

POSTER ABSTRACT

Building a narrative for compassionate communities: the case of Getxo Zurekin

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Introduction: Getxo Zurekin is a social awareness, training and network of care, which seeks to promote a new integrated palliative care model, empowering health/social care providers and the community, as leaders in the compassionate community movement.

Previous experiences have shown that implementation of these kinds of initiatives are highly context-dependent and their success requires a deep understanding of the dynamics and networks of care, and the needs and aspirations of people and caregivers at the end of life.

This study aims to 1 identify the needs of those in need of palliative care and get relevant insight into the perceptions and improvement opportunities; 2 identify an underlying narrative of change, aligned with the sociocultural characteristics of the community; 3 make communities become more involved in palliative and end of life care.

Methods: The methodology is based on the innovative approach to develop a Social Lab, focused on connecting entities and existing initiatives around the same project and objective. The working framework considers 4 ongoing phases: listening, co-creation, modeling and evaluation.

For the listening phase, a range of complementary qualitative research methods are being used. Information has been collected through 50 audiotaped semi-structured interviews to relevant stakeholders, such as families and caregivers, social/healthcare professionals, neighbours and local institutions. Other group sessions and socialization activities have also been employed to collect narratives, within a co-design/co-production theoretical framework.

All interviews are transcribed and information is peer-revised. Common topics and repeated patterns are extracted, shared and contrasted again by community agents at "review meetings", which are part of the co-creation phase.

The last two phases are planned to carry out within the approach of evaluation and improvement process in the following months.

Results: A new listening platform has been developed for end of life care in Getxo. Narratives have highlighted the necessity for specialized support, increased information and accessibility to public, private and communitarian resources, teaching in palliative care for professionals and families, and social awareness on palliative care.

Ongoing organization of activities and socialization allow for co-design and participation and so building a network thus transforming Getxo into a compassionate community.

Discussions: Traditional studies may only address the symptoms rather than the actual needs of the community. This research allows us to carry out more holistic research, generating a more comprehensive and interconnected series of interventions.

Conclusions: A transformational narrative has been created based on shared values and aspirations. Narratives allow to understand strengths, challenges and priorities in end of life care, as well as to set up specific priorities and actions in each community. The listening platform with collective challenges has allowed us to build a shared vision and a narrative of change.

Lessons learned: Communities matter! Their culture, values, identities shape the way they approach dying.

Limitations: Although the approach and methods used can be extrapolated to other contexts, the findings are highly contextual.

Suggestions for future research: An evaluation from a community perspective is needed to assess the effectiveness of this approach.

Keywords: end of life; compassionate communities; co-design; narratives; ethnographic research
