

## Time matters: Co-design for communication and digital narratives in dementia care

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We are going to present three studies that culminated on the concept of a product to enhance communication between carers, family, and persons with dementia using digital storytelling. First, in order to identify the state of the art about digital storytelling and dementia we conducted a systematic mapping. The databases used were: Scopus; Science Direct; Springer. Inclusion criteria were complete published studies; Portuguese or English language; Approaches to the elderly, dementia, caregivers, and health professionals. Twelve studies and eleven apps were analysed. There were 11 applications found on PlayStore that could support digital narratives with the possibility of using videos, audios, photos, texts, location, filters, and others. Based on the mapping performed, there is a lack of guidelines and evidence in the state of the art of digital narrative on technical and ethical issues in the use of digital narratives as a tool to improve communication between dementia patients, caregivers, and family members. Then, we selected an app (Com-Phone) and conducted a case study (Abrahão et al., 2018). In this case study, we explored the potential of mobile digital storytelling in a care home context. It was used for four weeks as a form of multimedia communication between formal and informal carers inside and outside the home, and a care home resident suffering from dementia. The home was located in São Carlos, Brazil as part of a larger international project called Time Matters (Frohlich, Chrysanthaki, Grato & Castro, n.d.) (UK and Brazil), in which Time stands for 'This is me'. Participants in the trial made fifteen digital stories, which is about one for every visit of the researchers to the care home. Stories focused mainly on the resident; capturing aspects of everyday life discussed in Visit conversations (4), documenting Social events (3) inside or outside the home, recording Therapy sessions (3) with the resident or Health reports (3) by professional careers, and forming Media albums (2) of the residents' art or life. In general, the technology was most useful for facilitating richer conversations with the resident and other participants and stimulating greater expressivity and creativity in the resident herself. The desire to document the resident's current life and interests in the home for later reminiscence by their family stands in contrast to conventional reminiscence therapy and related digital systems. These use media artefacts to stimulate reminiscence of residents' past life outside the home. On the last study, we aimed to explore issues and communication requirements with formal and informal caregivers in the context of older persons with dementia and, in turn, to evaluate their reactions to digital narrative technology as a new technological intervention in home care. The study included semi-structured interviews with 10 end users (formal and informal caregivers of elderly with dementia) at home. The results point to the social nature of technology and the importance of the caregiver's role as a facilitator in this process. In addition, caregivers reported that they would adopt digital narratives as a form of multimedia communication between people with dementia and with each other to coordinate care, as well as identifying communication requirements and needs. Reactions to the printed photos with audio files (talking album) were the most positive, which points to a concept of using augmented paper for the final product, as photo on prototype shoed on figure 1. Inclusive social media and digital narratives are viable as a means of communication in the context of dementia as long as design is centered on end users.

### References

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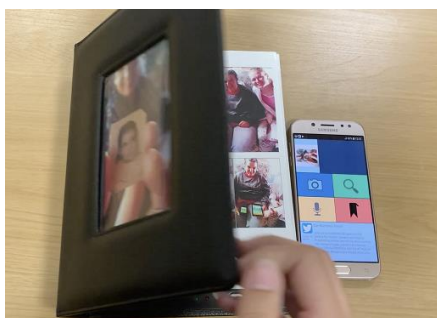


Figure 1. Talking photo album from the case study