. (2017). Pilot feasibility study of a digital storytelling intervention for immigrant and refugee adults with diabetes. The Diabetes Educator, 43(4), 349-359.

Wiet, S. G. (2005). Future of caring for an aging population: trends, technology, and caregiving. Studies in Health Technology and Informatics, 118(3), 220-230.

Wijma, E. M., Veerbeek, M. A., Prins, M., Pot, A. M., & Willemse, B. M. (2018). A virtual reality intervention to improve the understanding and empathy for people with dementia in informal caregivers: results of a pilot study. Aging & mental health, 22(9), 1121-1129.

Wilson, D. K., Hutson, S. P., & Wyatt, T. H. (2015). Exploring the role of digital storytelling in pediatric oncology patients' perspectives regarding diagnosis: A literature review. SAGE Open, 5(1), 2158244015572099.

Woodford, J., Farrand, P., Watkins, E. R., & LLewellyn, D. J. (2018). " I Don't Believe in Leading a Life of My Own, I Lead His Life": A Qualitative Investigation of Difficulties Experienced by Informal Caregivers of Stroke Survivors Experiencing Depressive and Anxious Symptoms. Clinical Gerontologist, 41(4), 293-307.

Yamamoto, Y., Hayashino, Y., Yamazaki, S., Takegami, M., & Fukuhara, S. (2009). Violent patient behavior is associated with bodily pain and a high burden on informal caregivers. Journal of general internal medicine, 24(10), 1085-1088.

Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 54(1), P12-P22.

Zheng, R., Hicken, B. L., Hill, R. D., Luptak, M., Daniel, C. M., Grant, M., & Rupper, R. (2016). Digital technology and caregiver training for older persons: Cognitive and affective perspectives. Educational Gerontology, 42(8), 540-550.

Zigante, V. (2018). Informal care in Europe. Exploring formalisation, availability and quality, EC, 4-38.

Zygouri, I., Cowdell, F., Ploumis, A., Gouva, M., & Mantzoukas, S. (2021). Gendered experiences of providing informal care for older people: a systematic review and thematic synthesis. BMC health services research, 21(1), 1-15.

8 APPENDIX

Appendix 1

Category (Questions)	Initial codes - Quotes	Refined codes	Final themes (e.g., refined codes used)
Exposition (5. Can you describe how did you become a caregiver, which event led to this situation?)	Passing of a parent; Worsening of the health; family reasons; the only choice available; sudden health deterioration; no other home available; could not afford care; other siblings not involved; living arrangements; availability; ability to manage illness; sharing the household for 20 years; caregiving always present since marriage; the destiny; love and duty; able to manage illness; I am the daughter; he is my husband; children not available to provide care; refuses external assistance; cannot afford external assistance; they are my parents; cannot afford caregiver; siblings refused to help; illness; after surgical intervention; the only sibling that accepted to be a caregiver; only sibling available; out of duty	No other choices available; obligations due to family ties; financial resources not available for paid care; involuntary acceptance upon the health issue appeared; living arrangements-imposed care; family duty.	**Lack of choice** (e.g., no other choice available, involuntary acceptance upon health issues appeared, imposed care); **Sense of duty** (e.g., obligations due to family ties, family duty); Financial issues (e.g., financial resources not available for paid care).
Category (Question)	Initial codes - Quotes	Refined codes	**Final themes** (e.g., refined codes used)
Rising action (6. What are some of the changes that you had to make in your everyday life in order to incorporate the caregiving role?)	From full to part-time job; in-house paid help; hygiene care for the patient; apply changes in routine; day care center; drop social interactions; drop personal routine; family time; work time; lower the social life; everything revolving around care recipient; usual daily activities; change family balance; lose freedom; day care center; organize the day in the service of the care recipient; family involved in	Shifts in routine; Changes in usual/regular patterns of living; Adopting new responsibilities; Drop of social activities/loss of social activities/time constraints for social activities; changes/disturbances in the usual family functioning; limited/non existent	**Change in routine** (e.g., shifts in routine, adopting new responsibilities); **Loss of social life** (e.g., drop of social life, loss of social activities, time constraints for social activities); **Drop of personal care** (limited time for personal needs,

	all changes; help with hygiene of the care recipient; had to give up everything; daughter cannot help; find help in the house; giving up personal time; family vacations with her; husband neglected; arrange shopping and medical appointments; take a long leave from work; left job; daughters moved far away; lost privacy, friends drifted apart; lost social life; I can never leave him alone; no time for anything; social life does not exist; no sleep at night; cannot care for personal health; relationship with daughters worsened; no social life; home stay; adapt working hours; gave up habits; quit job; family balance; give up self; cannot go home for longer time; monitor her during the night; left job; limited freedom; give up traveling; give up personal things; hire caregiver; return to minimal work hours; no vacations with husband; give up time with daughters; work part-time.	time for personal needs; formal help hiring/full-time help in the house; work pattern shift/full-part time/job loss; time constraints/time-giving up/lack of time for personal things; family time limits/family patterns change/limited family interaction.	non-existent time for personal needs); **Changes in employment arrangements** (e.g., work pattern, shift to part time from full time, job loss); **Family balance** (family time limits, family patterns change, limited family interaction); **Professional/formal help** (e.g., formal help hiring, full-time help in the house); **Time-management** (e.g., time constraints, time giving-up, lack of time for personal things).
Category (Question)	Initial codes - Quotes	Refined codes	**Final themes** (e.g., refined codes used)
Rising action (7. Can you describe what your average day looks like?)	Waking up early in the morning; providing help with medications; assisting with hygiene needs; dedicating all free time to the care recipient; early wake up; assisting with the showering and dressing; distributing medicines; day care center; going to work; loss of personal time; weekend dedicated to the care recipient; early morning wakeup; hygiene and medication help; day care center; afternoon organized around her; spouse tends to children; night terrors and lack of sleep for everyone; waking up at 4:30; working till	Early morning wake-up; Showering and dressing the care recipient; Medication organizing and delivery; Mealtime; Day care center preparation; Home stay; lunch time and cooking; afternoon time with care recipient/activities with care recipient; evening time and preparation for sleep/helping with preparation and going to bed).	**Early wake up** (e.g., early morning wake-up); **Assistance with hygiene, food, and medicines** (e.g., showering and dressing the care recipient, medication organization and delivery, mealtime); **Home care/Day care** (e.g., day care center preparation, home stay); **Meals** (e.g., lunch time and cooking);

			Mutual quality time (e.g., activities with care recipient, evening time); Bedtime (e.g., preparation for sleep, helping with preparation, going to bed).
	8:30am and returning to help with hygiene and food; day care; lunch; rest of the day completely dedicated to her; Saturday and Sunday dedicated to her; wake up 7:15; wash her and help her get dressed; day care center; house chores; putting her to sleep at 9; wake up at 7; assist with care neds; breakfast and medications; day dedicated to her; refuses to stay alone; wake up 7:30; self-care; breakfast and medication for him; grocery shopping; walking; lunch, quality time; bed time; wake up early; tend to the house; work time; caring for them in the afternoon till evening; sleep for a couple of hours at night; early wake up; house duties; his hygiene needs; medications; lunch time; nap; dinner time; professional caregiver present; 9pm bed time; early wake up; hygiene needs; breakfast preparation; mutual time; lunch time; dinner; bedtime; lack of sleep at night;		
Category (Question)	Initial codes - Quotes	Refined codes	**Final themes** (e.g., refined codes used)
Rising action (8. What are some of the situations that you find most psychologically and emotionally challenging in your caregiving role?)	Loosing the main functions while still young; sitting on the couch and watching "through" TV; psychological breakdown; sense of abandonment/being alone in the decision to provide care; remaining patient; physical tiredness; psychological tiredness; emotional tiredness; not being able to spend time with children; sense of isolation; loss of friends; sense of guilt for not having the time for everyone; powerlessness towards the situation; sense of inadequacy; overwhelmed by the care responsibilities; not	Abandonment/being left alone in the care situation; Loneliness; Being responsible for the health-related decisions; Fear of outcomes/ fear of decision related outcomes; personal time/freedom to plan personal time/spend personal time; Lack of training/knowledge; Feeling inadequate for the role/part of the role; Inability to change the course of	**Fear** (e.g., fear of outcomes, fear of decision-related outcomes); **Disappointment** (anger, negative perception of the role, negative perception of the events within the role, role-shift/not being able to be a "mother" to the parent); **Powerlessness towards the irreversible change** (e.g., inability to

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	being heard; being ignored or left by those who have equal responsibility for care; the moments of aggression; no freedom of movement; loss of independence; being financially dependent on others for the caregiving expenses; being single/primary caregiver; seeing the weaknesses of the care recipient who use to be care taker; assessing/not assessing the emergency situations; feeling angry and lonely/abandoned; lack of communication with the care recipient; patience; becoming a mother of the parents; witnessing the suffering that is irreversible; feeling rejected; adapting to illness; feeling oppressed due to lack of freedom; the change of roles from daughter into being a mother of my mother; continuous agony of not being recognized by your parent; the inability to cure the disease; sense of powerlessness towards the disease; leaving her in nursing home;	illness/outcomes of illness; anger/negative perception of the role and events within the role; role-shift/not being able to be a "mother" to the parent.	change the course of illness, inability to change the outcomes of the illness); **Loneliness** (e.g., abandonment/being left alone in the care situation, loneliness); **Sense of inadequacy** (e.g., lack of training, lack of knowledge, feeling inadequate for the role, feeling inadequate for some parts of the role); **Lack of personal freedom** (e.g., personal time, freedom to plan personal time, freedom to spend personal time).
Category (Question)	Initial codes - Quotes	Refined codes	**Final themes** (e.g., refined codes used)
Climax/Critical point (9. Can you describe the most critical points that occurred in your caregiving role and made it difficult to continue the caregiving role?)	Father's denial for the care needs; inability to maintain work; difficulty focusing on anything but the care recipient; personal health issues; the provision of assistance becomes impossible; lack of family support; lack of involvement of other family members; care cannot be provided due to personal illness; choosing between care recipient and children; epileptic crisis where caregiver did not know what to do; personal health issues; having to force her to day care;	Fearing the outcomes; Negative emotional experiences/ tiredness/exhaustion; Tired of advice or criticism; Physical exhaustion/health issues preventing care; feeling hopeless about the continuation of care that leads to no positive outcomes; fatigue/physical; fatigue/emotional; distrust in personal strength and ability to continue care	**Fear of loss/facing the possibility of loss/ facing the reality** (e.g., facing possible death, facing the idea of loss); **Facing the fact that care cannot be given anymore** (e.g., distrust in personal strength and ability to continue care **Psychological and emotional exhaustion** (e.g.,

	missing personal life; feeling over as a person; seeing no perspective of the future; not knowing if the momentary health stat of the care recipient is serious or not; not knowing what the outcome of the short term colds will be; feeling guilty for keeping him in life while knowing he would refuse that if aware; the moment he became aware of his state and wished to be killed; progressive physical and emotional fatigue; inability to find professional assistance; combining work and care; witnessing her gradual decay; seeing the care recipient being abandoned by everyone else; physical fatigue that prevented me to see the situation clearly; days in which nothing else can be done; accepting his change; fear of confronting the fact that there is no going back; fact that my siblings refuse to share the responsibility for care; feeling alone and criticized by my siblings; being angry, frustrated and resentful; loneliness;	provision; facing possible death/facing loss; inability to further contribute to care recipients care.	negative emotional experiences, tiredness, exhaustion, tired of advice/criticism, physical exhaustion, health issues preventing care, feeling hopeless about the continuation of care that leads to no positive outcomes, fatigue/emotional).

Appendix II

Caregiver Story

I remember that day as if it was yesterday, I was sitting in the doctor's office. I was feeling so worried about her.
In fact, I have been worried about her for quite some time now.
She hasn't been herself for over three months now. Although some of her friends told me that it was even longer than that. I was truly busy with my work, with my life. It seemed as if she didn't really need me.
But now, all of the sudden here I was, in the doctor's office, waiting for him to confirm my biggest fear.
"I am sorry I have to tell you this, but her condition is rapidly progressing. Is she staying alone home? She will need a lot of home care, someone to overview her daily life" – the doctor said.
We left the doctor's office.
On our drive back home, she was quiet. She was looking through the window as if she wasn't even there.
There were million thoughts running through my head, I had to get home to help my son with some tasks and make some dinner. I was wondering if there was any food in her fridge so that I could cook something for her before I head home.
"Tomorrow I will organize the rest and think about what doctor said", I thought to myself.
"Are you driving me home?" She asked, suddenly breaking the silence.
"Yes" I responded.
"Good", she said, "I can't wait to see my father, I have so much to tell him about today".
"Your father? What do you mean your father, your father died years ago".
"No, he didn't, no he didn't you are lying", she yelled in extreme distress. All this was taking place while I was driving.
"Take me home right now!" – she said. [act her raising her voice slightly]
"Okay, okay", I said, "I am taking you home".
My heart was racing, there is no "tomorrow", I must think right now about what the doctor said. I absolutely cannot leave her alone tonight. This is how my story started.
I think I can describe it simply; I did not have a choice, but to take her with me that night. "It is my duty" – I said to myself - because she is my family. Besides, I cannot afford someone to take care of her.
As the days were going by, I had to change so many things in my life, one after another. I had never expected all of it to happen that way. I had to reorganize the space in my house and empty a room for her.
All my morning routine had to adapt to her from day one. I had to change my working hours and shift to part-time work because I couldn't get to work by 9 any longer and stay there until 5. It is difficult sometimes to follow my own schedule.
My spouse often complains, and I do understand him, but I don't see what else I can do. I can't put her into a nursing home. My children didn't seem bothered at the beginning. In fact, they were excited to have grandma home, but there comes a time when they try to make plans for us to go to the park on the weekend, as we use to, but I can't promise anything because I do not know if she will be in her good mood that weekend and able to leave the house. My family balance is completely disturbed.
I remember my childhood weekends. Those times when I was being taken care of. I was so careless and happy. My mother was sometimes organizing lunch time with our family friends. There would be many children around. The fathers were barbequing, while my mother and her friends would bring the radio out and talk and laugh for hours. Those were some of the most beautiful memories I have from my childhood.
Before all this happened, I used to meet my friends at least two or three times a week for some wine or afternoon coffee. But now, I have almost lost touch with all my friends. They are calling, but I can never join them, and I think they are tired of calling me. There is always

something happening, and I don't have the time to go. I think they simply don't understand me. They are not in my situation.

Every day is different, and you end up living with the illness yourself. You adapt to it and with time you try to learn how to handle it. My morning is starting at 5 now. I used to wake up at 7. But those days are now gone.

In the morning, I wake up and quickly prepare for the day so that I can wake her up and help her shower and get dressed. Sometimes she gets upset about the clothes I pick for her and refuses to wear them but if I let her choose alone, she picks summer clothes in the wintertime. All this can take around two hours.

Then we go to the kitchen together, and I pretend I need her help because that is the only way I can convince her to have breakfast. I ask her to put some marmalade on the bread for her, for me and for the kids when they wake up. She is busy with the marmalade while I am packing her lunch to take to the day care. In the meantime, I am waking up my kids for school. Once we share a slice of marmalade bread, I give her the medications and walk with her outside where she is picked up by the day care centre bus. She stays at day care from 8 in the morning until 12 in the afternoon.

In the afternoon, after we all have had lunch together, the kids will go outside with their friends to play. And we stay home alone. On most of the days, when she feels fine, we talk about her memories about her parents. She likes to remember those days. It seems that this gives her some sort of comfort. And I like to see her happy.

We have some coffee and share occasional laughs. I smile when she smiles. There are moments when I feel that her "old self" is back, just the way she used to be. I feel this huge happiness in those moments. She asks me about the kids and how they are doing at school. I show her some of their homework, or recent photos with their friends. On other days she is completely disoriented and spends the time sitting quietly; it almost seems as If she is afraid. But then I talk to her about her parents, and she seems to calm down. Our evenings end with me putting her to bed and then doing the rest of the house chores before I go to bed.

One morning I woke up, and she was already awake, showering all by herself. On the bed she had prepared the clothes that she would wear that day. I can't explain how I felt in that moment. That was after three years of care. Everything seemed to have finally fallen into place, "She is fine again", I thought. My life could be fine again. Suddenly I felt so energetic. For a moment I started planning how we could reorganize our life and go back into the old routine. But soon, my happiness was gone. She came out from the bathroom and said she was late for work. We went downstairs and I didn't know what to do. I took the marmalade out, and I was telling her that she needs to eat because they were coming to drive her to day care, and she became aggressive. She threw down the plate and yelled that she was going to work. My children heard everything, came into the kitchen to see what was happening. They were really scared. She didn't recognize them, and I think she wasn't recognizing me. Fear, this is how I can describe such moments. I did not know what to do. I was scared for her, for my children. It was fear that didn't let me think for a moment. I felt powerless because she wasn't getting any better; she was either the same or getting worse. I couldn't make her get better and I think I was making her worse by not knowing what to do exactly. I was completely alone. No one could truly understand what I was going through. I didn't know what to do and I had no one to call. Everyone I knew had already advised me many times to consider nursing home. I couldn't just take a break to have a moment for myself to think. It had been like that for months. I had lost my personal freedom. I felt trapped.

I took the phone and called ambulance.

She was taken to the hospital under extreme distress. She was aggressive, upset, and disoriented. I only felt fear.

In the ambulance car, she was restrained. It is painful to see your parent like that. I couldn't handle her at home, and they couldn't handle her in the ambulance. A thought crossed my mind "What if this is the last time I am seeing her?"

I was sitting in the hospital hallway, completely exhausted. It was psychological and emotional exhaustion. It seemed as if the world had disappeared. I wanted to take care of her, I wanted to do everything, but I seemed to be unable to even move from the chair I was sitting on. I was confronted with all my feelings and realized that I couldn't continue like that

anymore. I was praying that she was alive and well and I could take her back home. After a while the doctor came in and told me she is okay.

"But what should I do if she is not okay again? What shall I do when she becomes like this?" I asked the doctor.

He gave me a look of sympathy and said that there is only as much as a person can do before there is nothing else left to do.

It was the first time I had realized and accepted that I needed help. In the house, I could manage. But inside my mind, I needed to know what was happening to me. It all happened so fast and then it slowed down, it became like a new life I had not chosen. Now when I think of everything that happened during the last three years, it helps me see and understand how this part of my life unraveled.

It matters how you will tell your story. Sharing your story and organizing your thoughts is such a powerful way of changing the perspective on everything that happens to us.

Now I always pay attention how I think of the events inside of my mind, and how I verbalize them. I feel like I was not admitting how hard it was for me to start the caregiving, but also, I feel I was so tired and worn out that I overdramatized some events. I don't know, this is how I see it now.

People don't often think of giving the voice to their story. How would this story sound? Everything has a beginning, the moment where things slightly or suddenly changed, and you had to follow it by changing too. If I had known what was going to happen to me, I would have been able to get ready. I would have known better. Not only for the illness, but also mentally ready.

Now I am visiting self-help group in one association for caregivers. It's free of charge.

I am learning how to tell my story to others, and I can see others feel better when they hear my story. But I also feel better because they truly understand me. They don't feel sorry for me, they feel what I feel. One day I took a notebook, and I drew a line, and I started marking everything on this line, chronologically. I drew a circle on the line to symbolize the beginning, and under that I wrote how it started. Then the next circle was what happened after it all started, how it all had to change. Then I drew a circle for my daily routine, how my day looks like now, what I normally do. Also, I added a circle for the problems that arise, when I think I can't do all the caregiving anymore.

This is my moment of the day when I have time to make and remake my story. On some days I can see what my problems were two weeks ago, and I laugh about them. Sometimes it's better, sometimes it's worse.

Once, in the self-help group, we were telling our story as if it was something that we heard from our friend. One different perspective, and I felt different about it too. There was a man who has just joined us, he listened carefully. He had just started taking care of his father, and it was obvious that it was all new to him.

We collect these stories now in the group. We were saying we have to make a book out of all our experiences. Anyone should make a small book out of his caregiving. I wish I had such a book when I started taking care of my mother, everything would be different. I think I would also be different.

It is important to know how to re-focus positively when all seems dark. How to accept things sometimes, instead of opposing life. I am learning this now.

I am taking a deep breath and hope for a fresh new day tomorrow.