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Dementia behaviour management programme at home: impact of a palliative care approach on care managers and professional caregivers of home care services

Miharu Nakanishi[a], Kaori Endo[b], Kayo Hirooka[b], Taeko Nakashima[c], Yuko Morimoto[b], Eva Granvik[d], Lennart Minthon[d], Katarina Nägga[d] and Atsushi Nishida[b]

[a]Mental Health and Nursing Research Team, Tokyo Metropolitan Institute of Medical Science, Tokyo, Japan; [b]Mental Health Promotion Project, Tokyo Metropolitan Institute of Medical Science, Tokyo, Japan; [c]Department of Economics, Rutgers University, The State University of New Jersey, Camden, NJ, USA; [d]Clinical Memory Research Unit, Department of Clinical Sciences Malmö, Lund University, Malmö, Sweden

ABSTRACT

Objectives: Care managers and professional caregivers of home care services are sometimes unaware of the psychosocial approaches to the challenging behaviour of dementia. Therefore, we developed a Behaviour Analytics & Support Enhancement (BASE) programme. We investigated the effects of the programme on the attitudes towards dementia care among professionals.

Method: Forty-six participants in Japan received training in August 2016. The ongoing monitoring and assessment system was introduced to the participants for repeated measures of challenging behaviour. A 1-day follow-up meeting for debriefing was also performed after two months. A baseline and follow-up questionnaire survey was administered to the participating caregivers using a Japanese version of the Approaches to Dementia Questionnaire (ADQ) and the Zarit Burden Interview (ZBI).

Results: A significant improvement was observed in the total ADQ score among the participating caregivers from baseline to follow-up assessment. There was no significant difference between the baseline and follow-up assessment in the ZBI scores. In the follow-up meeting, several participants reported challenges and suggested solutions in facilitating a discussion on an action plan among professionals from various organizations.

Conclusion: The implementation of the programme resulted in enhanced attitudes towards dementia care among the participants without an increased burden of care. Future studies should examine the programme's effectiveness on the challenging behaviour of persons with dementia.

Introduction

Dementia is one of the biggest global public health and social care challenges facing people today. The Alzheimer's Disease International estimated in 2015 that 46.8 million people worldwide are living with dementia. This number is estimated to increase to 131.5 million by 2050 (Alzheimer's Disease International, 2015). Challenging behaviours such as shouting, wandering, agitation, and resistance to care are common in people with dementia (Lyketsos et al., 2002; Savva et al., 2009), leading to caregiver burden and subsequent nursing home placement (Gaugler, Yu, Krichbaum, & Wyman, 2009; Yaffe et al., 2002).

Several countries have developed national dementia plans and implemented palliative care approaches to address the challenging behaviours (Nakanishi & Nakashima, 2014; Nakanishi et al., 2015). Non-pharmacological, psychosocial approaches are set as a priority to address the challenging behaviour. However, the evidence concerning individual therapy is limited (Testad et al., 2014; Verkaik, Can Weert, & Francke, 2005). Since challenging behaviour is a form of communication that implies the unmet needs of persons with dementia, treatment should be tailored for individual needs.

Behaviour management programmes have been developed mainly for nursing home residents with dementia (Gallagher & Long, 2011; Pieper et al., 2016; Simard & Volicer, 2010; Stacpoole, Hockley, Thompsell, Simard, & Volicer, 2015;

Testad et al., 2014). Since most people with dementia live at their own home (Alzheimer's Disease International, 2015) and people with dementia are vulnerable to a change in place of care/residence (Mitchell et al., 2009; Sampson, Blanchard, Jones, Tookman, & King, 2009), behaviour management in home care settings is a critical issue among dementia care strategies.

Japan is also facing a striking increase in people with dementia. It is estimated that the number of persons with dementia will reach approximately 7.3 million by the year 2025 (Ministry of Health, Labour, and Welfare, 2015). To address this social challenge, the national government established the Japanese Dementia Plan (Nakanishi & Nakashima, 2014; Nakanishi et al., 2015). The national dementia plan aims to help people with dementia live in their own home as long as possible, and encourages non-pharmacological and socio–psychological approaches for behaviour management. Under the public long-term care insurance programme, care managers handle monthly care plans for home care clients. The clients usually purchase home care services from providers other than the care managers. However, care managers and professional caregivers of home care services are sometimes unaware of the palliative care approaches that prioritize psychosocial interventions aimed to address the challenging behaviour, and inappropriate approaches such as the use of physical restraint and antipsychotic drug treatments are often

used for people with dementia living in their own homes (Nakanishi, Hirooka, Morimoto, & Nishida, 2016). Home care providers usually have a few hours per week in touch with a client at home so that they may face difficulty in sharing their understanding of the person and integration of home care services based on the palliative care approach. To date, there has been no examination of the effectiveness of the behaviour management programme on care managers and professional caregivers of home care services. Therefore, we developed a Behaviour Analytics & Support Enhancement (BASE) programme to enable care managers and professional caregivers of home care services to identify the unmet needs, to explore and implement an action plan, and to evaluate the efficacy of the intervention (Figure 1).

In the present study, we investigated the effect of the BASE programme on the attitudes towards dementia care among care managers and professional caregivers of home care services. We hypothesized that the participants would exhibit attitudes towards dementia care and a sense of competence without an increased burden of care.

Methods

Design

Our trial was conducted with 24 long-term home care providers from three different districts of the Tokyo Metropolitan Government, Japan. The Tokyo prefecture has the largest population throughout Japan and faces an unprecedented increase in the number of people with dementia, which is expected to reach 600,000 in 2025 (Tokyo Metropolitan Government, 2015). In order to systematically evaluate the programme, a mixed measure design including a qualitative approach was adopted.

Participating providers were recruited from three districts within local long-term care providers of the Tokyo Metropolitan Government. Forty-six participants (39 care managers and 7 professional caregivers) from the providers received educational training, and were introduced to an ongoing monitoring and assessment system focusing on the psychosocial interventions to challenging behaviour. Data collection was performed on 22 August 2016 (baseline) and 2–4 November 2016 (follow-up).

Sample

In each provider, the participants applied the BASE programme to clients who had a diagnosis of dementia and who were aged 65 years or older, if written proxy consent was received. Each provider recruited up to six clients.

The sample size was calculated for the primary analysis via the software G*Power 3.1.9.2 (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007). Assuming an alpha level of .05 and 95% power, the required number of participants to observe an effect size of .5 in the attitudes towards dementia care was 45.

Behaviour analytics & support enhancement (BASE) programme

Training

All participants underwent a 2-day training course on 22–23 August 2016. The Japanese training course was developed via a workshop between a Japanese working group and a Swedish team from the Behavioural and Psychological Symptoms of Dementia (BPSD) Program of Care (Regeringskansliet, 2014). The BPSD Program of Care is a working tool for professional caregivers focusing on psychosocial interventions for challenging behaviours, and is based on the well-developed national guidelines for dementia care (Nakanishi et al., 2015). The training course originally addressed (1) dementia as an illness, (2) the assessment of challenging behaviours, and (3) the unmet needs and action plans in Swedish BPSD Program of Care. Pain assessment was expanded in reference to other international palliative care programmes such as Comfort
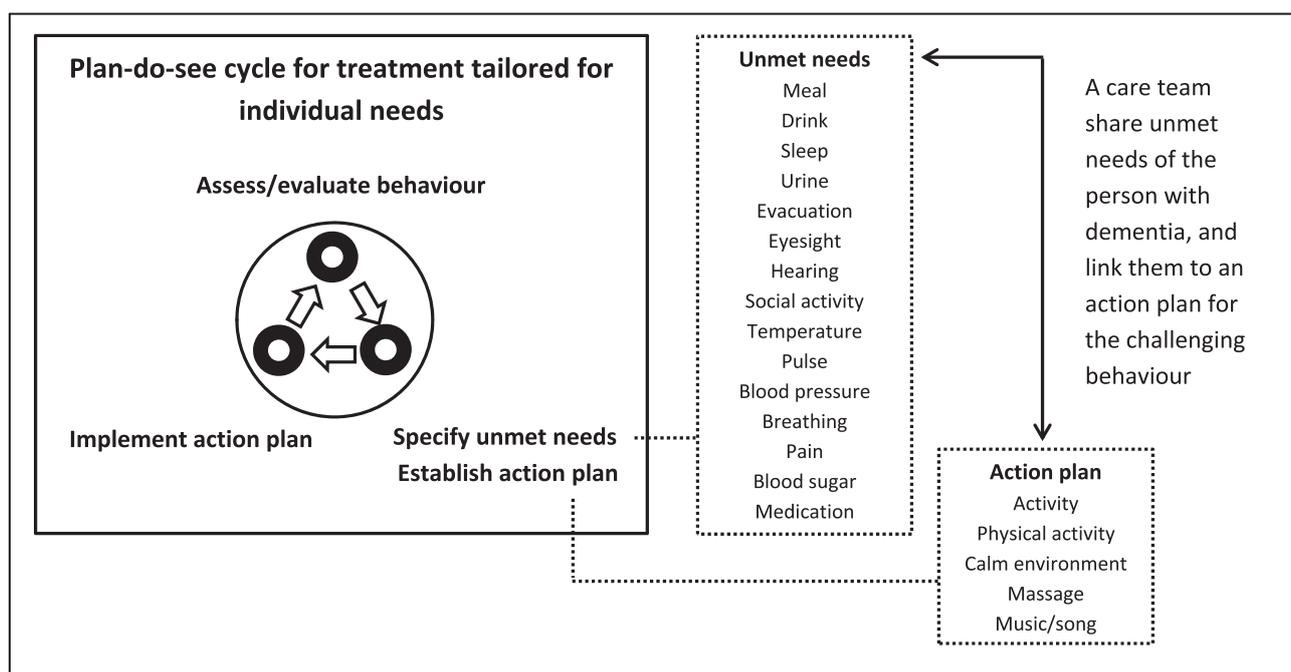

Figure 1. Treatment for challenging behaviour that is tailored to the individual needs in the BASE programme.

Matters™ (Gallagher & Long, 2011), STA OP! (Pieper et al., 2016), and Namaste Care Program (Stacpoole et al., 2015). The core principle of the training course was based on a palliative care approach, and deemed challenging behaviour as a form of communication that implies the unmet needs of persons with dementia. After the training course completion, the participants received a certification of 'Administrator' of the BASE programme. All 46 participants completed the course and received the certification.

Baseline assessment of clients

The participants launched input of measures of their clients using the web-based tool at baseline in September 2016. The participants were required to evaluate the challenging behaviours of a client with dementia in face-to-face interviews with other professional caregivers who provided care to the client.

Action plan

There was a multi-agency discussion meeting with the participants to specify the unmet needs of each client; then, they established an action plan based on the needs. Unmet needs were categorized: meal, drink, sleep, urine, evacuation, eyesight, hearing, social activity, temperature, pulse, blood pressure, breathing, pain, blood sugar, and medication. The contents of the action plan included activity, physical activity, calm environment, massage, and music/song.

Ongoing monitoring and reassessment

The participants implemented an ongoing monitoring for the challenging behaviour of the client with dementia. Then, they conducted a monthly multi-agency discussion to reassess the behaviour and unmet needs, and revise the action plan for the client. The care managers scheduled a mandatory monthly meeting with the providers of home care services regarding the management of the monthly amount of care for the client as per the public benefit schedule.

Follow-up meeting for debriefing

A 1-day follow-up meeting for debriefing was held for all participants from 2 to 4 November 2016. On each day, the participants were divided into three groups with 5–6 members per group to implement three workshops: (1) sharing good examples for the action plan, (2) discussing the implementation and practice of the BASE programme, and (3) proposing solutions for the action plan implementation challenges. We determined the number of groups per day to ensure enough time for presentation and sharing of each participant's reflections. This allocation was based on the choice of the participants.

Quantitative measures

A questionnaire survey was conducted on the day of training (baseline) and at a follow-up meeting (follow-up) to evaluate the attitudes towards dementia care, sense of competence, burden of care, and personal characteristics of the participants.

Attitudes towards dementia care were measured using the Japanese version of Approaches to Dementia Questionnaire (ADQ) (Lintern & Woods, 2001; Lintern, Woods, & Phair, 2000). The ADQ includes 19 statements with 5-point Likert scale ranging from '1 = strongly disagree' to '5 = strongly agree' to capture the respondent's attitudes towards people with dementia. A total score (range = 19–95) and two sub-scores, 'hope' (range = 8–40) and 'person-centredness' (range = 11–55) can be derived. Higher ADQ scores are indicative of more positive attitudes towards people with dementia. The Japanese version of the ADQ shows acceptable reliability and validity (Cronbach's alpha = .83) (Suzuki et al., 2009).

Sense of competence in dementia care was assessed using the Japanese version of the Sense of Competence in Dementia Care Staff (SCIDS) scale. The Japanese SCIDS was developed for this study because there was no established measure to assess the competence in dementia care in Japan. The original English SCIDS includes 17 items (Schepers, Orrell, Shanahan, & Spector, 2012). All 17 items were translated into Japanese by two researchers separately: a registered nurse and a psychiatric social worker. Then, they discussed their approach to integrate the two translations. An integrated translation was back-translated into English by a professional translator fluent in both languages. The original author of the English SCIDS confirmed that the translation was appropriate, with a small amendment. The amendment was incorporated, and the Japanese SCIDS scale was finalized.

The revised SCIDS was scored on a 4-point Likert scale ranging from '1 = not at all' to '4 = very much', with higher scores indicating a higher level of sense of confidence. The total score ranged from 17 to 68. The SCIDS scale comprises four subscales: professionalism, building relationships, care challenges, and sustaining personhood. The SCIDS scale at baseline had moderate Cronbach's alpha coefficients of .75 for professionalism, .77 for building relationships, .68 for care challenges, and .48 for sustaining personhood. The Cronbach's alpha coefficient of the total scale was .81.

The burden of care was assessed using the subscale 'personal strain' from the 8-item short version of the Japanese version of the Zarit Burden Interview (ZBI). The ZBI is an instrument used for assessing the burden experienced by family caregivers who care for the community-residing impaired elderly (Zarit & Zarit, 1990; Zarit, Reever, & Bach-Peterson, 1980). The ZBI includes 22 statements with 5-point Likert scale ranging from '0 = *never*' to '4 = *nearly always*'. The Japanese version of the ZBI (J-ZBI) (Arai et al., 1997; Arai, Zarit, Sugiura, & Washio, 2002) and the short version of the J-ZBI (J-ZBI_8) have been developed (Arai, Tamiya, & Yano, 2003). The J-ZBI_8 consists of two subscales: personal strain (range 0–20) and role strain (range = 0–12). Personal strain refers to how personally stressful the experience is and is applicable to professional caregivers. Role strain refers to the stress due to role conflict or overload. The reliability and validity of personal strain scale have been confirmed (Cronbach's alpha = .87) (Cronbach's alpha = .87) (Arai et al., 2003; Kumamoto & Arai, 2004).

Personal characteristics including age, sex, education level, tenure in elderly care, and nursing license were also obtained and examined.

Qualitative measures

The research team that included both Japanese members of the BASE programme and Swedish members of the BPSD Program of Care participated in the follow-up meeting to observe and record reflections from the participants. After the meeting, each member of the research team reviewed the reflections and identified common issues that were regularly expressed throughout the 3-day workshop.

Ethical considerations

The research team explained the study's aim, the voluntary nature of participation, and an assurance of anonymity for all participants to the care managers and professional caregivers of each provider. Identification numbers were assigned to agencies and participants.

Approval was obtained from the Ethics Review Board of the Tokyo Metropolitan Institute of Medical Science (Project number 15–4, approval for training course on 16 March 2015; 16–2, approval for web-based tool on 9 March 2016). This trial is registered at the UMIN Clinical Trials Registry (UMIN000021966).

Statistical analysis

To test the convergent validity of the developed Japanese SCIDS scale, a pairwise correlation was examined for total scores of the SCIDS, ADQ, and ZBI at baseline assessment. Changes in total scores of the ADQ, SCIDS, and ZBI scales were examined using a paired t-test. The effect size was calculated with Cohen's d for each outcome measure using the correlation between the two means. The effect size is low if the value of d varies around .20, medium if d varies around .50, and large if d varies at more than .80 (Cohen, 1988; Morris & Deshon, 2002).

All statistical analyses were conducted using Stata SE for Windows, version 14.0 (StataCorp, College Station, Texas, USA). The two-tailed significance level was set at .05.

Results

Participant characteristics

Forty-nine applicants were initially enrolled in the study. Three declined to participate in the training course. The remaining 46 participants underwent the training course and received certification as an Administrator; then, they started use of the online system. The participants comprised 37 care managers, 7 nurses, and 2 other care workers (Table 1). Clients with dementia ($N = 141$) were registered by the participants at baseline.

Outcomes of participants

Among all participants, at the baseline assessment, the total score on the SCIDS scale did not show a significant correlation

Table 1. Characteristics of participants at baseline.

Type of provider, n (%)	
In-home care services	39 (84.8)
Home-visit nursing care	5 (10.9)
Group home	2 (4.3)
Mean age (years), (SD)	43.6 (7.9)
Sex (male), n (%)	10 (21.7)
Type of profession, n (%)	
Care manager	37 (80.4)
Nurse	7 (15.2)
Other care worker	2 (4.3)
Education level, n (%)	
Junior high school	2 (4.3)
High school	9 (19.6)
Vocational school	19 (41.3)
University	16 (34.8)
Tenure in elderly care, month, mean (SD)	102.2 (72.0)

Note: SD: Standard deviation.

Table 2. Outcomes at baseline and 2-month follow-up assessment.

	Mean (SD)					
	Baseline	Follow-up	t (45)	p-Value	Correlation	Cohen's d
Attitudes towards people with dementia	74.6 (6.2)	76.2 (5.4)	2.53	.015	.738	.379
Competence in dementia care	36.5 (3.9)	37.5 (5.3)	1.89	.065	.718	.297
Personal strain	6.8 (3.3)	6.2 (3.4)	1.14	.261	.498	.168

Note: SD: Standard deviation. Attitudes towards people with dementia were measured by the Japanese version of Approaches to Dementia Questionnaire. Competence in dementia care was measured by the Japanese version of the Sense of Competence in Dementia Care Staff scale. Personal strain was measured by the short version of the Japanese version of Zarit Burden Interview.

with the total score on the ADQ scale ($r = .29$, $p = .052$) or the ZBI scale ($r = −.20$, $p = .180$).

At follow-up, the mean score on the ADQ scale was significantly higher than that at the baseline. There were no significant differences between the base line and follow-up scores in the SCIDS or the ZBI scales. The effect size was medium on the ADQ scale, and low on the SCIDS or the ZBI scores (Table 2).

Reflections in the debriefing meeting

In the follow-up meeting, several participants reported challenges in setting up a discussion on an action plan among professional caregivers from various organizations. For example, one client with dementia received personal care at home from several different care workers: a direct care worker (provider A), another at the day care centre (provider B), and a care manager (provider C) who handled monthly amounts of care as per the public benefit schedule. The care manager was not involved in direct caregiving; however, he/she had to implement the action plan via other caregivers such as nurses and direct care workers. Both advantages and disadvantages were identified in the multi-agency discussion on the assessment of challenging behaviour, care needs, and tailoring care to the needs. Different caregivers had different perspectives on the challenging behaviour of persons with dementia. This could result in difficulties in integrating divergent perspectives; however, the discussion process helped improve the understanding of persons with dementia.

Further, some of the suggested action plan components such as massage, activity, and music/song were not allowed under the benefit schedule of the public, long-term care insurance scheme. For instance, the benefit schedule did not allow for massage to be included in personal care to a client. Therefore, some participants who were care managers considered massage as inapplicable to the client who used personal care service at home only. This could imply difficulties in the establishment of action plans based on the needs of the client with dementia, and requested successful examples in home care settings, although they had been noticed in the training course that this pilot study was the first trial of the BASE programme. It was also reported that it could be difficult to distinguish the needs of family members from those of the client. One clear identified advantage was that the BASE programme could encourage and facilitate communication with family members to assess the needs of the client.

Most participants proposed a common solution for challenges in the action plan and its implementation. They suggested that a multi-agency discussion should be directed to clarify several actions that each professional caregiver already implemented. The pre-existing actions would be reviewed to select a feasible one and establish a simplified action plan for the client with dementia.

Discussion

This study first examined the effectiveness of a behaviour management programme on care managers and professional caregivers of home care services for persons with dementia. Implementation of the BASE programme improved the attitudes towards dementia care among the participants. The burden of care was not significantly changed from the baseline to follow-up assessment. Hence, the BASE programme was successful at enhancing the perspectives of care managers and professional caregivers without increasing their burden of care.

A combination of training, ongoing monitoring, and assessment system focusing on the unmet needs may have enabled the participants to translate the concept of palliative care approach into their practice with clients with dementia. Improved perspectives regarding palliative care for dementia among care managers have been associated with a better quality of life of people with dementia who received care under the care management programme (Nakanishi et al., 2016). In the follow-up meeting, several participants described their process of reframing care approach during discussion on the assessment of challenging behaviour, care needs, and tailoring this care to the needs. The participants, especially the care managers, had to share the concept of the BASE programme with other professional caregivers who provided personal or nursing care to clients with dementia. This sharing process may have helped the participants progress their understanding of palliative care approach themselves.

Another characteristic of the BASE programme was specified in the follow-up meeting. As the evidence is limited for individual therapy (Testad et al., 2014; Verkaik et al., 2005) and challenging behaviour is a form of communication that implies the unmet needs of persons with dementia, the BASE programme encourages the participants to tailor an action for the individual need. The participants found themselves unfamiliar with the process of planning an action based on the needs of a client. Care managers usually communicate with family members who serve as substitute for the client with dementia in purchasing home care services under the public, long-term care insurance programme. Therefore, they may have been used to delivering a care plan of the client with dementia in consideration of the public benefit schedule and family members' needs. Challenges that the participants raised in the follow-up meeting may imply the challenges in dementia care due to the current long-term care system rather than deficits of the BASE programme.

Sense of competence in dementia care did not show a significant change between the baseline and follow-up assessment. Our 2-month follow-up period may have been too short to observe competence improvement among the participants. The findings are also limited to a small number of organizations and participants, which inhibited further investigation of moderating variables such as caregiver and organizational characteristics. Future research should examine the long-term effects of the BASE programme on participants' competence in dementia care in home care settings while controlling for professional and organizational characteristics.

Another limitation of this study was that we lacked an outcome measure on persons with dementia such as change in challenging behaviour and use of antipsychotic medication. Future studies should examine the effectiveness of the BASE programme on challenging behaviour and other outcome measures for persons with dementia who receive long-term care via the BASE. Cost-effectiveness of the programme as well as long-term outcomes should be assessed. Although care managers have a mandatory monthly multi-agency meeting, the discussion under the BASE programme was described as having goals different from those of the mandatory meeting. Therefore, it would have been an addition to their usual pattern of work and may have involved a cost for attendance to the discussion series.

Conclusions

This study was the first to examine the effectiveness of a dementia behaviour management programme on care managers and professional caregivers of home care services in Japan. The implementation of the BASE programme resulted in enhanced attitudes towards dementia care among the participants without an increased burden of care. In the follow-up meeting, several participants described their process of reframing the care approach during the discussion on the assessment of challenging behaviour, care needs, and tailoring this care to their needs. Future studies should examine the effectiveness of the BASE programme on challenging behaviour and other outcome measures for persons with dementia.

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