

Implementing Evidence into Practice for Best Dementia Care

Park, Myonghwa

College of Nursing, Chungnam National University, Daejeon, Korea

Purpose: The purpose of this paper was to discuss the need for translation studies in dementia care and current translational endeavors, and to provide recommendations for evolving evidence-based dementia care. **Methods:** A literature review yielded current evidence and translational efforts. **Results:** Dementia care interventions need to be implemented at various service levels. Barriers to translation include evidence gaps, lack of the use of a conceptual framework to explain the implementation process, and unsupportive funding mechanisms for applying innovations. **Conclusion:** There is clear evidence of the need for and benefits of evidence-based dementia care for patients with dementia, family caregivers, and care professionals. The urgent need now is finding ways to advance translational activities and facilitate future research into translation science.

Key words: Evidence-based practice, Dementia, Translational research

INTRODUCTION

Worldwide, the number of patients with dementia is 47.5 million. About 610,000 individuals in South Korea are living with dementia. Large numbers of family caregivers take care of daily lives of these people, providing direct hands-on support [1]. Patients with dementia may present with many different types of behavioral and emotional problems, along with cognitive impairments. Those with dementia often develop conditions that require intense attention and personal care from caregivers [2].

Over the last few decades, healthcare personnel have developed many nonpharmacological interventions and care programs to help persons with dementia and their family caregivers. Numerous dementia-care interventions have shown to be efficacious in clinical trials [3]. Despite the considerable number of evidence-based interventions, most are not well known except to the re-

searchers who developed and implemented them and their funding organizations. Although several programs are currently available to people with dementia and their family caregivers in a few organizations, few are broadly accessible in real practice settings.

A translation science is a research method used to determine whether evidence-based interventions, tested in the highly structured research setting, can be delivered effectively and result in positive outcomes in real settings. However, translation science in dementia care is even less well known. Translational science is most often used in health science and refers to the translation of bench science to bedside clinical practice or to community-based interventions [2]. Translation science can be enhanced across the following four steps of research (Figure 1). Translation 1 (T1) references basic science and its translation into clinical research. Translation 2 (T2) focuses on creating more specific evidence of clinical effectiveness to identify the right in-

*This study was supported by the Basic Science Research Program through the National Research Foundation of Korea (NRF) funded by the Ministry of Science, ICT and Future Planning (NRF-2013R1A2A2A01069090) and by the Ministry of Education, Science and Technology (NRF-2010-0024922).

Address reprint requests to : Park, Myonghwa

College of Nursing, Chungnam National University, 266 Munhwa-ro, Jung-gu, Daejeon 35015, Korea
Tel: +82-42-580-8328 E-mail: mhpark@cnu.ac.kr

Received: July 5, 2015 Revised: July 6, 2015 Accepted: July 21, 2015

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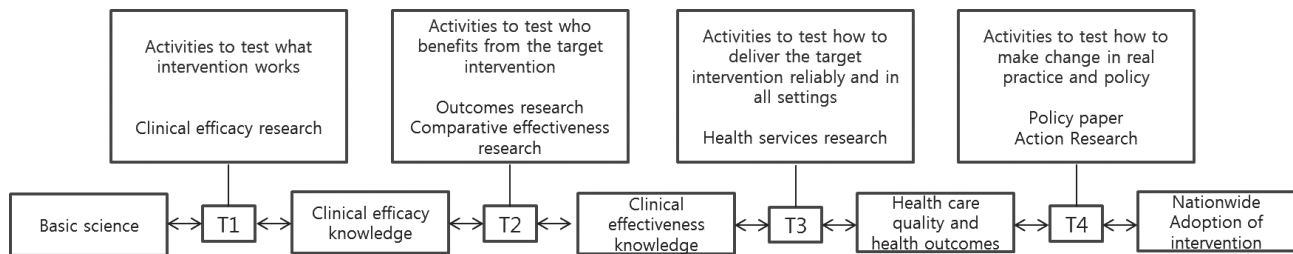


Figure 1. Four steps of translation science.

intervention [4,5]. It also includes translation of practice guidelines for patients, clinicians, and policy makers [6]. Translation 3 (T3) explores the way health care is delivered so evidence-based interventions are reliable in all care settings and improve health outcomes. Activities in T3 also include policy changes necessary to improve health outcomes. Finally, once T1, T2 and T3 have reached their goals and been proven effective, researchers conduct new policy research in Translation 4. T4 is an effort to find the best way to impact care professionals and patients with a nationwide policy concerning the new intervention [7].

This paper discusses the current status of translational efforts to disseminate evidence-based interventions for people with dementia and their family caregivers into practice settings; address knowledge gaps in current evidence and research; use state of the art conceptual frameworks to facilitate the translation of evidence-based care available to individuals with dementia and their family caregivers; and provide recommendations for next steps to facilitate translation and future research.

1. Gaps in Current Evidence and Research

Some important limitations exist in the evidence and research leading to translation into practice for dementia care. First, many studies still rely on convenience samples because it is difficult to recruit patients with dementia and their family caregivers. Study results can differ according to major characteristics of patients or caregivers, limiting generalizability of interventions [8]. In addition, limited evidence exists on intervention outcomes for specific subgroups (early stage dementia, young-onset dementia, non-Alzheimer's dementia, late-stage dementia, male caregiver, and the patients living alone with dementia) who are increasing and are vulnerable to negative outcomes. Furthermore, most evidence-based interventions focus primarily on family caregivers.

Because of the deteriorating disease characteristics of dementia, family caregivers are considered the main proxy. More research is needed on patients with dementia or patients and family caregivers together.

Second, most studies do not specify study participants. As interventions are not linked to specific dementia stages or types and caregiving characteristics of family caregivers, it is difficult for service providers to decide which programs to provide for which targeted patients, and at what point in the caregiving trajectory. Additionally, several specific topics in Alzheimer's or other dementias require more research. Difficult behavioral problems or hospice care in dementia are still understudied.

Third, in most studies, costs of intervention or cost effectiveness are not reported. Service providers hardly ever estimate needed enablers to implement and verify possible cost benefits. In addition, no generally accepted classification of evidence-based interventions exists aligned with target population, type of intervention, and the main problems addressed by the interventions. Last, most studies do not adequately document benefits to service providers. Healthcare organizations, including the Ministry of Health and Welfare, National Health Insurance Service, and Health Insurance Review and Assessment, focus more on use of interventions and their obvious treatment effects. It is challenging to show clinical significance of small or moderate differences in most frequently measured outcomes of non-pharmacological interventions in dementia care, such as burden or distress.

2. Conceptual Models to Guide Translational Efforts

Many implementation theories promoting effective implementation have been developed. Reviewing published conceptual frameworks can facilitate identification and understanding of the numerous relevant frameworks and how they may apply in lead-

ing the translation of evidence-based dementia interventions. Only a few studies in dementia care reported using a conceptual framework to guide their implementation of evidence. Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) is the most frequently used approach. The lack of use of an evidence-based translation framework can be an important barrier to fully understanding the translation process in the previous studies. Other conceptual frameworks, such as Promoting Action on Research implementation in Health Services (PARIHS), Consolidated Framework for Implementation Research (CFIR), or Normalization Process Theory (NPT), Practical, Robust Implementation and Sustainability Model (PRISM), and Theoretical Domains Framework (TDF) need to be employed to understand contextual facilitators and supporters of implementations.

1) Reach Effectiveness Adoption Implementation

Maintenance: RE-AIM

RE-AIM is a framework to advance the effectiveness of translating research to practice and to better evaluate the public health impact of an intervention. The RE-AIM framework has five elements: reach, effectiveness/efficacy, adoption, implementation, and maintenance [9]. The RE-AIM elements are described as follows: Reach refers to the number and characteristics of individuals who participate in a program or intervention; Effectiveness refers to the impact observed from the program or intervention; Adoption refers to the number and characteristics of settings or providers who initiate the program or intervention; Implementation refers to how providers follow the program protocol and how they establish the program at the setting level; Maintenance refers to the extent to which the program or intervention becomes part of the routine practices of the organization. These five RE-AIM elements should be examined prior to setting intervention efforts. The framework can also be used to evaluate results. RE-AIM has been used widely since it was introduced; more than 230 study publications used this framework.

2) Promoting Action on Research Implementation in

Health Services: PARIHS

The PARIHS framework is a three-dimensional structure used to interpret successful implementation of evidence, explaining that elements could be located on a continuum of low to high evidence

and context. In the PARIHS framework, successful implementation is represented as a function (f) of the nature and type of evidence (E), the qualities of the context (C) in which the evidence is being introduced, and the way the process is facilitated (F); $SI=f(E, C, F)$ [10,11].

The main assumptions of this framework are as follow: (a) Evidence encompasses sources of knowledge, including research evidence, clinical experience including professional intrinsic knowledge, patient and family preferences and experiences. (b) Implementing evidence in practice requires negotiation and a shared understanding of the benefits, harms, and risks of the new over the old intervention. (c) The contexts that have transformational leaders, features of learning organizations, appropriate monitoring, and evaluative and feedback mechanisms contribute to the successful implementation of evidence into practice. (d) The type of facilitation includes the role and skill of the facilitator in accepting and understanding evidence, the receptivity of their place of work or context in terms of resources, culture, values, leadership style, and evaluation activity [12].

3) Consolidated Framework for Implementation Research: CFIR

The CFIR provides a pragmatic organization of constructs on which theories hypothesizing specific mechanisms of change and interactions can be developed and tested empirically. The CFIR specifies a list of constructs in five domains that may positively or negatively influence implementation: the intervention, inner and outer setting, the individuals involved, and the process by which implementation is accomplished [13].

The first domain relates to characteristics of the intervention being implemented in a particular organization. Without adaptation, interventions usually are introduced to a setting as a poor fit, resisted by practitioners who will be affected by the intervention, and requiring a strategic process to accomplish implementation. The next two domains are inner and outer setting. Healthcare organizations have relationships within and with other organizations. Changes in the outer setting can influence implementation, often intermediated through changes in the inner setting [14]. The outer setting includes the economic, political, and social contexts and the inner setting includes features of structural, political, and cultural contexts [15]. The fourth domain is

the practitioners involved in the intervention or implementation process. Individuals can make choices and apply power and influence to other professionals with outcomes for implementation. The fifth domain is the implementation process. Effective implementation requires an active change process to achieve individual and organization-level use of the intervention [15].

4) Normalization Process Theory: NPT

NPT provides a set of tools to explain the social processes through which new practices are operationalized in healthcare and other institutional settings [16–18]. The theory concerns three core problems: implementation, embedding, and integration. Implementation means the social organization of bringing a practice into action. Embedding means the processes become routinely incorporated in the everyday work. Integration means the processes by which a practice is reproduced and sustained among the matrices of an organization. NPT is a theory of action that emphasizes human agency.

5) Practical, Robust Implementation and Sustainability

Model: PRISM

PRISM is a comprehensive model for translating research into practice, developed using concepts in the areas of quality improvement, chronic care, the diffusion of innovations, and measures of the population-based translation [19]. PRISM evaluates how the healthcare program or intervention interacts with target groups to influence adoption, implementation, maintenance, reach, and effectiveness. PRISM includes key elements to enhance implementation and sustainability of implementation. The domains include Program (Intervention)—organizational and population perspectives of the intervention; External environment; Implementation and sustainability infrastructure; Recipients—organizational and population characteristics. The model targets personnel across an organization, including senior leadership, midlevel managers, and frontline staff.

6) Theoretical Domains Framework: TDF

The TDF, which includes constructs from 33 behavior-change theories, was developed to make theories more accessible to researchers. The TDF uses expert consensus and validation to identify psychological and organisational theory relevant to

healthcare practitioner's clinical behavior change [20]. A set of 12 domains covering the main factors influencing clinical behavior change are knowledge, skills, social/professional role and identity, beliefs about capabilities, beliefs about consequences, motivation and goals, memory, attention and decision processes, environmental context and resources, social influences, emotion, behavioral regulation, and the nature of the behaviors. These 12 domains provide an extensive framework that has greater coverage of potential barriers to change, and thus implies a greater range of potential intervention components.

3. Recommendations for Translational Activities to Enhance Evidence-based Dementia Care

Previous translational research yielded some critical interrelated translational activities for strategic movement. First, a critical need exists for financial support for translational studies in non-pharmacological interventions. Most funding has been allocated to the original studies or translational studies of clinical treatments. In addition, a need exists for ongoing long-term funding through a research roadmap from T1 to T4 studies. Each funding source usually supports original research, which hardly connects T1 to T4 activities. Within this research funding mechanisms, significant gaps persist in knowledge of best practices for various needs of patients with dementia and family caregivers.

Second, stakeholders need to find service providers who can deliver evidence-based interventions. It is important to form partnerships with stakeholders including potential practitioners and administrators to identify effective ways to develop programs and integrate them into routine practice pathway. Systematic training programs would enhance the feasibility of the program.

Third, researchers generally agree that translation studies should maintain the main mode of the original studies, to maintain their expected outcomes. However, it is doubtful that one can maintain the fidelity of the original studies. Researchers need to identify unchangeable and changeable aspects of interventions, guided by a theoretical framework. Reconsidered dose and intensity of interventions, based on previous evidence, improves the possibility of implementation. In addition, researchers should formulate intervention manuals for use in practice settings collaborating with program providers. To advance interventions,

these manuals should arrange intervention targets with those identified in previous studies and involving stakeholders and target users early in development of the program.

Fourth, the role of the original researchers can be adjusted according to the phase of translation. The original researchers may not be the best people to determine best practices in real practice setting. The person who knows the practice sites well can provide leadership and training appropriate to the target users. In addition, we need to evaluate the readiness of practice settings to implement an evidence-based program. Evaluation of available resources such as staffing, management, training, and finance can facilitate implementation.

Conceptual frameworks are important in understanding translational processes and interrelated factors to facilitate or inhibit the implementation. Using conceptual frameworks in translational studies helps researchers evaluate barriers and enablers for uptake by interventionists, adoption at sites, and outcomes for participants. Furthermore, theoretical frameworks can guide conceptual consensus for activities, establish criteria to identify which interventions should be translated, and standardize activities. Future translational efforts should clearly address each of these strategies so interventions can be translated consistently.

CONCLUSIONS

The purpose of this paper was to reflect on the state of the art of translation science and discuss the issues and recommendations for translational endeavors in evolving evidence-based dementia care. The translation of non-pharmacological interventions for patients with dementia and family caregivers is at the beginning stage. Conceptual frameworks, research methodologies, and funding mechanisms are not well established. Conceptual frameworks provide an important guide for translational efforts, identifying the barriers and facilitators of implementation. By identifying several critical recommendations, such as available funding, specialized training, shared decision making with stakeholders, and adapting the manual to practice sites, more dementia patients and their family caregivers can benefit from evidence-based dementia care.

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