JAMDA xxx (2017) 1–8

JAMDA

journal homepage: www.jamda.com

Original Study

Experiences and Effects of Structurally Involving Residents in the Nursing Home by Means of Participatory Action Research: A Mixed Method Study

Lien Van Malderen MSc, PhD [a,b,*], Patricia De Vriendt MSc, PhD [a,c], Tony Mets MSc, MD, PhD [a], Dominique Verté MSc, PhD [a], Ellen Gorus MSc, PhD [a,d]

[a] *Department of Gerontology, Vrije Universiteit Brussel, Brussels, Belgium*
[b] *Research Foundation Flanders, Brussels, Belgium*
[c] *Artevelde University College, Ghent, Belgium*
[d] *Geriatric Department, Universitair Ziekenhuis Brussel, Brussels, Belgium*

Keywords:
Quality improvement
culture change
empowerment
quality of life
participation
active aging

A B S T R A C T

Objectives: This study aimed to examine the effects of introducing participatory action research (PAR) within the nursing home (NH) on residents' quality of life (QoL) and NH experience and participation, and to explore their experiences with PAR.
Design: A mixed methods design was chosen, including a clustered randomized controlled trial (RCT) and qualitative interviews.
Setting: For the RCT, 3 NHs were randomly allocated to 3 conditions: an intervention (weekly PAR activity), an active control (weekly reminiscence-activity), or passive control (care as usual). The qualitative study took place in the intervention NH.
Participants: Within the RCT, about 30 residents were recruited for assessments per NH, including 9 PAR participants and 10 reminiscence participants. Qualitative interviews were held with all PAR participants (residents and internal moderator).
Intervention: PAR is a method to structurally involve residents in the NH operation. Weekly PAR sessions were held with 9 residents and 2 moderators. Here, residents critically analyzed and discussed the NH operation, identified possible problems, suggested improvements, which were further implemented by the NH and monitored by the PAR group.
Measurements: Residents' NH experience (NH Active Aging Survey), QoL (Anamnestic Comparison Self-Assessment), and experienced participation (Impact on Participation and Autonomy) were measured in the RCT at pre-test, post-test (6 months), and follow-up (12 months). The qualitative study took into account interviews with the PAR stakeholders after 6 months.
Results: The RCT showed residents' QoL improving more between pre-test and follow-up in the intervention and active control NH compared with the passive control NH. No other effects were observed. The qualitative data revealed a positive PAR experience. Participants enjoyed the activity and indicated various positive influences. Still, there was room for improvement, including communication toward other residents and between staff.
Conclusions: Notwithstanding the modest quantitative effects, PAR led to positive experiences and can have a future in the NH when solving some limitations.

Participation of nursing home (NH) residents is important for optimizing their quality of life (QoL). Fulfilment of wishes and needs of residents implies listening to them.[1] Although an increased autonomy leads to a higher QoL and a higher participation in social activities,[2] the degree of residents' participation and autonomy in reality is limited,[2] because of many restraining factors,[2–4] including routine procedures and protocols.[5] When regarding the involvement of

This work is part of a PhD project supported by the Research Foundation Flanders (Fonds Wetenschappelijk Onderzoek-Vlaanderen) [grant number FWOTM623].
The authors declare no conflicts of interest.
* Address correspondence to Lien Van Malderen, MSc, PhD, Department of Gerontology, Vrije Universiteit Brussel, Laarbeeklaan 103, Brussels, Belgium.
E-mail address: Lien.van.malderen@vub.ac.be (L. Van Malderen).

http://dx.doi.org/10.1016/j.jamda.2016.12.072
1525-8610/

residents in the NH organization, the resident council is often the highest existing form of residents' influence.[6] These councils are, however, often seen as irrelevant by the NH, and residents experience that the proposed suggestions are not heard or followed through.[6,7] Nevertheless, participation within the organization appears to improve dignity, self-respect, responsibility, social identity, empowerment, and quality assurance.[6–8] In a NH, residents' participation and input might, furthermore, enable innovative strategies in the daily operation. The existing literature shows that there are still different challenges on this issue,[3,5,7,9] and new ideas and projects are desired.

A method consistent with this context is participatory action research (PAR), which is a "systematic inquiry, with the participation of those affected by the problem being studied, for the purpose of education and action or effecting social change."[10] As PAR applies to NHs, residents cooperate to identify problems, to critically reflect, and to develop a shared vision and actions on possible improvements, beneficial to all, which are later implemented.[11–13] As such, PAR contributes to a quality improvement of the facility, making the operation more responsive to the wishes of residents. Simultaneously PAR aims to empower residents. Attempts have been made to introduce PAR to residents in NHs,[13–16] but effects of PAR remain unclear.

The purpose of this study was implementing PAR in a NH to examine the effects on residents' QoL, participation, and NH experience, and to explore the experiences of the PAR participants.

Methods

A mixed method design, combining a randomized controlled trial (RCT) with a qualitative study was used.

Clustered RCT

The pilot clustered RCT encompassed a 12-month multicenter study including a PAR intervention, an active control situation (introducing reminiscence as group activity), and a passive control situation (care as usual), which were randomly allocated to 3 NHs. The RCT was approved by the ethical committee of the UZ Brussel, Belgium, and written informed consents were obtained from all participants.

Participants

NHs were informed of the study and could apply to participate when interested. To be included, NHs had to have an engagement to co-organize weekly group sessions with a staff member and to implement the proposed changes if they were the intervention NH (INH). Furthermore, PAR nor reminiscence could be part of their existing activity program. Three comparable NHs were purposively included; these were large (number of residents >150) public facilities situated in small cities. They were randomly allocated to 1 of the 3 conditions: the intervention, active control, and passive control (by means of SPSS; SPSS Inc, Chicago, IL).

In all NHs, collective and individual information sessions about the study were organized for residents without dementia. Furthermore, in the INH and active control NH (ACNH), residents were enlisted when interested to participate. In the INH, a group of 9 residents formed the PAR. In addition, 19 residents were randomly selected for assessments because the PAR decisions would be implemented in the entire NH, possibly leading to a quality improvement, also benefitting other residents. Following similar procedures, 10 residents were recruited in the ACNH to follow reminiscence sessions; in addition, 20 other residents were randomly selected for the assessment. For the passive control NH (PCNH), 30 residents were randomly recruited for assessment.

Procedure

In the INH, the intervention comprised weekly PAR sessions. The development of the intervention is described in detail elsewhere.[17] Briefly, the study encompassed a preparatory phase, the intervention phase, and a follow-up phase, each lasting 6 months. During the preparatory phase, the principal investigator became acquainted with the NH. She informed and trained the staff, built confidence, and informed, recruited, and assessed the residents. First meetings with the participants were organized to become familiar with each other and with the methodology. During the intervention phase, weekly PAR meetings took place. In these group sessions, moderated by the principal investigator and a staff member of the NH, the participants' lives in the NH and the NH operation were discussed and analyzed, problems and complaints were detected, and actions for improvement were developed by the residents. Every 2 weeks, these suggestions were further presented during the staff meetings. The NH engaged itself to implement the proposed improvements. On a regular basis, the PAR group monitored and evaluated the implementation of the changes. All residents in the INH were informed by the PAR changes by means of an extra PAR column in the monthly newsletter. During follow-up, PAR continued without the presence of the principal investigator. In the ACNH, reminiscence was chosen because it does not intend to increase residents' organizational influence in the NH. One staff member was selected to organize and lead the group sessions and was trained in the methodology. A weekly kept journal, together with frequent visits and contacts, allowed the monitoring and support by the research team. After 6 months, the reminiscence sessions further continued, without the support of the researchers. The PCNH provided care as usual, and no new activity was introduced.

Measurements

All measurements took place at pre-test, after 6 months of intervention (post-test), and after 6 months of follow-up. Demographic features were gathered.

Experienced Operation of the NH

The Active Aging Survey for NHs (NHAA survey[18]) contains 61 statements, encompassing 9 determinants contributing to a QoL enhancing environment.[1] For each statement residents indicate their experienced reality (5-point Likert scale) and the subjective importance (3-point Likert scale). A NHAA score was computed, with the formula: subjective importance $\times$ (2 $\times$ experienced reality−subjective importance).[18,19] Sum scores can be calculated for the entire survey as well as for the different determinants.

QoL

The Anamnestic Comparative Self-Assessment scale (ACSA)[20,21] is a self-anchoring scale, measuring the overall QoL, allowing the participants to judge their subjective well-being, relative to their previous experiences. They evaluate their current QoL, on a scale ranging from -5 to $+5$. The lowest score refers to how they felt during the worst period of their lives, the highest score to their best moment in life.

Experienced Participation

The perceived participation was examined by means of the impact on participation and autonomy scale (IPA).[22] Thirty-two statements measure the experienced obstacles and problems that participants encountered in their autonomy, their family role, social relationships, and work and education. The lower the score, the less obstacles and problems, and, therefore, the higher the perceived autonomy and participation.

Statistical Analyses

SPSS v 22.0 (SPSS Inc) was used. Intention-to-treat analysis was chosen. Because of the small number of participants per group ($n \leq 30$) and that data were not normally distributed, nonparametric tests were opted. As outcome measure, the proportional changes over time between pre-test and post-test and between pre-test and follow-up, respectively, were examined by means of Kruskal-Wallis and Mann-Whitney U tests.