

**Title: The challenge of providing a timely and holistic approach to support people with dementia and their caregivers**

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People with dementia and their family caregivers often experience distressing symptoms and consequences of dementia which have been the focus of many interventions and services. Interventions targeting dementia symptoms tend to focus on improving behavioural and psychological symptoms of dementia (BPSD), cognition and function while those targeting caregivers tend to focus on depression, burden and coping. Other outcomes of interest include rates of institutionalisation and hospitalisation. The progressive, long-duration and terminal nature of dementia creates a societal challenge in terms of providing an effective, co-ordinated, holistic response that is timely and prevents poor outcomes. In this volume Kawakita and colleagues (2019) explore the outcomes of the Initial-phase Intensive Support Team for Dementia (IPIST), an early intervention community-based program in Japan targeting both the person with dementia and their family caregiver.

There has been many studies examining psychosocial interventions for people with dementia and their family caregivers. A systematic review of these interventions for caregivers highlights that the most effective interventions incorporate education about dementia and caring with a psychological therapy such as cognitive behavioural therapy (Dickinson, Dow et al.). Psychological approaches can be effective in reducing BPSD particularly when focusing on individual interventions rather than providing techniques in group settings (Livingston, Johnston et al. 2005). However, there have also been many reviews showing mixed and inclusive findings (Pinquart and Sorensen 2006, Schoenmakers, Buntinx et al. 2010).

Case management programs, incorporating various models and disciplines including medicine, occupational therapy, social work, nursing and psychology, have often been implemented to help ensure a co-ordinated and integrated response to support the needs of people with dementia and their caregivers. Despite their promise, systematic reviews of these programs show inclusive results of community-based primary health care case management (Khanassov, Vedel et al. 2014) and integrated care and consumer directed care (Low, Yap et al. 2011). Dementia case management has also shown mixed results in relation to avoiding institutionalisation and hospitalisation (Tam-Tham, Cepoiu-Martin et al. 2013, Reilly, Miranda-Castillo et al. 2015).

Limited benefits from interventions targeting those with moderate to advanced dementia have led to calls for earlier intervention and possibly commencing before diagnosis is confirmed given the often long timeframe of the diagnostic process (Minkman, Ligthart et al. 2009). Specialist multidisciplinary memory clinics play a key role in enabling early and differential diagnosis of dementia in numerous countries (Monsch, Ermini-Fünfschilling et al. 1998, LoGiudice, Waltrowicz et al. 1999, Moore, Goodison et al. 2019). Having involvement in the pre to post diagnostic phase they are well situated to implement or refer clients on to early intervention programs. However research indicates dementia is underdiagnosed, particularly in low or middle income countries where there are few services dedicated to diagnosis and continuing care. With diagnostic coverage estimated to not exceed 5-10% (Prince, Comas-Herrera et al. 2016), the majority of people in low income countries will not have access to the treatment, care and organised support that getting a formal diagnosis can provide (Alzheimer's Disease International 2011).

Early intervention and post diagnostic support may be essential to establishing an effective and timely response for the whole dementia trajectory by preparing families for what is to come, potentially delaying or preventing symptom burden and institutionalisation (Andrén and Elmståhl 2008). Dementia is now the seventh highest cause of death worldwide (World Health Organization

2017). The European Association of Palliative Care has produced a white paper with recommendations for optimal palliative care in dementia and highlights the importance of recognising dementia as a terminal condition as the basis for anticipating future needs and providing palliative care (van der Steen, Radbruch et al. 2014). It also recommends that advance care planning should be pro-active and start as soon as dementia is diagnosed.

Memory clinics, however, may be limited in the extent to which they can provide post-diagnostic support. In the UK, for example, some clinics provide extensive support over the longer term with education programs, ongoing counselling and treatment programs such as cognitive stimulation therapy (Jolley and Moniz-Cook 2009). However, funding of the health service at a local level may lead to substantial geographic variation in the capacity of clinics to provide post diagnostic support (Moore, Goodison et al. 2019). In addition, the role of memory services in performing functions beyond diagnosis may be contested. Issues around end of life and palliative care may be considered too early at the time of diagnosis and we found that only 41% UK memory clinics routinely told caregivers that dementia was terminal and only 37% told the person with dementia (Moore, Goodison et al. 2019). However, even among family caregivers of nursing home residents in the moderate to advanced stages of dementia, many do not recognise dementia as a disease you can die from (van der Steen, Onwuteaka-Philipsen et al. 2013). Therefore, there remains gaps in who is helping families plan and prepare for the future. The IPIST program may offer an alternative to the memory clinic where the need for support after the diagnosis of dementia is recognised and pro-actively supported.

Kawakita and colleagues (2019) also recognised the importance of measuring effectiveness of the IPIST intervention for subgroups of their client population. This enabled differential outcomes to be found for different client groups based on severity of cognitive impairment, function in activities of daily living and BPSD. They identified four clusters of client groups including a mild and moderately

cognitively impaired group, a moderate group with severe BPSD and a severe group with severe BPSD. Looking at those with specific unmet needs can help identify the effectiveness of specific interventions. Many intervention studies fail to target their intervention to those with unmet needs, such as providing an intervention that aims to reduce depression to a broad group of caregivers including those who do not have depressive symptoms, or measure outcomes that may not directly reflect the primary target of the intervention. For example, in our systematic review of educational interventions for carers that incorporated information about the progressive or terminal nature of dementia, we found among 11 included RCTs only two included a measure of knowledge improvement while all measured outcomes relating to burden or depression (Moore, Lee et al. 2019)

Kawakita and colleagues (2019) study is not the first to find differential benefits for different cohorts of service users. Chu and colleagues (2000) found that a case management program for people with mild-moderate dementia helped delay institutionalisation for those with moderate dementia but not those with mild dementia. Kawakita and colleagues (2019) did not find improvements for patients who did not have high levels of BPSD. These findings may simply reflect a ceiling effect with limited capacity to demonstrate improved outcomes for those with low intensity of symptoms.

Demonstrating prevention and delay of poor outcomes for patients with dementia and their carers through early intervention is marred by the need for large samples sizes, a comparison group and follow-up that is more consistent with the duration of dementia. These studies are costly and difficult to implement, however, can provide useful evidence to support practice (Brodaty, Gresham et al. 1997).

While Kawakita and colleagues' (2019) study was unable to demonstrate improvements for those with mild symptoms, the intervention helped reduce carer burden across all four clinical groups and suggests that early intervention may be particularly beneficial to carers throughout all stages of

dementia. The intervention was holistic and included dementia education, carer psychological support and connections with peer support, in addition to specialist or general practitioner referrals. The IPIST team facilitating the intervention were interdisciplinary care professionals and included a nurse, social worker, occupational therapist, and psychiatric social workers. Users of IPIST were also introduced to other dementia health care services following the six month intervention.

Despite an increase in research demonstrating statistically significant benefits for family carers and people living with dementia, a persistent gap between evidence provision and implementation of interventions in real world settings remains. The pressing need to promote implementation in practice is well documented, as are the challenges associated with replicating research findings which include; difficulties identifying the active component of interventions, generalisability, unknown cost benefits, resources and time (Orrell 2012, Gitlin, Marx et al. 2015). It is important to evaluate outcomes in real contexts as findings from research do not always translate well into practice. For example, van de Ven and colleagues (2013) found that whilst an explanatory cluster Randomised Control Trial (cRCT) demonstrated that dementia-care mapping reduced agitation in people with dementia, their pragmatic cRCT that emulated real life situations found no significant effect on agitation. A further consideration is of the additional obstacles experienced in low to middle income countries, where it is unlikely there will be the capacity to offer the level of support required in IPIST due to resource limitations and a lack of specialist services (Alzheimer's Disease International 2011).

Despite extensive research on interventions to support people with dementia and their caregivers throughout the dementia trajectory, beneficial outcomes in research are not commonly translated into practice with similar results. The IPIST community intervention helped reduce carer burden across all four clinical groups, including those caring for someone with mild dementia where no significant improvements in cognition or activities of daily living were found. It supports previous

literature that early intervention and support has a positive impact on carer burden (Andrén and Elmståhl 2008). Where patients experienced high symptom intensity, in the case of BPSD, significant improvements were found. Further work is needed to examine whether early interventions such as IPIST have longer term benefits in preventing decline in cognition and activities of daily living and to identify which specific elements of interventions are more effective and for whom. This more nuanced approach will help enable a more responsive, proactive response to the needs and people with dementia and their caregivers to support them through the often long and unpredictable journey with dementia.

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