

Change – The transformative power of citizen science

## “I am more confident to talk about death now”. Students’ response to the citizen science project SoKuL

Barbara Pichler\* (a), Gert Dressel (b), Evelyn Hutter (b), Elisabeth Reitingner (b),  
Katharina Heimerl (b)

(a) CAREWEB, Association for the promotion of societal care culture,  
Vienna, Austria, [barbara.pichler@univie.ac.at](mailto:barbara.pichler@univie.ac.at)

(b) Department of Nursing Science, University of Vienna, Vienna, Austria

---

### Abstract

In the citizen science project “Storytelling about caring cultures at the end of life. Students and citizen scientists are doing research in intergenerational and intercultural exchange (SoKuL)”, students (n=6) reported in qualitative interviews and focus groups on their learning experiences in the project.

The students were able to gain varied and sustainable experiences. As a result of their participation in the project, they perceived personal development, which they describe as valuable for their internship and their future profession in elderly care. This concerns the development of an attitude that makes it easier to deal with and address the topics of dying, death & mourning and a learning process in conducting dialogues.

The in-depth learning experiences of the participating students illustrate the interventional nature of the research project. The participation of citizen scientists as co-researchers not only serves the advancement of knowledge in sciences. Their participation in the project was accompanied by a transformative learning process.

**Keywords:** citizen science, end of life, palliative care, participatory research, storytelling, transformative learning.

© 2024 Barbara Pichler, Gert Dressel, Evelyn Hutter, Elisabeth Reitingner, Katharina Heimerl

This is an open access article distributed under the terms of the Creative Commons Attribution License (CC BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Published by NHM, BOKU and ECSA and peer-reviewed under responsibility of ECSA-ÖCSK-2024 (Change – The transformative power of citizen science)

---

\* Corresponding author. E-mail address: [barbara.pichler@univie.ac.at](mailto:barbara.pichler@univie.ac.at)

## Introduction

October 2022 was the launch of the citizen science project “Storytelling about caring cultures at the end of life. Students and citizen scientists are doing research in intergenerational and intercultural exchange (SoKuL)”. We cooperated with the School for Elderly Care in the “Caritas Ausbildungszentrum für Sozialberufe” in Vienna. In the beginning of the project, we performed workshops and storytelling cafés with one class of this school. Over the course of the project, a core team of six students was formed for more intensive joint research work and other citizen scientists, mainly older people, were involved as contributors in storytelling cafés. By December 2023, 13 storytelling cafés on the topic of the end of life had taken place at various locations (nursing homes, museum, library, etc.), with between 7 and 32 people taking part. The students took on different roles in the storytelling cafés. They could spend the required time during their training period, any additional time was rewarded with a small amount of money. The other participating citizen scientists received no financial compensation.

Within the citizen science discourse (Eitzel et al. 2013), the SoKuL project can be located in the tradition of participatory action research (Hockley et al. 2014). This goes hand in hand with an understanding and the intention that (participatory) research processes intervene in social systems and thus change them. We understand the learning processes initiated through participation in the project as transformative educational processes in the sense of resonance pedagogy, a concept of learning by doing (cognitive, physical and emotional) (Beljan 2019; Rosa 2021).

The aim of this study is to reflect on and systematically record the learning experiences in relation to the project topic *care cultures at the end of life* and the *storytelling café method* from the students’ perspective. What resonance experiences did students have as a result of participating in the project? What did their participation in the storytelling cafés change for the students?

## Methods

In December 2023, five students from the core team received a training on interviewing and consequently interviewed each other about their experiences in the project and in the storytelling cafés. They conducted qualitative semi-structured interviews. In addition, two focus groups (n=5/n=6) were held in December 2023 and January 2024, where, as in the interviews, the project and storytelling café experiences were reflected upon. The interviews and focus groups were recorded, pseudonymised, transcribed verbatim and analysed thematically by the researchers (Clarke and Braun 2006).

All of the participating students are completing their second education. They are between 30 and 52 years old, four of them are female and two are male, half of them are migrants.

## Results

The students were able to gain varied and lasting experiences, particularly through their participation in the storytelling cafés.

*“What surprised me so much was the really very private, intimate stories that were actually told. (...). I was very touched. And that will stay with me forever, yes, it does something to you, the experience”* (AS/FG5, 11).

They could perceive changes in themselves as a result of participating in the project, which they describe as valuable for their practical training and their future profession in elderly care. They feel *“more confident to talk about death now”* (AS/I4, 91). This concerns 1) the development of an attitude that makes it easier to deal with and address the topics of dying, death & mourning and a 2) learning processes in conducting dialogues.

### **1) Dealing with dying, death and mourning**

Participation in the project encouraged the students' personal engagement with the topic of end of life.

*“I heard a lot of stories in the storytelling café, I also told a lot myself (...), maybe it was difficult to address the topic at the beginning. It got better as time went on. I feel good in this project and have developed well, really being able to deal well with these situations at the end of life (...) for me personally”* (EL/I5, 14).

The attitude that the participating students have a more open approach to the topic of dying and death is perceptible. They increasingly find themselves in situations where they talk to someone about it, whether it is a nursing home resident, a relative or a colleague.

*“Everything that has to do with death is something that tends to be marginalised in our culture. And you don't really know if you're allowed to talk about it now. Or when you see that someone is dealing with it, is sad, is worried. I have to say, I've lost my fear as a result. So I deal with it more openly. Very openly now, actually. And that's what the project has done to me”* (SJ/FG5, 20–22).

By listening to a variety of stories about the end of life in the storytelling cafés, the students learnt about many different ways of dealing with dying, death and grief, which is perceived as an enrichment for their professional activities.

## **2) Conducting dialogues**

The importance of listening was very much emphasised as an aspect that could be taken away from the storytelling cafés, especially for their work with the elderly. “*I first have to listen and look before I can help*” (TS/FG4, 119). However, this aspect is not taken for granted in everyday working life.

Another important aspect is described by the students as allowing emotions, enduring silence and not judging.

*“What I take away is that silence is also a form of communication, and in the internship, when I talk to people, I allow their feelings. And I don’t have to comment on anything, just take it, and yes. I’ve learnt that”* (AS/FG5, 47).

## **Discussion and Conclusion**

The in-depth learning experiences of the participating students illustrate the interventional nature of research projects (Ukowitz and Hübner 2019). The participation of citizen scientists as co-researchers not only serves the advancement of knowledge in sciences. Their participation in the project was accompanied by a transformative educational process that is reflected in the students’ changed practices.

The storytelling café on the topic of the end of life with subsequent reflections is not only a social science survey method, but also proves to be a suitable method for acquiring the necessary skills in palliative care. The required specific attitude and conducting dialogues are skills that cannot be acquired purely cognitively. They require spaces of experience and resonance (Rosa 2022).

In the course of the storytelling cafés, encounters at eye level and a non-judgemental framework proved to be both a conducive learning environment and favourable in the collaboration between scientists and citizen scientists. The storytelling café is particularly suitable as a citizen science method, as it promotes mutual understanding, initiates change and learning processes and generates knowledge at the same time (Pichler et al. 2023).

## **Acknowledgments**

The project is funded by the Austrian Federal Ministry of Education, Science and Research (BMBWF) as part of the OeAD – Sparkling Science 2.0 program.

## **References**

Beljan J (2019) Schule als Resonanzraum und Entfremdungszone. Eine neue Perspektive auf Bildung. Beltz, Weinheim.

- Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2). 77–101.
- Eitzel MV, Cappadonna JL, Santos-Lang C, Duerr RE, Virapongse A, West SE et al. (2017) Citizen Science Terminology Matters: Exploring Key Terms. *CSTP* 2 (1), 1. DOI: <https://doi.org/10.5334/cstp.96>
- Hockley J, Frogatt K, Heimerl K (Eds.) (2013) *Participatory Research in Palliative Care. Actions and Reflections*. Oxford University Press Incorporated. Oxford.
- Pichler B, Dressel G, Hutter E, Reitinger E, Heimerl K (2023) The Storytelling Café as a Citizen Science Method: generating knowledge, communication and education. In: *POS Proceedings of Science (ACSC2023)* 016. <https://pos.sissa.it/442/016/pdf>.
- Rosa H (2019) *Resonance. A sociology of the relationship to the world*. Cambridge, UK, Medford, MA, USA: polity.
- Rosa H (2022) Das Erzählcafé als Resonanzraum. In: Dressel G., Kohn J, Schnelle J. (Eds.): *Erzählcafés. Einblicke in Praxis und Theorie*. Juventa, Weinheim, 18–27.
- Ukowitz M, Hübner R (Eds.) (2019) *Interventionsforschung*. Springer Fachmedien. Wiesbaden.