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Original Study

Process Evaluation of an Intervention for the Management of Neuropsychiatric Symptoms in Young-Onset Dementia

Britt Appelhof MSc [a,b,c,*], Christian Bakker MSc, PhD [a,c,d], Jeannette C.L. van Duinen-van den IJssel MSc [a,c], Sandra A. Zwijsen MSc, PhD [e], Martin Smalbrugge MD, PhD [e], Frans R.J. Verhey MD, PhD [f], Marjolein E. de Vugt MSc, PhD [f], Sytse U. Zuidema MD, PhD [g], Raymond T.C.M. Koopmans MD, PhD [a,c,h]

[a] *Department of Primary and Community Care, Radboud University Nijmegen, Medical Centre, Nijmegen, the Netherlands*
[b] *Archipel, Landrijt, Knowledge Center for Specialized Care, Eindhoven, the Netherlands*
[c] *Radboudumc Alzheimer Center, Nijmegen, the Netherlands*
[d] *Florence, Mariahoeve, Center for Specialized Care in Young-Onset Dementia, The Hague, the Netherlands*
[e] *Department of General Practice and Elderly Care Medicine / Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, the Netherlands*
[f] *School for Mental Health and Neuroscience, Alzheimer Center Limburg, Maastricht University Medical Center, Maastricht, the Netherlands*
[g] *Department of General Practice and Elderly Care Medicine, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands*
[h] *De Waalboog "Joachim en Anna", Center for Specialized Geriatric Care, Nijmegen, the Netherlands*

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A B S T R A C T

Objectives: A process evaluation was performed for an intervention aimed at improvement of the management of neuropsychiatric symptoms in young-onset dementia. Data about sample quality and intervention quality was evaluated to better understand internal and external validity. In addition, data about the implementation strategy and factors affecting implementation were evaluated to improve further implementation of the intervention.
Design: A model proposed by Leontjevas and colleagues consisting of first-order (validity) and second-order (implementation) data was used.
Setting and Participants: Care units delivering specialized treatment and support for residents with young-onset dementia.
Measures: A description of the recruitment, randomization procedure, and intervention reach was carried out to determine sample quality. To determine intervention quality, data on satisfaction, relevance, feasibility, and fidelity were collected through a questionnaire and reports logged on the server of the web-based intervention. A description of the implementation strategy was provided. Barriers and facilitators for implementation were collected by a questionnaire and analyzed by deductive content analysis.
Results: Care units varied in size and were recruited from different geographical regions in the Netherlands. The informed consent rate of the residents was 87.7%. The majority of the nursing home staff were satisfied with the intervention. However, parts of the intervention were perceived as less relevant for their own organization. The feasibility of the intervention was considered low. The fidelity differed between care units. The implementation strategy did not overcome all barriers. Factors affecting implementation covered 3 themes: organizational aspects, culture of the organization, and aspects of the intervention.
Conclusions: In general, our results showed sufficient internal and external validity, warranting further effect analyses. Adaptations to specific steps of the care program should be considered to increase

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* Address correspondence to Britt Appelhof, MSc, Department of Primary and Community Care, Center for Family Medicine, Geriatric Care and Public Health, Radboud University Medical Center, Nijmegen, P.O. Box 9101, 6500 HB Nijmegen, the Netherlands.
E-mail address: Britt.Appelhof@radboudumc.nl (B. Appelhof).

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feasibility and sustainability. In addition, integration of the care program into the electronic health records is expected to further improve implementation.

In institutionalized people with young-onset dementia (YOD), neuropsychiatric symptoms (NPS) are highly prevalent.[1,2] NPS have been associated with negative health outcomes like a loss of quality of life, increased cost of care, and a high workload for nursing home (NH) staff.[3–5] Psychotropic drugs are often used in the treatment of NPS in institutionalized people with YOD,[1] which are negatively associated with quality of life in both YOD and LOD.[3,6–8] Therefore, in the Behavior and Evolution of Young-ONset Dementia part 2 (Beyond-II) study, an intervention for the management of NPS in YOD was implemented on long-term care units offering specialized treatment and support in YOD.[9]

A randomized controlled trial (RCT) was conducted to evaluate the effect of the intervention on the prevalence of NPS and psychotropic drug use (PDU) in NH residents with YOD, and workload, absenteeism, and job satisfaction of the NH staff.[9] To interpret the outcomes of the RCT, information about internal and external validity is important.[10] Internal validity refers to the extent to which effects are a result of the intervention.[11] For example, an RCT could fail to find an effect of a potential successful intervention because of too small sample sizes.[11] External validity refers to the generalizability of the effects of the intervention.[11] For instance, if recruitment rates are low, the research population might not be representative of a wider population.

Besides information on validity, a better understanding of the implementation process is necessary to understand why the intervention was or was not effective and how to improve sustainability in clinical practice.[10,12,13] A recent editorial stated that as a result of practical difficulties in conducting applied research in the context of daily practice, it is naïve to expect that complex intervention in NHs are always completely carried out as planned.[14] Therefore, potential successful interventions might fail to show effect because they were not delivered as intended.[12,15–17] This is expressed as low treatment fidelity.[12,17] To allow for conclusions about the effectiveness of the intervention in clinical practice, it is important to understand the relationship between contextual factors and the effectiveness of the intervention, rather than trying to control for contextual influences.[13,16] This context consists of all factors, external to the intervention, that might facilitate or hinder implementation.[17] Previous implementation studies in NHs have already reported on the contextual barriers for implementation such as staff turnover, staff shortage, low staff motivation, lack of leadership, absence of management support, and organizational changes.[18–20] To try to overcome these contextual barriers and increase effectiveness of our intervention, an implementation strategy was developed alongside the intervention. Reporting on the used implementation strategy and how it was received is important as it would provide future users of the intervention with vital information about how to reproduce the intervention.[10,17,21]

A process evaluation provides knowledge on validity and implementation.[10] Therefore, in this study, a process evaluation was performed for an intervention aimed at improvement of the management of NPS in institutionalized people with YOD (1) to establish internal and external validity and (2) to provide information about the implementation strategy and factors affecting implementation.

Methods

This process evaluation is part of the Beyond-II study and was conducted before effect analysis of the intervention. The design of the Beyond-II study and information about the development of the intervention are described in full detail elsewhere.[9,22]

Intervention

The intervention in this study is based on the "Grip on Challenging Behavior" care program.[22,23] After implementation of this care program in late-onset dementia (LOD), a decrease in NPS and PDU as well as an increase in job satisfaction of the NH staff was found.[24,25] The care program provided guidance for the multidisciplinary team involved in the management of NPS in Dutch NHs (nursing staff, specially trained elderly care physicians and psychologists)[26,27] to structure the process of detection, analysis, treatment, and evaluation of NPS (Figure 1). NPS could be every form of behavior that is perceived as challenging by the NH resident or by people surrounding the residents (eg, NH staff, relatives, other residents), encompassing various symptoms including affective symptoms such as depression, anxiety, and apathy, and behavioral symptoms such as aggression, agitation, disinhibition, delusions, and hallucinations.

The steps of the care program were consecutive and formed a cycle, except for the evaluation of appropriateness of psychotropic drug prescription, which was a separate step (Figure 1). The first step of the care program was detection of NPS. This occurred through usual observations of the multidisciplinary team or with the use of a screening tool every 6 months by a vocational nurse. The screening tool was based on the Neuropsychiatric Inventory–Questionnaire (NPI-Q).[28] After NPS were detected, a structured analysis of the NPS was conducted by the vocational nurse. The analysis contained questions regarding the time and place of occurrence of the NPS, possible causes, and actions already undertaken by the care staff. In addition, a tool for the detection of unmet needs possibly underlying the NPS was used by the vocational nurse. The tool was adapted and extended based on the Dutch version of the Camberwell Assessment of Need for the Elderly (CANE).[29,30] When necessary, the physician and/or the psychologist continued the analysis. Their analyses consisted of a checklist to rule out physical or psychiatric causes (physician) or a functional analysis of the NPS (psychologist). After the analysis of the clinician, treatment options were discussed within the multidisciplinary team and a treatment plan was established by a clinician (psychologist or physician). The treatment plan contained a specifically defined, measurable treatment goal. The care program did not prescribe a specific intervention. The choice of the intervention relied on the hypothesized causes of the NPS, the preferences of the resident, and the available options in the NH. However, in accordance with the guidelines on the management of NPS,[31–33] psychosocial treatments were preferred, with PDU only if other treatments had little or no effect. Treatment outcomes were evaluated by the multidisciplinary team. The frequency and severity of NPS before and after treatment were compared and if unsatisfactory, other treatments were considered or the analysis was performed again.

In a separate step of the care program, the physician used a tool for the evaluation of appropriateness of psychotropic drug prescription within the first 2 months after implementation for all residents (with our without NPS). The tool was adapted and extended based on the Appropriateness of Psychotropic Drug Prescription In Dementia (APID) instrument.[34,35] After this initial screening, the tool was used at the physician's own discretion.