SAFER-DEM: GENERATING CO-DESIGNED ADAPTATIONS TO A DISCHARGE CARE PLANNING BUNDLE FOR PEOPLE LIVING WITH DEMENTIA

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Abstract

Individuals living with dementia are often excluded from care transitions research and discussions around their discharge from hospital. In collaboration with people living with dementia, their carers and mental health professionals we sought to co-design a dementia inclusive discharge care planning bundle (SAFER-DEM) based on an existing intervention (SAFER mental health care bundle). We used sequential co-design workshops and 'think aloud' methodology to adapt the resources. Think aloud interviews were analysed using Thematic Analysis and highlighted key changes such as simplified language, flexible timings, personalised support, digital and non-digital formats. Better communication and dementia-inclusive hospital environments and processes are needed to improve hospital discharge, the SAFER-DEM shows potential to improve dementia care during hospital discharge.

Keywords: Mental health services research, care transitions, inpatient mental health services, dementia, shared decision making.

1. Introduction

Individuals living with dementia are often excluded from care transitions research (Piraino et al., 2012), leading to unclear understanding of their specific needs in inpatient mental health settings. People living with dementia are seldom involved in their own discharge discussions (Corrado et al., 2019), making the navigation of this vulnerable period challenging for them and their carers. The SAFER-MH care bundle seeks to improve discharge quality for those transitioning from mental health hospitals to the community (Tyler et al., 2023). This study aims to co-design adaptations to the care bundle to make it more applicable to people with dementia.

2. Objective

In collaboration with people living with dementia, carers, and a graphic designer this study aims to co-design a dementia-inclusive version of the SAFER-MH care bundle, termed SAFER-Dem.

3. Methods

Three stakeholder groups were involved: people with lived experience of dementia, carers and healthcare professionals. Four co-design workshops were held with 17 participants from diverse backgrounds. Participants were presented with the original SAFER-MH (Tyler et al., 2023) resources and ideas for potential adaptations were invited and discussed, revised prototype resources were fed-back as

the workshops progressed. This was followed by 12 'Think Aloud' interviews (Tourangeau, 1984) using prototype resources. A thematic analysis was conducted (Braun & Clarke, 2012). Figure 1 shows the methods used to develop the resources and figure 2 shows an example of a scenario card protocol developed during the workshops and presented to participants in the 'Think Aloud' interviews.

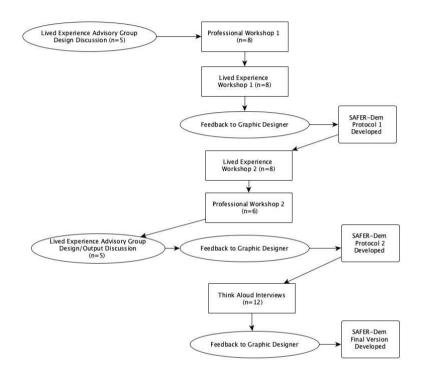


Figure 1. Summary of the methods used to develop the protocols.

Figure 2. Example of protocol scenario card developed at Protocol 2 stage and presented to participants during the 'Think Aloud' Interviews.



4. Results

In the workshops, participants recommended simplifying materials and tailoring them to different levels of dementia severity, favouring realistic illustrations over cartoons or photographs. They also suggested developing scenario cards and 'talking mats' to enhance communication. The Think Aloud interviews identified two main themes: dissatisfaction with discharge procedures, particularly regarding communication issues and suggestions for practical improvements to the SAFER-Dem care bundle. Recommendations focused on improving appropriateness by using clear, relatable imagery and offering both digital and non-digital formats. Practical changes included flexible timing, individualized involvement of carers, and addition of memory aids. Usability improvements emphasized the need for simplified language and personalized support. Table 1 provides a summary of the themes and subthemes that emerged from the 'Think Aloud' interviews.

Themes	Sub-themes
Appropriateness	Usefulness
	Accessibility and inclusivity
	Capacity
	Idealism
Practical Changes	Resources format
	Digitalisation
	Simplification and clarity
	Emotive responses
Usability	Timing
	People involved
	Additional Aids

Table 1. Themes and subthemes from the thematic analysis of responses during the 'Think Aloud' Interviews.

5. Discussion

The SAFER-Dem care bundle was well received by stakeholders, showing promise for improving the quality of discharge practices for people with dementia. However, participants identified areas for improvement to enhance accessibility and effectiveness. Key concerns raised were around communication and environmental issues during discharge, highlighting the need for more dementia-sensitive approaches. Practical suggestions focused on refining the bundle's usability and appropriateness to better meet the unique needs of this population. These findings suggest that with further refinement, SAFER-Dem could become a valuable tool in supporting dementia-inclusive discharge practices. Research, patient and public involvement and co-design with people living with dementia have been instrumental in understanding needs and experiences during discharge.

6. Key Implications

- The SAFER-Dem care bundle shows potential to improve dementia care during hospital discharge.
- Better communication and dementia-inclusive hospital environments are needed for smoother discharges.
- Engaging people living with dementia, their caregivers, and professionals in co-designing discharge solutions is crucial to addressing their needs effectively.

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References

- Braun, V., & Clarke, V. (2012). Chapter 4: Thematic Analysis. In H. Cooper (Ed.), APA Handbook of Research Methods in Psychology (Vol. 2, pp. 57-71). https://doi.org/10.1037/13620-004
- Corrado, O., Swanson, B., Hood, C., Morris, A., Ofili, S., Capistrano, J., Butler, J., & Bourke, L. (2019). National Audit of Dementia Care in General Hospitals 2018-2019 Round Four Audit Report. www.hqip.org.uk/national-programmes.
- Piraino, E., Heckman, G., Glenny, C., & Stolee, P. (2012). Transitional care programs: who is left behind? A systematic review - PubMed. *International Journal of Integrated Care*, 12(5). https://doi.org/10.5334/ijic.805
- Tourangeau, R. (1984). Cognitive Aspects of Survey Methodology. National Academies Press. https://doi.org/10.17226/930
- Tyler, N., Angelakis, I., Keers, R. N., Planner, C., Hodkinson, A., Giles, S. J., Grundy, A., Kapur, N., Armitage, C., Blakeman, T., Campbell, S. M., Robinson, C., Leather, J., & Panagioti, M. (2023). Evaluating a co-designed care bundle to improve patient safety at discharge from adult and adolescent mental health services (SAFER-MH and SAFER-YMH): protocol for a non-randomised feasibility study. *BMJ Open*, 13(4). https://doi.org/10.1136/bmjopen-2022-069216