

Reflections on developing a community-based program to stimulate intergenerational conversations about death and loss

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Elderly and children working together to create a collage of flowers that expresses feelings of sorrow and loss.

Methods

This is a community based participatory research (CBPR) project in which we collaborate with community organizations to develop the project and simultaneously study the development process and its implications. This study draws on data from 14 interviews exploring the experiences of other people who have developed comparable projects (marked with * in the diagram), complemented by observations of and reflections about the development process of a first iteration of our project (marked with **).

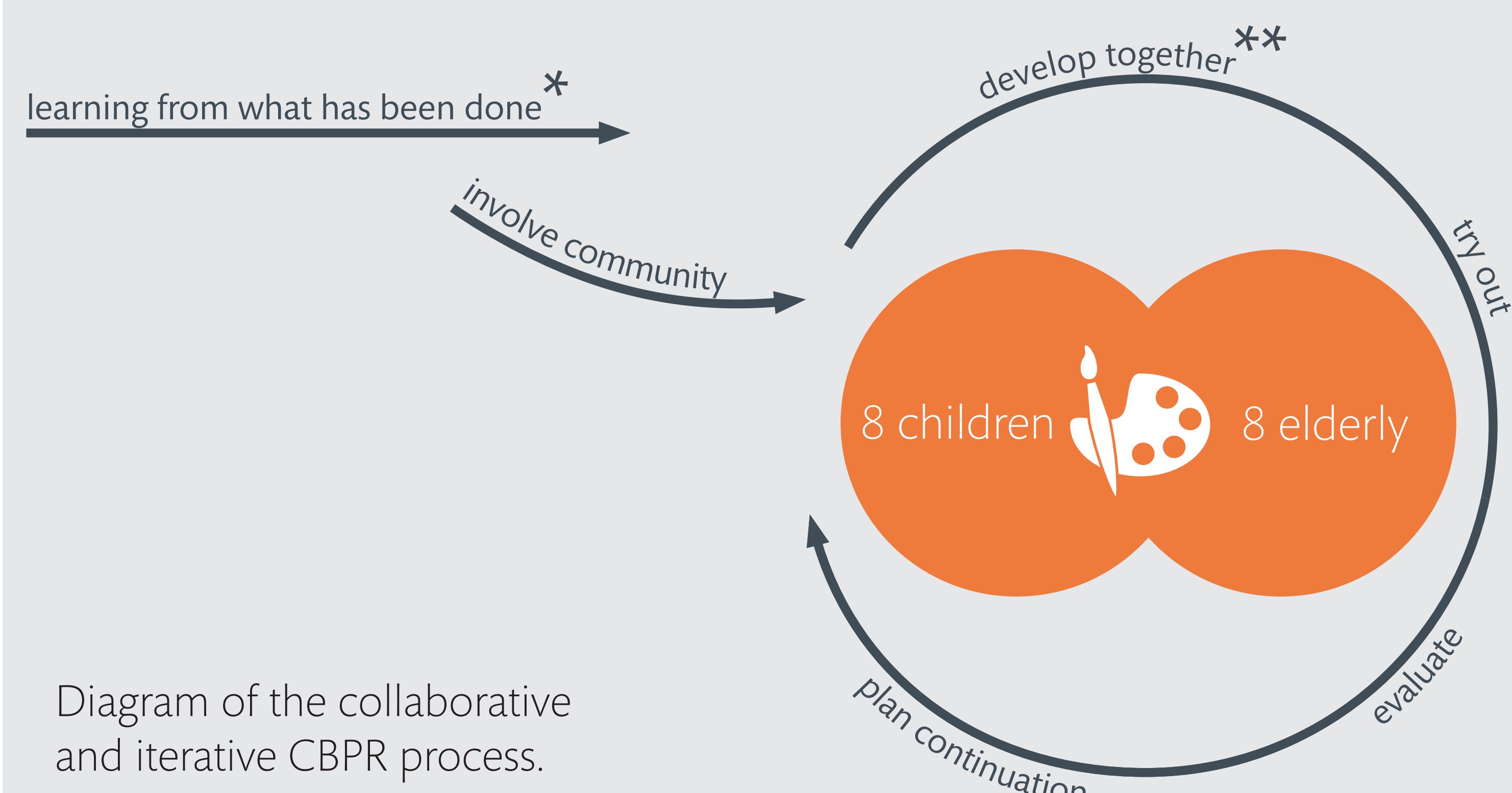


Diagram of the collaborative and iterative CBPR process.

Meetings and interviews were audio recorded and transcribed verbatim. Data is analyzed through a process of inductive content analysis.

Results

The term "the adults in between" refers here to those who develop these projects for children and elderly (including researchers). We found that the adults in between are in a position of power and responsibility in relation to children and elderly as described in the following ways.

Aim

A project was developed for children (9 y/o) and elderly (mostly 80+) using the arts to stimulate conversations about dying, death and loss. We did this in collaboration with community organizations in a multicultural suburban area of Stockholm, Sweden. To inform the development of this project we conducted interviews with people who have worked on comparable projects.

The aim of this qualitative study was to identify challenges and facilitating factors for developing intergenerational and arts-based projects about death and loss.

The adults in between:

- Decide which children and elderly to invite as participants in this project, and how to recruit them.
- Control the content and facilitation of the arts-based activities that the participants engage in.
- Mediate the intergenerational conversations about death and loss. These conversations could for example be silenced when adults feel unprepared for supporting children or elderly who may become sad or upset, or when they are worried for not being able to answer questions about death and loss.



Conclusion

We argue that challenges and facilitating factors have to do with power structures and feelings of responsibility between people of different ages. To facilitate a constructive use of power and responsibility it is important for the adults in between to share their own thoughts, experiences and emotions about death and loss. Many of the adults in between who were part of this study have expressed that it takes courage to do this. The lessons we have learned so far will be applied during the development of a second iteration of this project in collaboration with other community organizations in another city in Sweden.

DöBra

This project is part of the DöBra research program at Karolinska Institutet.

DöBra is a pun meaning both 'dying well' and 'awesome' in Swedish.



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