

Translating Dementia Research into Practice

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'The greatest problem with communication is the illusion that it has been accomplished'

George Bernard Shaw

Summary

- The Knowledge Gap
- Knowledge Translation
- Key Players for KT in Dementia Research
- Challenges for KT in dementia
- Key Features of Effective Dementia KT
- Where do we go from here?

The Knowledge Gap

- 30-45% of patients do not receive care supported by current scientific evidence
- 20-25% of care provided may be unneeded or harmful (Gaddis et al 2007)
- In Germany it is estimated that only 20% of dementia patients are adequately treated (Vollmar et al, 2007)



Knowledge Translation or Knowledge Transfer?

- Many terms used ⇒ Confusion
- Knowledge Translation (KT) involves the dissemination, management and utilisation of knowledge.
- 2 way exchange between researchers and those applying knowledge
- Blends new with existing knowledge (Tetroe et al, 2007)
- Knowledge transfer is just one aspect of KT that involves the active passing of knowledge from one person to another (Major and Cordey-Hayes, 2000)

KT as a new paradigm

- Traditional practice - researchers perform research and disseminate their findings within academic settings
- New KT paradigm – researchers (& others) disseminate findings more widely and ultimately effect changes in community awareness, clinical practice and health policy.
- KT is more than providing information, it is transmitting skills and capabilities, changing mindsets and workplace cultures to bring about change in practice.

Key Players for Dementia KT

- Researchers
- Educators
- Service Providers
- General Public
- Carers and Consumers
- Policymakers & Health Services



Researchers

- Need to be aware of importance of KT in their research
- Include KT as part of grant proposals (as occurred with recent Dementia Research Grants) e.g. strategy for broader application of new treatment (effectiveness vs efficacy); communication strategy; educational strategy
- Obtain training in KT methods and how to apply them

Educators

- Aged care has poor profile amongst undergraduates in health disciplines (e.g. Moyle, 2003)
- Educators often do not recognise the importance of their role (Xiao et al, 2008)
- Dementia has variable coverage in undergraduate nursing, OT, SW curricula (Pulsford et al, 2007)
- Consensus core competencies about dementia care have yet to be established for curricula
- Nursing graduates report gaps in knowledge on BPSD (Henderson et al 2006, Hsu et al, 2005)

Educators – Effective KT

- Quality placement working with good clinicians as role models in aged care are key KT educational tools (Abbey et al., 2006, Xiao et al., 2008).
- Generic teaching about persons with dementia coupled with placement hours may not be sufficient; tailored strategies also required (Fruhauf et al., 2004).
- Emphasis for KT in dementia education should be upon changing negative attitudes towards aged care and the provision of tailored, problem-based information alongside positive and practical placement experiences.

Service Providers

- GPs have difficulties with aspects of dementia diagnosis and management e.g. communicating diagnosis, management of BPSD, availability of local services, their role in dementia care in relation to specialists (Turner et al, 2004)
- Medical specialists – issues relate to adherence to CPGs & EBM
- Non-medical – similar knowledge gaps to medical

Service Providers – Effective KT

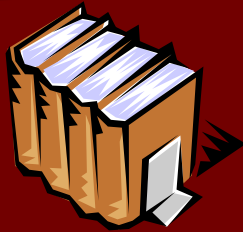
- Types of effective KT varies between service providers though overall understanding of what works is poor
- For nurses & allied health personal transmission of knowledge & experience is important (Estabrooks et al, 2005; Gira et al, 2004)
- No best practice established for GPs but decision support software built into an EMR system and practice-based workshops were both effective compared with no intervention (Downs et al 2006).

Service Providers – KT Barriers

- Attitudes
- Lack of time
- Lack of resources
- Lack of administrative support for training



General Public – Dementia Literacy



- Dementia literacy surveys indicate following beliefs:
 - Dementia as part of normal ageing
 - Poor knowledge of causation
 - Poor knowledge of risk reduction
 - In some countries poor understanding of symptoms
- (Low & Anstey, 2007; Arai et al, 2008)

General Public – what information?

- Need information on the symptoms of dementia, including early signs, and how to seek assessment, treatment and services.
- Public misconceptions may form a barrier to the incorporation of new information about symptoms into existing belief systems.
- Require information on dementia risk factors to encourage risk reduction behaviour.
- Minority groups have less knowledge

General Public – Effective KT

- KT should involve public health departments, health professionals, educators and Alzheimer's organisations.
- No studies of barriers to undertaking risk reduction strategies for dementia.
- In preventative public health, multi-component interventions tend to be more effective and more intensive strategies tend to have the strongest outcomes (Wells et al, 2004)
- Mass media can improve use of health interventions in community (Grilli et al, 2002)

Consumers - Carers

- Carers of persons with dementia need more information on diagnosis, treatment, legal and financial issues (Wackerbarth & Johnson, 2002)
- European dementia carers reported that they did not receive information at the time of diagnosis about dementia as a disease (50%), disease progression (66%), drug treatments (48%), their local Alzheimer's Association (59%), and services (82%) (Georges *et al.*, 2008)

Consumers – Persons with Dementia

- Information needs to be provided in a format that cognitively impaired person can comprehend
- 25% of dementia brochures published at unsuitably high readability levels, 75% font too small (Weih et al, 2008)



Consumers

- Key players for KT are service providers, Alzheimer organizations and social service organizations
- Barriers include denial, stigma and fear by both the persons with dementia and caregiver and a perception that they do not require help (Wackerbarth and Johnson, 2002a, Vernooij-Dassen et al., 2005, Bond et al., 2005; Brodaty et al., 2005)



Consumers – Effective KT



- Unclear what is an effective strategy for persons with dementia
- Carers appear to respond well to group-based supportive interventions, no evidence for the effectiveness of technology or individual interventions (Thompson et al, 2007)

Consumers – where to?

- Consumers need to accept a responsibility for KT and make other groups aware when their needs are not met.
- Focus should be on providing more information in an accessible and user-friendly way.
- Consumers should be encouraged to communicate with service providers and policy makers.



Policymakers - Australian examples

- 'The Problem of Dementia' (Henderson & Jorm, 1986, 1990, 1993, 1998)
 - Major impact upon service development, consumer groups, policy - Why? According to Tony Jorm (2008)
 - 1. It was requested by the public service because of policy development needs - therefore had a receptive audience.
 - 2. People liked quoting figures on dementia projections for advocacy purpose - as a government publication, it gave the figures some semi-official status.
 - 3. The prevalence data came from an innovative meta-analysis which was an advance on existant data
 - 4. It drew together a lot of information about dementia care in Australia that was convenient and not easily found elsewhere.

Policymakers – Australian examples



- Support for carers 'Living with Memory Loss' program
 - Based on original research in Australia by Henry Brodaty & colleagues in 1980s & 90s
 - Why successful?**
 - High quality research on consumer oriented topic
 - Involvement of Alzheimer's Australia
 - Opinion leader involvement

Policymakers – Australian examples

BPSD 7-tiered model (Brodaty et al, 2003)



Policymakers – Australian examples

BPSD 7-Tiered model – why did it have an impact?

Kate Jackson, senior policy adviser NSW Older Persons Mental Health (2008)

- It was in a format that worked with policy and planning frameworks (ie incorporating needs/epidemiological analysis, service models/ responses, and continuum of care approach that aligns with policy frameworks)
- It was published and cited the evidence base for the model (which allows busy policy-makers to use it as an evidence-based approach)
- It was publicised in the right places (ie at key forums and with people leading policy developments in dementia nationally and at the state level)
- The time was right.... people were receptive to clear research that lent itself to service planning.

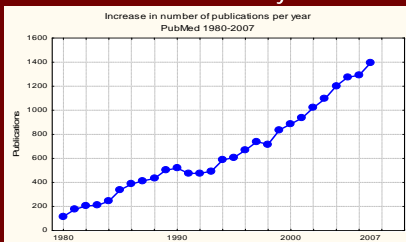
Effective KT & Policymakers

- Key politicians and bureaucrats need to be ready to make change,
- Quality evidence-based research that addresses policy requirements needs to be available,
- The research needs to be presented in a format that is understandable and appealing to policymakers,
- Opinion leaders from consumers, policy and research need to be involved.



Challenges in Dementia KT

- Volume of evidence
 - Well over 1000 new articles on dementia are available from PubMed each year



Challenges in Dementia KT

- Accessibility & Quality of Evidence
 - Daunting task for clinicians & managers to find, access & maintain current 'best practice'
 - Numerous clinical practice guidelines (CPGs) in dementia but they lack evaluation & have inconsistencies (Hogan et al, 2001; Beck et al, 2000)
 - October 2008, the Cochrane Library Dementia and Cognitive Improvement Group had 75 active systematic reviews on the treatment of dementia and cognitive impairment, with approximately 50% having not been amended for over 2 years
 - Service delivery evaluation often published in non-peer reviewed reports or unpublished (Runge et al, 2008)

Challenges in Dementia KT

- Role of Independent Bodies to Evaluate & advocate Best Practice



- National Institute for Health and Clinical Excellence (NICE) in UK is an example
- Controversial recommendations about prescription of cognitive enhancers that are inconsistent with other published guidelines (NICE, 2006; APA, 2007; Waldemar et al, 2007)

In whom lies the responsibility for KT?

- Is it researchers?
 - Granting bodies now tend to expect applications to contain a KT component (Tetroe et al, 2008)
 - But is the knowledge producer necessarily the best at KT?
 - Simplistic approach disregards that KT is a complex, intensive, iterative two-way process, and that successful KT requires a consistent simple message (where multiple researchers may produce multiple differing messages).

In whom lies the responsibility for KT?

- For KT to be successful the responsibility needs to be shared between those producing the knowledge and those applying it.
- Dedicated experts in KT might be required to make and maintain the connections between the key players e.g. Dementia CRCs; Sax Institute; KT persons on research teams

Premature Action

- Restraint is important to ensure that treatments are not adopted before their effectiveness is proven
 - New Drug Developments
 - Over 80 being researched
 - Mild Cognitive Impairment
 - No clear clinical guidelines
 - Risk Factors for Dementia
 - Broad consensus on many factors still lacking



Lack of KT Resources

- Effective KT is complex and can be resource intensive
- The planning of KT activities needs to be realistic
- Operational definitions should be devised so that the KT responsibilities are clearly defined (Tetroe et al., 2008)
- If research studies have some KT component, then the resource cost entailed should be included in the budget
- CME should be regarded favourably by employers of health care workers and funded accordingly

Research on effective KT strategies

- KT should be evidence-based in the same way as dementia care
- Some gaps in knowledge with regard to KT for dementia include:
 - factors that contribute to the adoption of knowledge and changes in dementia practice across health care professions
 - Evaluation of the effectiveness of current KT practices for persons with dementia and their carers
 - Outcomes of KT to the public (rather than just processes)

Challenges of the Dementia Workforce

- The majority of paid caregivers have received limited education and minimal training (Richardson & Martin, 2004)
- Often have poor literacy, come from a minority background, less competent in English (Kiata et al., 2005)
- High staff turnover (Castle, 2005).

Key Features of Effective Dementia KT

1. A simple, compelling message
 - Information must be integrated, simplified, then communicated to different audiences in the most appropriate way (Choi, 2005)
 - Each target group requires a different strategy and method for effective KT
 - The language used should match the audience
 - The central message must be clear, concise, consistent, continuous, and compelling and take into account existing knowledge (Abernethy et al, 2001)

Key Features of Effective Dementia KT

- 2. Use of interpersonal contact and roles
 - KT acknowledges the role of human nature
 - Quality relationships and trust between those transferring and those using the knowledge have to be built (Roberts, 2000)
 - Good communication pathways, both within and between services and groups, are integral to successful KT

Important Interpersonal KT Roles

- Opinion leaders - influential persons to whom others go for advice
- Facilitators - have a formal role of helping implement change processes
- Champions - unsolicited advocates of ideas or projects with overwhelming enthusiasm and strong connections
- Linking agents - problem solvers that identify relevant knowledge and connect it to a need
- Change agents - work with people to change their behaviour (Thompson et al., 2006).

Important Interpersonal KT Roles

- Persons acting in such roles improve the effectiveness of KT (Crookes and Froggatt, 2004).
- Opinion leaders can be a useful strategy to promote changes in health care practice
- Staff at all levels can act as facilitators and change agents.
- Consumers acting as champions also have a powerful influence, particularly with policy makers.

Key Features of Effective Dementia KT

- 3. A practical framework and emphasis on 'know-how'
 - In business and technology there is an emphasis on the importance of skill-based knowledge or 'know-how' (Pfeffer and Sutton, 2003, Roberts, 2000)
 - Efficient KT methods are those that support the acquisition of new skills and experiences that create an impetus for changes in practice
 - Placements for students and interactive workshops emphasize practical applications of knowledge
 - Follow-up is required to ensure that material learnt crosses the 'knowing-doing gap' and is actually converted into practice (Pfeffer and Sutton, 2003)

Key Features of Effective Dementia KT

- 4. The provision of support and resources for KT
 - A person who has gained knowledge will revert back to the status quo if not supported by other staff and management (Crookes and Froggatt, 2004)
 - Management need to be supportive of dementia KT (Crookes and Froggatt, 2004)
 - Junior staff should be made aware of expectations for them to participate in KT practices and to be supportive of their peers
 - Incentives for undertaking KT should be introduced to foster KT practices within services and consultations across the groups involved in dementia

Conclusion

- Transforming dementia research into practice is vital, otherwise research investments are not maximised
- KT in dementia involves multiple way communication between key players
- All key players need to be engaged for effective KT to occur and all are responsible for ensuring translation into practice
- Facilitation of KT by dedicated experts might be required
