Involving stakeholders in development of a self-help behavioural activation intervention INVOLVERA for people with dementia: a qualitative study

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Introduction

• Depression is prevalent in people with dementia, despite this access to psychological interventions is limited
• Guided low-intensity behavioral activation is a potential solution
• Necessary to adapt interventions to meet the needs and preferences of key stakeholders to enhance acceptability and relevance

Aims

(1) Explore the needs and preferences of key stakeholders concerning the content and delivery model of a guided low-intensity behavioural activation intervention INVOLVERA.
(2) Adapt the intervention to ensure cultural appropriateness, relevancy, and acceptability to people with dementia and their caregivers in Sweden.

Methods

• Semi-structured interviews and focus group discussions
• Participants (key stakeholders): People with dementia (n=18); Informal caregivers (n=19); Health and social care professionals (n=18); Community stakeholders (n=7)
• Provided to participants prior to interviews: Draft of translated workbooks
• Written description of proposed delivery model
• Open-ended questions explored intervention content and delivery preferences
• Data analysed using manifest content analysis

Results

Results from content analysis with three categories, nine subcategories, and example quotations (see Figure 1).

Figure 1. Categories, subcategories and example quotations.

Content
• Cultural aspects
  • Inclusivity
“[Memory impairment] is a good word. Everyone understands it, and it is not that dramatic either. If you say dementia, then you directly think of old grandma lying in a bed at home.” (Person with dementia)

Delivery procedures
• Availability
• Delivery mode
• Setting
• Support and guidance
“I am old-fashioned. [I want] to be able to hold the material [in my hands].” (Caregiver J). “(Informal caregiver)

Illness trajectory
• Burden of care
• Burden of material
• Timing
“I do not think this [intervention] is applicable if you are too advanced in the illness. This must be put in place immediately upon diagnosis, because then the person is in an early stage and then something like this can be a help.” (Community stakeholder)

Conclusions

• Proposed guided low-intensity behavioural activation intervention was well received by people with dementia, informal caregivers, health and social care professionals, and community stakeholders
• We were able to explore needs and preferences to inform adaptation and tailoring of intervention to enhance cultural appropriateness, relevancy, and acceptability
• In accordance with MRC complex interventions framework results will inform a future pragmatic feasibility study to further explore acceptability and feasibility of the intervention

References

INVOLVERA Study protocol


Leung DKY, Chan WC, Spector A, Wong GHY. Redesigned workbooks and new modern illustrations.


Figure 2. Example of adaptation of intervention content with new modern illustrations.

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