A Structured Cognitive Intervention Pathway as a decision-support tool for non-pharmacological interventions within a dementia care service (Innovative practice)

Mark Carter (ID)
Care Visions China, Beijing, China; Care Visions, Stirling, Scotland

Zara Quail (ID)
Care Visions, Stirling, Scotland

Allison Bourke
Shider Consultancy, Brisbane, Australia

Charles Young
Care Visions, Stirling, Scotland; Guys and St Thomas NHS Foundation Trust, London, UK; Wiley, London, UK; Capita plc, London, UK

Abstract

Individual cognitive interventions for Alzheimer's disease have been shown to be beneficial and cost effective when evaluated as sole interventions. However, there is a need for a systematic, person-centric, structured approach to guide non-pharmacological intervention selection based on disease stage, symptoms, outcome assessment, and individual requirements. Our Structured Cognitive Intervention Pathway aims to facilitate the selection of first-line, or subsequent, non-pharmacological management for people with Alzheimer's disease living at home and in elderly care facilities. We discuss the Pathway's conceptual basis and evaluation of implementation as a decision-support tool within a dementia care service in China.

Corresponding author:
Zara Quail, Care Visions Group, Bremner House, Stirling FK9 4TF, Scotland.
Email: zara.quail@carevisions.co.uk

Background

Nineteen percent (9.48 million) of the estimated 50 million people globally with dementia live in mainland China, where the reported dementia prevalence of 5.3% is expected to increase to 6.7% (23.3 million people) by 2030 (Patterson & Alzheimer's Disease International, 2018; Wu et al., 2018; Xu, Wang, Wimo, Fratiglioni, & Qiu, 2017). Alzheimer's disease accounts for 60 to 70% of all dementia cases (World Health Organization, 2017). With no current cure for Alzheimer's disease, and only modest benefits combined with potentially serious side-effects of medications used to treat cognitive and neuropsychiatric symptoms, there is an urgent global need for further research and innovative solutions for dementia care (Patterson & Alzheimer's Disease International, 2018). Existing research indicates that individual non-pharmacological interventions can improve cognition, reduce behavioural and psychological symptoms of dementia, and are cost-effective (Cammisuli, Danti, Bosinelli, & Cipriani, 2016; de Oliveira et al., 2015; Scales, Zimmerman, & Miller, 2018). Choice of the best non-pharmacological intervention requires assessment of all facets of the individual's needs, preferences, symptoms, level of ability and understanding of their underlying diagnosis and disease stage.

Having delivered adult domiciliary care services in the United Kingdom since 2009, we recognised a growing need for dementia social care services in China where more specialised care beyond assisting with the basics of activities of daily living is still rare (Chen et al., 2017). In 2015, we established our dementia care service in Beijing with the aims of improving quality of life for people with dementia and reducing stress on caregivers through a multi-component care programme which now includes:

- An in-depth needs assessment leading to a focused, practical care plan
- Strategies and non-pharmacological interventions to manage or better cope with dementia symptoms, supported by the Structured Cognitive Intervention Pathway
- Community-based social activities targeted at reducing social isolation
- Dementia education and training for families, nursing homes, hospitals and surrounding communities.

To best understand the development of a sustainable, goal-driven dementia care service in China, we evaluated gaps in the current diagnostic systems, referral pathways and use of non-pharmacological interventions for dementia. We found that there was no available model or tool which combines a person-centred social model of care with biomedical disease information to allow logical and systematic selection of non-pharmacological interventions for people with dementia (Cammisuli et al., 2016). We also noted that choice and utilisation of single non-pharmacological interventions were frequently based on care-provider capability rather than the needs of the person with dementia. In July 2017, we therefore set out to develop a Structured Cognitive Intervention Pathway, referred to as the Pathway for brevity, as a decision-support tool to augment a person-centred approach to dementia care.

In this paper, we describe the Pathway's conceptual basis and from November 2017, evaluation of its implementation as a decision-support tool within a dementia care service in China.

The Structured Cognitive Intervention Pathway concept

The current version of the Pathway is presented in Table 1. The table displays the correlating stages and scores of three reliable and well-validated dementia screening and staging instruments: the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), the Clinical Dementia Rating (CDR) stages of 0, 0.5, 1, 2, 3 (Morris, 1993) and the 7 stages of the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982). In turn the more common symptoms from the cognitive, functional, behavioural, psychiatric and physical domains of dementia are displayed. The disease stages, scores and symptoms are in turn mapped to non-pharmacological interventions based on available published literature for intervention efficacy in Alzheimer's disease. The Pathway provides flexibility to select appropriate individual interventions for either a defined disease stage and/or from exhibited symptoms. After initial intervention selection, the Pathway is used to enable consistent re-evaluation of the selected intervention's perceived success along with feedback from the person, carer or dementia care provider, to facilitate ongoing intervention adjustment or new intervention selection.

In the context of our work, we consider a cognitive intervention to be a non-pharmacological treatment that is intended to maintain or improve cognitive function, behavioural or psychological symptoms, activities of daily living or overall quality of life (Cammisuli et al., 2016; de Oliveira et al., 2015). Importantly, in contrast to medication prescribed for the cognitive and neuropsychiatric symptoms of dementia, these non-pharmacological interventions have few reported side-effects (de Oliveira et al., 2015).

In developing the Pathway, we recognised that there was a lack of published evidence on systematic approaches to non-pharmacological intervention selection for people with dementia. We therefore sought expert advice from academics at the Wicking Dementia Research and Education Centre at the University of Tasmania whose input was integral to development of the Pathway. In addition, we undertook an extensive peer review survey of the Pathway and obtained 100 peer reviews from dementia experts in 23 countries. Eighty percent of reviewers agreed that the disease process was accurately represented, and 82% agreed that the relevant non-pharmacological interventions were appropriately and accurately assigned to relevant symptoms or stages. Detailed comments provided by the expert reviewers have been used to inform updated iterations of the Pathway.

Steps to implementation of the Pathway

An initial challenge in implementing the Pathway as a decision support-tool was around adoption of a comparatively new model of care offered by our dementia care service. In China, engagement, local knowledge and education have been key to establishing confidence in the service in which the Pathway has been developed as a decision-support tool to improve service delivery.

Engagement with organisations, communities and families. On a national level in China, our service development activities led to agreements with government partners such as the Department

Table 1. The Structured Cognitive Intervention Pathway.

Mini Mental State Examination Score	Clinical Dementia Rating Stage	Global Deterioration Scale Level	Common symptoms	Intervention options	Stage Specific Intervention Group
30–27	0: No cognitive impairment	1: No cognitive decline	None	Cognitive reserve maintenance	Cognitive reserve maintenance
27–24	0.5: Questionable or very mild dementia	2: Very mild cognitive decline	Forgetting time and place		Cognitive stimulation therapy Reality orientation Reminiscence therapy
24–20	1: Mild	2: Very mild cognitive decline	Forgetting recent events Forgetting daily tasks, money, bathing, eating Signs of depression Difficulty in communicating thoughts Difficulty in finding and explaining words	Cognitive stimulation therapy Reality orientation Reminiscence therapy Talking therapy	Cognitive stimulation therapy Talking therapy Reminiscence therapy
		3: Mild cognitive decline	Difficulty in forming sentences Simple problem solving Familiar task completion – ADL's Unable to plan and complete tasks		Talking therapy Reality orientation Reminiscence therapy
20–13	2: Moderate	4: Moderate cognitive decline	Signs of depression Personality shift affecting judgement Withdrawn and reduced communication	Signs of depression	Music Therapy Art Therapy Smell Therapy

Table 1. Continued.

Mini Mental State Examination Score	Clinical Dementia Rating Stage	Global Deterioration Scale Level	Common symptoms	Intervention options	Stage Specific Intervention Group
	2: Moderate	5: Moderately severe cognitive decline	Sleeping pattern changes Hallucinations Disorientation / confusion Wandering Behavioural symptoms of distress	Music Therapy Art Therapy Smell Therapy Touch Therapy Food Therapy Reminiscence Therapy Validation Therapy Bright Light Therapy	Bright Light Therapy Touch Therapy Smell Therapy Food Therapy Reminiscence Therapy
	2: Moderate	6: Severe cognitive decline	Unable to recognise family Unable to recognise precious memories Inability to dress or odd dress habits Behavioural symptoms of distress Change in sleeping patterns Increased falls	Bright Light Therapy Music Therapy	Validation Therapy Music Therapy Smell Therapy Bright Light Therapy
Less than 13	3: Severe	7: Very severe cognitive decline	Repetitive behaviours Involuntary movements Inability to manage self-care Full time care required Full loss of neurological function Death	Music Therapy Physical Therapy Touch Therapy	Music Therapy Physical Therapy Touch Therapy

The full list of references for the interventions listed in the table are beyond the reference allowance for this paper but are available on request.

for International Trade UK, China British Business Council and Australian Chamber of Commerce all of which facilitated further partnerships and national exposure for our dementia service. Initial engagement with local Beijing communities included numerous meetings and information sessions with local authorities, non-governmental organisations, community associations and local facilities to build and establish partnerships and referral pathways to the service. We connected with local community leaders to assess their perceptions of dementia needs and challenges, as well as accessibility of pre-existing dementia services based on proximity, availability, and cost. While there was a diverse range of household income across communities, there was a preference to focus expenditure on younger members of the family. The community engagement process identified generally low levels of health literacy around dementia. Optimal modes of engagement for families included the use of social media and messaging through WeChat to share dementia-related information and advertise information sessions and lectures.

Gathering local knowledge in the cultural context. Our dementia service team members, who are all employed from the local Beijing area, have been immersed in the at-home and nursing home care settings in China. Their comprehensive local knowledge has been invaluable in understanding the factors influencing the diagnosis and management of dementia in the context of the cultural beliefs and needs in China. There is a cultural priority in China for people to remain in their own homes for as long as possible. Accompanying stressful family dynamics in dementia care include younger family members having to take over the role of senior decision-making and provide for ongoing care from limited financial means. In addition, family members often have to work away from their homes due to a growing trend of urban migration for employment and education. In China there are also numerous barriers to dementia diagnosis, referral and management, which in terms of health and social care infrastructure include little to no training on dementia in medical schools, lack of memory clinics, and lack of access to diagnostic support with blood tests and clinical imaging (Chen et al., 2017; Jia et al., 2016). In addition, with significant shortages of care staff in the community, there is an overuse of in-home domestic service workers and informal carers beyond their usual job description, capabilities and skills.

From the personal and family perspective, barriers to dementia diagnosis include significant stigma around dementia resulting in reluctance to obtain an official diagnosis; unwillingness to accept in home care, medication or additional support which may be viewed as recognition of a dementia diagnosis; and lack of awareness of non-pharmacological interventions and other support for people with dementia. Achieving acknowledgement of symptoms of dementia as a disease that requires supportive management, rather than cognitive and physical deterioration as an expected part of ageing, forms part of ongoing educational efforts to decrease the associated stigma and to increase the quality of care.

Cross-cultural care delivery is challenging in any country. The Pathway has its theoretical roots in Western evidence-based healthcare and recommends non-pharmacological interventions that may be perceived as very different from Chinese healthcare philosophies and traditional treatments. As a result, some family members were sceptical of the Pathway's origins and interventions, which posed an initial barrier to acceptance of the Pathway to facilitate care. However, with the team's knowledge of current low levels of health literacy, cultural context and barriers to dementia diagnosis and care, we were able to dedicate more time to educational efforts and family counselling in order to overcome the barriers to implementation. Overall, our experience has been invaluable in understanding the different

requirements for regional adoption of our dementia service and the decision-support Pathway as well as implementation in different care settings.

Delivering education. Education was an essential component in adoption of the dementia service and in turn use of the Pathway. The initial focus of our educational strategy was to dispel myths and breakdown stigma around dementia for the people and their families affected by the disease. Education for families was provided using multiple delivery platforms and settings and included group lectures and information sessions, information packages in printed handouts and shared as PDFs on the service website, and information sharing and online classes on WeChat. Lectures were delivered in our local offices, in hospitals, community centres, coffee shops and tea houses. Coffee mornings proved to be popular events for families at which information sessions for family members were run concurrently with group activity sessions for people with dementia. A similar range of information-sharing activities were organised with hospital and care-facility decision-makers and other related healthcare organisation leads, community leaders. We also developed educational partnerships with academic institutions at the forefront of dementia care such as The Wicking Dementia Research and Education Centre at the University of Tasmania whose massive, open, online course (MOOC), on 'Preventing Dementia' we promoted in China.

Individual needs assessments and family counselling. For each person with dementia who accessed our dementia service, a needs assessment was carried out and included a holistic assessment of the person's biopsychosocial history; dementia symptom frequency, severity and potential triggers; and risk of falls, injuries and nutritional deficiency. The assessment was complemented by a life story workbook to record aspects of the person's history, likes, dislikes and former hobbies. The findings were discussed with the family members and carers to further receive input on their concerns and stressors surrounding care provision. Financial means for longer term (minimum 3–6 months) programmes were considered with realistic setting of management goals and time scales for the person with dementia.

Family counselling has been essential for family members to be invested stakeholders in the care process. Counselling sessions covered understanding of dementia as a disease, the disease process, potential reasons for symptoms, and improving safety for people with dementia. Information on the Pathway included details on its use to more clearly identify optimal interventions, enable assessment processes and feedback loops with the goals of reducing distress from symptoms and improving quality of life. The optimal method of communication for families was regular, concise, easy to understand information delivered in person and through WeChat.

Once a good rapport had been established with a consistent team member to ensure care continuity, families seemed to be more open to discussing strategies to enhance existing dementia care service delivery using the Pathway to guide activities. However, due to scepticism from some family members, the consultation process on use of the Pathway to support care was often longer than expected, in many cases taking around four weeks to impart the necessary knowledge and understanding before deploying the Pathway. It was agreed between the team member providing care and the family that at each step of Pathway use, (for assessment, intervention choice, or intervention amendment), the family would be kept fully informed. It was important to set the expectations of the person with dementia and the family regarding the development and implementation of a systematic approach to

non-pharmacological interventions where no previous system or pathway existed. Although potential benefits from non-pharmacological interventions for quality of life and/or symptoms may only be seen over a period of months, and interventions do not cure or slow the disease, many families expressed the need to see more immediate and tangible benefits. We found that clear, open communication and a good feedback loop facilitated a continued good relationship with the person with dementia and their family members.

Pathway implementation plan and feedback

From November 2017, we initiated an implementation assessment of the Pathway with a small cohort of people with dementia who were receiving our dementia care service at home and in nursing homes. Explicit consent was obtained from each person and their family for use of the Pathway to give a more structured approach to selecting and evaluating the non-pharmacological interventions. The aim of the implementation assessment was to observe any impact on service delivery in using the Pathway, the observations from which would be used to inform further Pathway development and subsequent use. Over a period of three months, the assigned team member worked with each participant for 1 to 1.5 hours per day, three to five times a week. At baseline and every four weeks the Mini-Mental State Examination (MMSE) (Folstein et al., 1975), Clinical Dementia Rating (CDR) (Morris, 1993), Global Deterioration Score/Functional Assessment Staging (GDS/FAST) scores (Reisberg et al., 1982), the Geriatric Depression Scores (GDS) (Yesavage, 1988), Barthel's Index of Activities of Daily Living (Barthel's ADL) (Wade & Collin, 1988) and Quality of Life Alzheimer's Disease (QOL-AD) (Logsdon, Gibbons, McCurry, & Teri, 1999) scores were assessed. After each activity session, levels of engagement and mood were assessed using the Menorah Park Engagement Scale (Camp, Orsulic-Jeras, Lee, & Judge, 2004) and a three-point mood Likert scale. Behavioural and psychological symptoms of dementia were tracked by frequency. Outcomes, intervention selection and feedback notes were recorded using a digital tablet.

Family feedback. It took on average three months of consistent Pathway use, feedback on outcomes and positive reinforcement to ensure acceptability from the families in using the Pathway to support care. A positive outcome for use of the Pathway was the increased involvement of family members in the care process. In some cases, it was possible to educate family members in helping to deliver a subset of non-pharmacological activities, for example use of reality orientation strategies, reminiscence therapy using a life story workbook and practical steps and interventions to cope with memory issues and triggers for behavioural and psychological symptoms. It was also noted that use of the Pathway facilitated re-engagement in cultural activities such as traditional music or gardening. There have been no negative outcomes reported from families after initial Pathway implementation.

Team member feedback. Team member feedback highlighted that the Pathway provided a new way of thinking about dementia management and there was a resultant growth in their own knowledge about dementia care. Use of the Pathway resulted in more intensive and focused application of the interventions and as a result it was noted that the person with dementia was more absorbed in intervention participation. In addition, the Pathway also facilitated more in-depth engagement and participation with the family members.

However, the monthly assessments initiated to monitor outcomes did result in more work for each team member. This organisational challenge was solved by restructuring staff duties by implementing a buddy training system for the monthly assessments which enabled delegation of the assessment task to more team members.

Facility feedback. In contrast to use of the Pathway within the in-home service, implementation of the Pathway in nursing homes was more readily adopted as existing nursing home staff had a higher level of health literacy and an acceptance of the use of clinical pathways already integrated into care within these settings. The assessment process and linear understanding of the therapeutic process integrated well into the elderly care facility setting.

Staff recruitment and training. It is widely acknowledged that there is a need to expand the health and social care workforce to meet the care needs for the growing prevalence of people with dementia (World Health Organization, 2017). Smooth implementation of the Pathway was enabled by our wide spectrum of allied health care staff members which consisted of a social care manager, social workers, nurses, physiotherapists, psychologists and counsellors, all of whom had post-graduate levels of education and further dementia training including use of dementia assessment instruments and non-pharmacological intervention delivery. We also noted that during the initial period of implementation of the Pathway, the training of newly hired team members was more efficient. Before the availability of the Pathway, only the initial needs assessment and life story workbook were used to choose interventions. We found that being able to provide a clearer framework with the Pathway for assessment and interventions based on available evidence enabled a more efficient training technique and quicker skills acquisition regarding intervention choice and delivery. It is possible that the training in the use of the Pathway could be further expanded and adapted to diversional therapists, activity co-ordinators, health care assistants, admiral nurses, nursing assistants, community members, volunteers, informal carers and family members. Being able to train and guide a wider group of people to deliver non-pharmacological interventions as part of dementia care is a worthwhile goal to reduce pressures on global health and social care systems.

Ongoing iteration and future steps

The Pathway and its supporting documents undergo regular refinement and update based on newly published evidence and expert opinion from reviewers. Since January 2018, the Pathway has been used to inform operational delivery of non-pharmacological interventions for people with Alzheimer's disease in the in-home and nursing home settings. The next step in further development of the current Pathway is to evaluate implementation in a tertiary hospital setting in Beijing.

   A limitation of the Pathway has been its exclusive use for people with Alzheimer's disease, for which it was originally devised. People with other forms of dementia are equally in need of supported non-pharmacological management plans. We continue in our iterative approach to Pathway development which will include further research and pilot studies planned with academic partners to refine and validate the Pathway in assessing patient-related outcomes for different dementia types, stages and care settings.

Conclusion

With nearly 10 million people around the word developing dementia every year, and no current pharmacological cure, there is a priority to develop systematic, rational and supportive guidance to delivering person-centric, non-pharmacological care and appropriate interventions (Cammisuli et al., 2016; World Health Organization, 2017). Our initial evaluation of integrating the Pathway into a dementia care service has highlighted how cultural awareness, local knowledge and community engagement and education are crucial to the development and implementation of innovative solutions to support dementia care. The Pathway has enabled both improved operational delivery of our dementia service's assessments and interventions as well as enhanced staff training. In addition, the Pathway has facilitated more intensive involvement in intervention participation for the person with dementia as well as deeper engagement with family members who have become more invested in the care process than was previously the case. Our experience in developing the Pathway in China has been invaluable in identifying the varying requirements for regional adoption and optimal care setting implementation where the team have been in a unique position to observe and document community-based dementia care needs in an under-resourced setting and develop an appropriate model of social care. Our overall goal remains to deliver optimal, person-centred care for people living with dementia.

ORCID iDs

Mark Carter https://orcid.org/0000-0002-4727-9972
Zara Quail https://orcid.org/0000-0003-4139-7932

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Mark Carter is the Managing Director and Director of Product Development and Service Delivery for Care Visions China. He qualified as a Registered Nurse in Australia, and has

worked within emergency care, geriatrics and general medicine, with a significant focus towards dementia management and innovative care for the elderly in hospitals and elderly care facilities as well as in community and home-based care programs.

Zara Quail is the Senior Clinical Editor at Care Visions. Her work as a clinical editor and medical writer focuses on clinical decision support, healthcare technology and chronic disease prevention and management. She also works part-time as a general practitioner locum in County Dublin, Ireland.

Allison Bourke is currently the Managing Director of Shider Consultancy in Brisbane, Australia. She was formerly Head of Education and Training at Care Visions China. She has created many training programmes including the accredited Care Visions '5 Senses Plus' training programme.

Charles Young is a non-executive director of the Care Visions Group; the Editor-in-Chief of Clinical Case Reports (Wiley); Senior Medical Officer for Capita plc; and Emergency Physician at St Thomas' Hospital, London, UK.