


The potential of transformative video design for improving caregiver's wellbeing

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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

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 refamiliarisation 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

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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.

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 Dementia Lens (Petrovic and Gaggioli, 2020).

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.

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.

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).

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.

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 one's 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

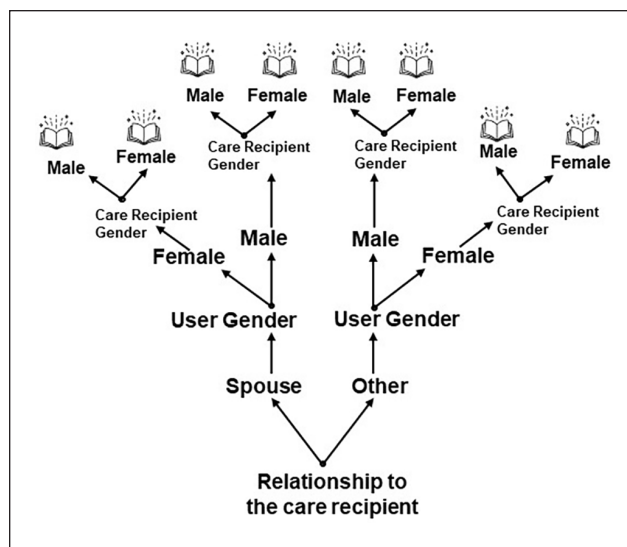


Figure 1. Preview of the initial storytelling structure.

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 1). 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.

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 2).

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

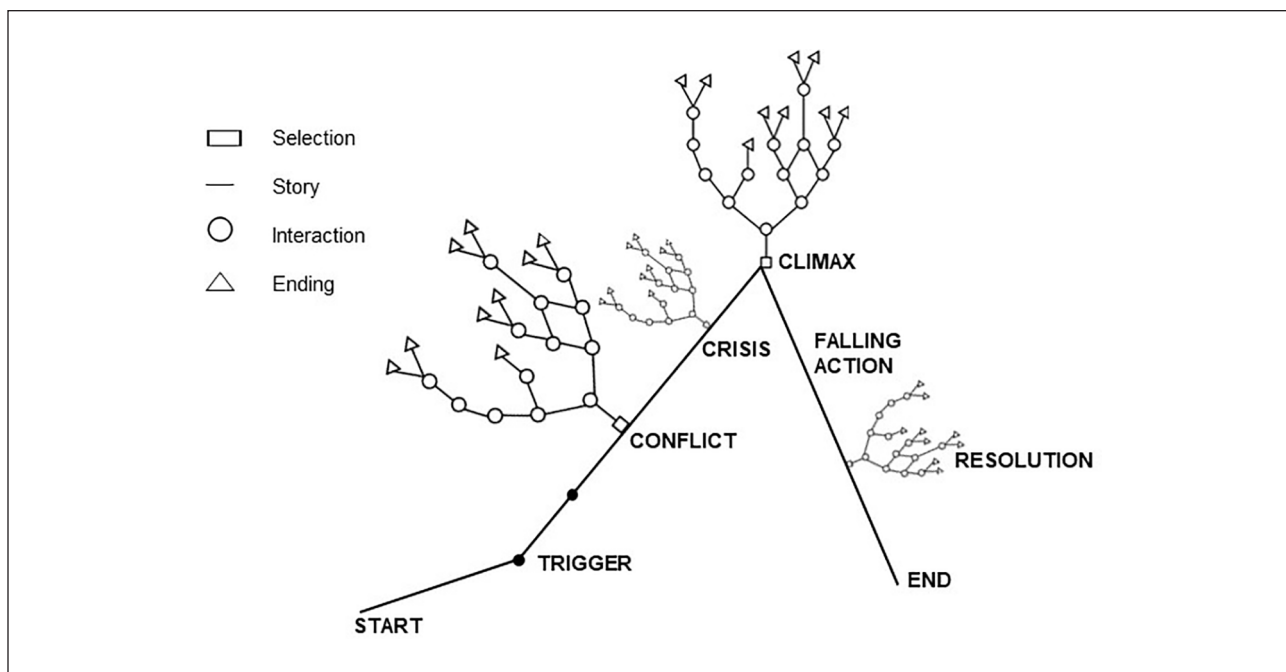


Figure 2. The story arc with interaction points.

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 3) when the video is paused, allowing the understanding of the rising action, critical point, interaction moment and denouement.

The methodological workflow of the design (Figure 4) 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.

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

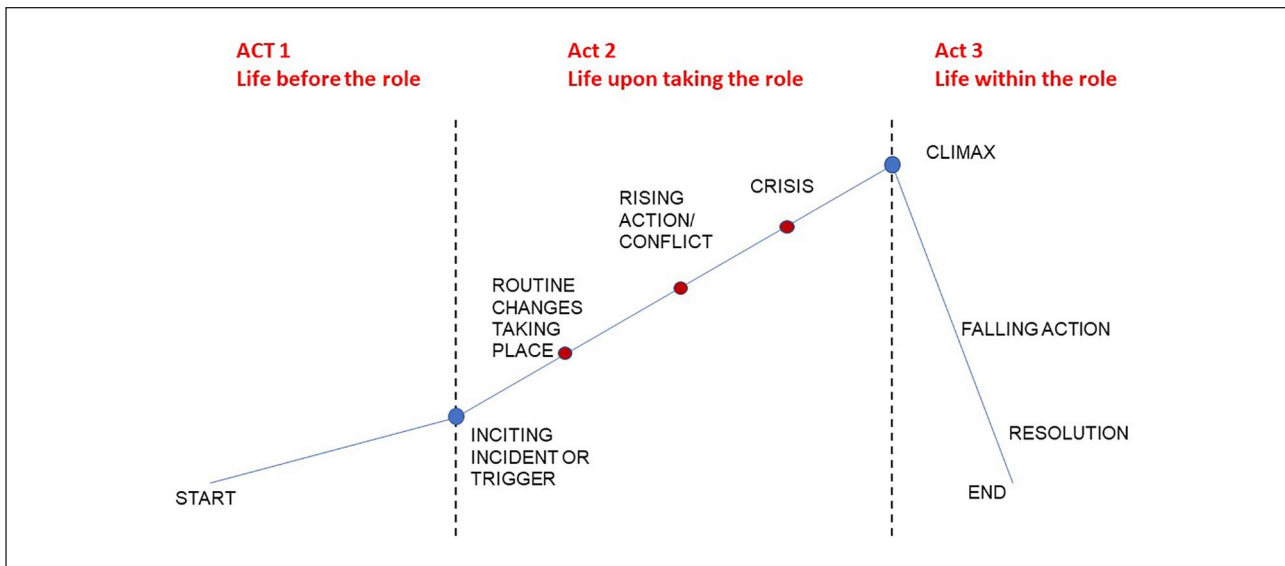


Figure 3. Sample of a story arc.

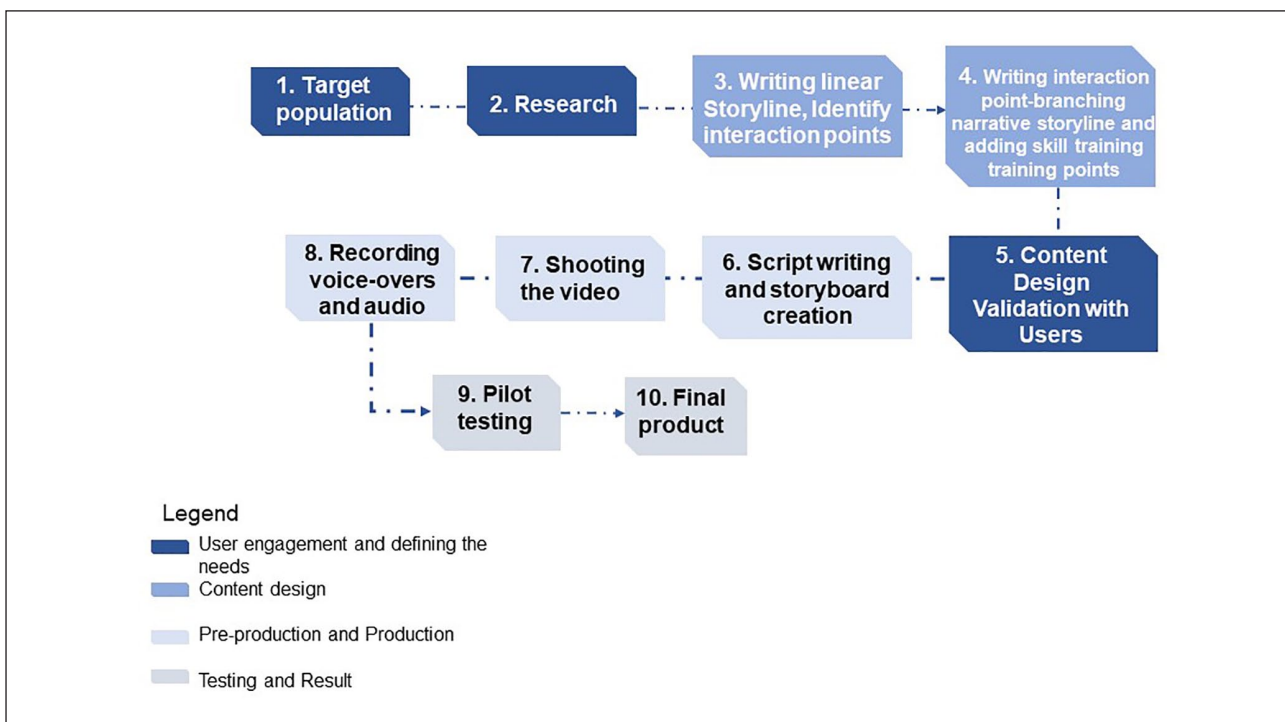


Figure 4. The overall design of the methodological workflow.

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.

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.

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