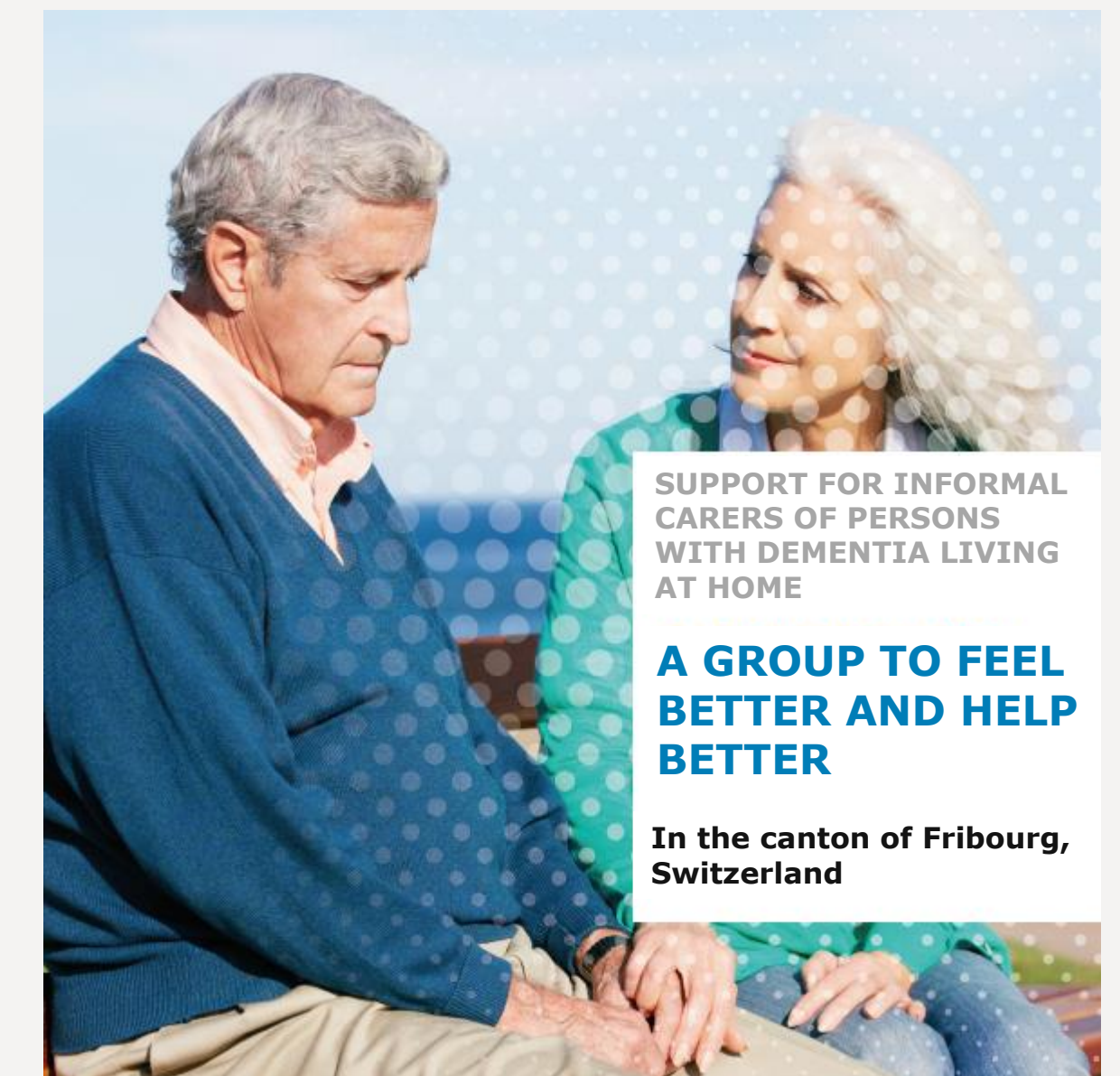


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Adapting a psychoeducative intervention to facilitate the participation of informal caregivers

The « learning to feel better to help better » (LFBHB) intervention



Introduction

- The LFBHB intervention aims at empowering informal caregivers of a person with dementia (IC-D) to cope with the daily stress of caregiving. This group intervention of 15 weekly sessions of 2 hours each was originally developed and tested with a randomized controlled trial in Canada (Hébert et al., 2003).
- It has then been pilot tested in Switzerland within a one group pre-post design, showing substantial improvements in burden, psychological distress and self-efficacy (Pihet & Kipfer, 2019).
- However, mobilizing IC-D to participate was a challenge. IC-D experience high levels of stress, which limits their time and personal resources to participate in support programs. In addition, IC-D often fail to perceive their own needs for support (Murphy et al., 2007).
- Other known barriers are for example an advanced age of the IC-D, difficulties to access the intervention site, time consuming interventions, the absence of a subsidiary caregiver during the intervention time or a lack of understanding of the support provider for the situation, the culture, the norms and values of the IC-D (Dibartolo & McCrone, 2003; Murphy et al., 2007; Whitebird et al., 2011).

Objective

Our project aimed at identifying barriers and facilitators for participation and at adapting the intervention accordingly.

Method

- Data on the recruitment process were collected in semi-structured interviews with 15 recruiters from ten organizations (Alzheimer Association, Red Cross Switzerland, memory clinics, day care centers, and home care), and submitted to an inductive summarizing content analysis (Mayring, 2010) to identify how the intervention could be adapted.
- The adaptation was conducted with a participatory approach, including former participants in the LFBHB intervention and representatives of four organizations working with IC-D.

Results of the content analysis

Compatible with the daily life & resources

- One of the biggest barriers to participate was the duration of the intervention (15 weeks). Due to their highly unpredictable daily life and caregiving challenges, IC-D mostly live from day to day. Organising assistance for the person affected for a long period of time is difficult.
- The intervention time in the afternoon was a barrier for employed IC-D, and the site was difficult to access for older IC-D living in rural areas and who were not driving anymore.
- The way the intervention was presented influenced the motivation to participate. The word “training” used in its description was associated by some IC-D with a lot of effort and high requirements, which hold them back from participating.

At the right time

- IC-D tend to ask for help when they are already exhausted and rather need respite services. At this timepoint they don't have the necessary cognitive resources to participate in a psychoeducative intervention. Participation is then perceived as an additional burden.
- IC-D need to be ready to leave the person with dementia in the care of someone else during the intervention time, which is often difficult when they have never used any respite service before.

Being familiar

- Recruiters who were familiar with the intervention were able to inform in more detail and more targeted about the content and purpose of the intervention. Others rather presented it as one more support option.
- Recruiting persons who were familiar with the specific situation of the IC-D were able to better identify which IC-D can benefit from the intervention and to inform them according to their needs and abilities.
- IC-D were more open and willing to participate in the intervention if it was presented and recommended by a person they know and trust.

Adaptions in the LFBHB intervention

Both IC-D and professionals have been involved to decide about how to improve the LFBHB intervention based on the previous results. Identified core barriers for participation were time investment and organization burden due to the length of the intervention, as well as the limited time and knowledge of recruiters. Therefore we conducted the following adaptations:

- A film was created to present the intervention and facilitate the recruitment, including stories of former participants.
- The duration of the intervention was reduced to 7 sessions of 3 hours each to reduce time investment and organization burden.
- 6 short films including examples of former participants were created to shorten and standardize information provision, and to facilitate knowledge transfer through role models.



The adapted LFBHB version has now been conducted with four groups of IC-D with similar effects on their quality of life compared to the original intervention.

Conclusion



Thank to the analysis of recruitment barriers and the involvement of IC-D and professionals in the adaptation, we achieved a better fit of the intervention to the resources of IC-D, and a higher efficiency of the intervention.

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