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The Kintun program for families with dementia: From novel experiment to national policy (innovative practice)

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Abstract

The Kintun program is the first public health strategy specifically designed for dementia care in Chile. It was launched in 2013 in the city of Santiago with support from the National Service for the Elderly and the Municipality of Peñalolén. Using an interdisciplinary team, the program seeks to promote community integration and better support for persons with dementia and their

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caregivers. The multicomponent program includes: an activity-based day care center, training and education of family caregivers, home visits, and community outreach to increase dementia awareness. Case management helps to monitor ongoing needs and link families to resources. To date, 259 dyads (persons with dementia and their families) have been enrolled in the program. Due to its success in 2015, the Kintun program received funding from the Ministry of Health. This has led to the integration of previously disparate initiatives, better consistency across services, and the development of a comprehensive national dementia plan for Chile.

Keywords
dementia, social support, community integration, day care, family caregivers, health policy

Background

The number of persons with dementia in Chile is estimated to be 180,000 and is projected to triple by 2020 (Fuentes & Albala, 2014). Although Chile is considered to be a developed country by global economic standards, there are high rates of health inequalities (Gitlin & Fuentes, 2012). This is evident in the low level of retirement pensions, high out-of-pocket health-related expenses, and the unequal trajectories of disability including dementia in older persons with low socio-economic levels (Fuentes-García, Sánchez, Lera, Cea, & Albala, 2013).

Chile has two kinds of insurance systems providing healthcare: private and public. The public system covers almost 80% of older persons. At present, neither private nor public systems provide specific care programs for people with dementia nor supportive services for their family members. Dementia care remains the primary responsibility of family relatives (mostly spouses and daughters) typically resulting in negative consequences for many, including high levels of stress and psychiatric symptoms (Slachevsky et al., 2013).

The unmet needs of family caregivers in Chile include the lack of education and skills to address daily care challenges and, for persons with dementia, the lack of access to and participation in meaningful activities as well as the lack of opportunities for socialization and support, among others (Guajardo, Tijoux, & Abusleme, 2015). The increasing number of persons with dementia, together with the lack of provision of evidence-based or evidence-informed interventions, motivated the National Service for the Elderly, a governmental agency part of the Ministry of Social Development, to fund the design and implementation of innovative programs for this population. The Kintun program for persons with dementia and family caregivers was initiated in 2013 as one of the first novel public dementia care projects supported by this governmental agency in Chile. It is offered free of charge to participants and families. This paper describes the Kintun program, highlighting its implementation, the evolution of its offerings, and its scalability and sustainability potential.

History of Kintun

As no specific public policies in Chile previously addressed the needs of persons with dementia and their families in 2013, the National Service for the Elderly funded a project in

alliance with the Municipality of Peñalolén that designed, implemented, and evaluated the first adult day care center for people with dementia in Chile. Peñalolén is a community with a population of 247,000 people located in Santiago, the capital of Chile. This community was chosen because of its socio-economic diversity and its prior experience in administrating projects for social innovation. To design the program, a professional team with expertise in dementia, including a geriatrician, neurologist, occupational therapist, and community mental health physician, was set up. This was followed by newly designed building named "Kintun," a word from the traditional language spoken by Mapuche (part of the native Chilean population), which means "to look at" or "to search for." This term was chosen by the team and community members to reflect the philosophy of the program and its goal, that is, to enable people with dementia and their family members to be visible to the community and to demonstrate that it is possible to promote the participation and community integration of persons with dementia with adequate supports. Kintun was deliberately built next to the Center for the Elderly, which in turn is located in the civic center of the municipality. The civic center is used by all ages and community members and provides services such as an office for citizenship and job center, a public library, a public swimming pool, sports, arts, leisure facilities, and other social activities. Thus, from its start, Kintun was designed to be fully integrated into the daily life of the community and to have a close connection with local authorities.

Components of the Kintun program

Overall, the Kintun program is delivered by an interdisciplinary team of health and human service professionals including an administrative assistant, dietitian, geriatrician, nurse assistants, occupational therapists, physiotherapist, psychologists, and social worker. Based on a geriatric comprehensive assessment, the program is designed to enhance participation and engagement of persons with dementia and to help caregivers' and family's adaptation to the condition.

Participation in and referral criteria to the center are for individuals who are: 60 years of age or older, have a diagnosis of mild-to-moderate dementia (any type), reside in the community of Peñalolén, are registered in public primary healthcare, and who are supported by a primary caregiver aged at least 18 years old. See Table 1 for a description of the program's five core components.

Evolution of the program from 2013 to 2016

Three phases of growth can be discerned from the inception of the Kintun program to 2016 (Table 2).

Each phase built on the findings and experiences from the previous phase leading to greater feasibility and positive results. Drivers that have triggered program adaptations include engagement with the community, improvement of skills and experience of the professional team, searching of evidence-based recommendations, deeper understanding and definition of targeted population, expansion of coverage territory, and awareness of potential impact on public policy. Table 3 and Figure 1 present the adjustment of contents and components through the implementation phases.

Table 1. Core components of the Kintun program.

Component	Description
Comprehensive geriatric assessment	Upon intake, a comprehensive assessment is conducted to learn about the clinical, cognitive, functional, and social profile of persons with dementia and caregivers. Based on the assessment, unmet needs are identified and clinical and family goals are established from which a plan of action to address issues is jointly developed with the family
Day care center	Day care center offers group activity routines in a protected environment, including leisure and social activities, physical exercise, cognition-based activities, and activities of daily living (especially self-care). Activities are tailored according to personal histories and group capacities. Day care center offers free shuttle and meal services. Groups of 8 to 17 people participate in the day care center once or twice a week, depending upon cognitive, behavioral, and physical characteristics and family needs
Home visits	Home visits are conducted by a member of the Kintun team. These visits provide critical information on home-based care and potential risks. During visits, families receive counseling and skills training in the context of real-life situations. Every participant receives at least one diagnostic home visit as part of the geriatric comprehensive assessment
Caregiver training	Caregivers commit to participate in at least one cycle of training, consisting of two sessions. The training program seeks to improve the caregiver's readiness (Gitlin & Rose, 2016) and abilities to cope with challenging situations, such as behavioral symptoms, as well as connect the caregiver with other supportive community resources
Case management	Once the person with dementia is admitted to the program, he or she is assigned to a case referent, a role filled by any professional member of the team. The case referent serves in part as a navigator for the person with dementia and caregiver through the different aspects of the program, as well as ensuring that the negotiated action plan is addressed appropriately and is effective. Specific cases are periodically discussed during weekly team meetings. The case referent also follows the participants' progress and identifies, solves, or refers emerging problems to other team members. Finally, the case referent manages follow-up assessments
Other actions	Other activities connect and integrate the Kintun program within the community. These actions may include team members providing community talks on dementia and cognitive ageing (community education), a volunteer program to enhance civic engagement that involves neighbors who assist in the day care center, and education and training of local primary care health teams to increase awareness of dementia and clarify and reinforce criteria for referral. Additionally, the Kintun team has more recently participated in the development of the national dementia plan

Lessons from implementation: Evolution from a novel experiment to a replicable model for dementia care in Chile

The Kintun program has been highly successful in terms of its acceptability, user satisfaction, and documented benefits to persons with dementia (e.g. behavioral symptom reduction, physical function improvements) and caregivers (e.g. distress reduction, improvement

Table 2. Implementation phases of the Kintun program from 2013 to 2016.

Period	Implementation phases	Description
November 2012 to June 2013 (8 months)	***Phase I*** Program development and design	Definition of components, protocols, and assessments Review of the literature and consultation with dementia care experts Context preparation, building of physical facility, connection with proximal network and team recruitment Raising awareness of dementia in local authorities through education programs and meetings Time-limited funding from governmental institutions
July 2013 to December 2015 (30 months)	***Phase II*** Proof of concept, evaluation of acceptance, feasibility, and benefits	Multi-component program is initiated Examination of acceptance and feasibility for persons with dementia and caregivers Qualitative and quantitative evaluation of results Refinement of target population and components Network is widened and stakeholders are included
2016 (12 months)	***Phase III*** Sustainability, dissemination and scaling up	Due to program success, it becomes a health policy, with stable funding from the Ministry of Health Refinement of components from evidence of previous phases of evaluation, and implementation drivers Relative relevance of each component is adjusted Stable and unlimited-time funding from Ministry of Health Program is translated to other locations in Chile, as "community centers for dementia"

of dementia knowledge, and use of effective care strategies). The Kintun program demonstrates the feasibility of reducing stigma by enhancing the inclusion of people with dementia into the community and supporting families. Furthermore, it bridges and integrates a social and medical model of care that can be replicated. As such, it has propelled and accelerated national policies for dementia care.

The Kintun program has been successful due to several factors. The program garnered vital support from key parts of government, including the Ministry of Health, the National Service of the Elderly, and the local authorities in the Municipality of Peñalolén. External support from key stakeholders continues to be essential.

Another factor contributing to success has been the early involvement of a highly committed, flexible, and motivated interprofessional team. The team collaborates with local primary care and social supportive structures, who in turn became facilitators and stakeholders in this program.

Following recommendations for the successful development and implementation of novel behavioral interventions (Gitlin & Czaja, 2016), careful consideration was given to contextual elements, such as culture of the community, readiness of caregivers, engagement needs

Table 3. Transformation of program based on evaluations from 2013 to 2016.

Programmatic element	Initial	Current
Goals	Focused on the person with dementia	Involve the interaction of person with dementia, caregivers, family and even the community
Components and main activities	Day care center is the main component, and delivery of structured activities is the main strategy (cognition-based, physical activity, leisure, and social activities) Other components are delivered sporadically and in lower doses. All participants receive same level of exposure to all components	Case management is the core component which all participants receive with participation in other components based on needs identified in assessment Program is tailored such that participants receive only those components they need
Primary outcomes	Rely on individual features of the person with dementia, particularly physical and cognitive function, and behavioral symptoms Outcomes based on type and number of interventions received	Involve person with dementia and caregivers, with outcomes related to participation and the perception of the experience of living with dementia, based on the negotiated plan. Outcomes based on previously negotiated goals
Duration	Average of three months	Average nine months, with trimestral evaluation of goals accomplishment
Coverage	45 participants per month in day care center	80 families per month, participating in program

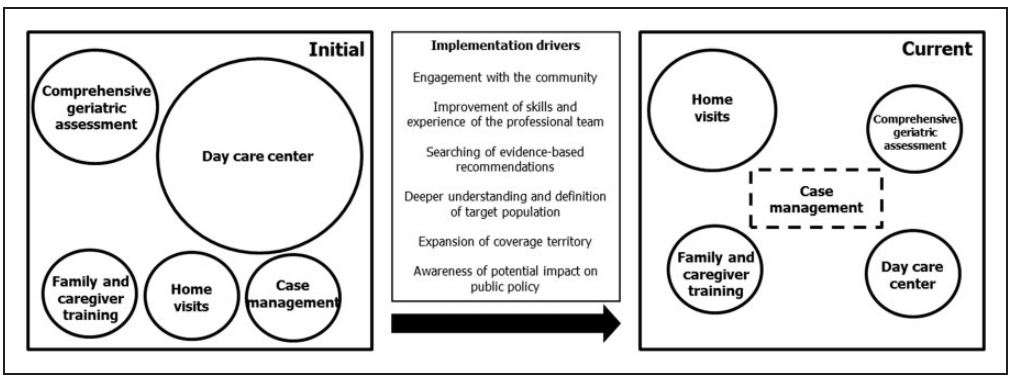

Figure 1. Evolution of the Kintun program from 2013 to 2016 and implementation drivers.

of persons with dementia, and physical space and environmental design. As such, the model integrates a social and medical perspective, demonstrating how both must co-exist and that the medical perspective does not take precedence over the social, psychological, and environmental perspective.

In 2015, the program received official support from the Ministry of Health, and nine new centers will be constructed in different regions of the country within the next two years.

Following this milestone, the Ministry of Health launched the first Chilean national dementia plan that will be implemented in 2017 through 2018 (Gajardo & Abusleme, 2016). In this plan, Kintun and similar dementia community centers throughout the country are expected to contribute to the advancement of specific activities and processes for dementia care in primary and secondary healthcare.

Kintun has become a national reference for practice in dementia care in Chile. Specifically, it has demonstrated that it is possible to implement initiatives for people with dementia and their families in community settings and augment dementia-related services to already existing settings, contributing to sustainability.

Declaration of Conflicting Interests

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