Younger Onset Dementia: A Recent Literature Review

Associate Professor Jan Sansoni, Cathy Duncan, Pam Grootemaat, Anita Westera, Jacquelin Capell, Peter Samsa
Younger Onset Dementia (YOD)

- Recent literature review concerning YOD and
- Consultations concerning a needs analysis and feasibility assessment of services for people with YOD
- Included any form of dementia occurring in those < 65 years
- Examined the service and care needs of people with YOD
- Provided some guiding principles for service design and development
YOD Literature Review

Methodology

- Systematic search of ten relevant bibliographic databases (including Medline, CINHAL, Scopus, ProQuest Central from 2000 in English)
- ‘Snowballing’ and hand searching methods used
- Rigorous search of ‘grey’ literature (e.g. from international ‘peaks’, health departments and relevant conferences)
- 301 papers retrieved and studies were rated for their strength of evidence
YOD Literature Review

- **Well-supported practice** – evaluated with a prospective randomised controlled trial
- **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication
- **Promising practice** – evaluated with a comparison group
- **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (e.g., pre- and post-testing, post-testing only, or qualitative methods) or historical comparison group (e.g., normative data)
- **Emerging practice** – evaluated without an independent assessment of outcomes (e.g., formative evaluation, service evaluation conducted internally)
- **Routine practice** (e.g., routine data)
- **Expert opinion** (e.g., peak bodies; government policy; opinion pieces, editorials or summaries from health professionals)
- **Case-study** (e.g. one shot case-studies or a group of case-studies that are largely anecdotal).
Most studies ranged from emerging practice to promising practice

Relatively few studies made use of appropriate comparison/control groups or used standardised assessment or outcome measures

Many papers concerned qualitative analyses of patient and family experience

Chapters include general literature, voices and experience of people with YOD and their carers, service design and development, particular programs and special needs groups
Some Common Themes: Clients and Carers

- Long quest to obtain diagnosis
- Adjustment to diagnosis and need for support
- Coping with behavioural and psychological aspects
- Changing roles for YOD client and carer over the trajectory
- Grief and loss
- Difficulties in planning for the future
- Carer - juggling caring role and other responsibilities
YOD Review: Key Issues

- Timely and accurate diagnosis - average delay 3-5 years and initial misdiagnosis still very common. High need for client & carer support post diagnosis (an enablement phase)

- Need for standardised assessment using more up to date, sensitive and valid tools (e.g. cognitive status); cultural appropriateness of measures

- Need for systematic evaluation and outcomes measurement re programs & interventions
Key Issues (Cont.)

- Need for individually tailored services – addressing life-cycle issues and the provision of age appropriate programs in both generic and specialist services;
- Specialist vs. generic service issues; need outreach arms for specialist services
YOD Review: Research Gaps

- Need current epidemiological data – prevalence, incidence, life expectancy (most estimates based on 1998 UK survey)
- Recent Australian ‘Inspired’ catchment study showing higher rate of alcohol related dementias
- Limited data concerning YOD in our Indigenous population but data suggests it may be higher than estimated
- Service utilisation and costs data – few studies – longer period to residential placement but low community service use reported
Research Gaps (Continued)

- Social and informal care costs
- Effectiveness and cost effectiveness of pharmacological and non pharmacological interventions
- Living alone with YOD – dearth of information
- More longitudinal research – Netherlands group
- Comparator groups e.g. late onset dementia – need to control for potentially confounding factors (e.g. duration of care, age, diagnostic composition of groups)
Optimal Service Design

- A focus on the young person with dementia with services tailored to individual need – whether generic or specialist services
- Integration of services to reduce fragmentation in the service system
- Service delivery that is ‘dementia friendly’; respect & dignity
- Service delivery that is timely and responsive to dementia progression and that balances need and risk
Service Design

- **Individualised model of service** (listening, person-centred, whole of family, ongoing needs assessment, recognise diversity)

- **Staff attributes** (skilled; holistic, enabling, & person centred; effective relating & communicating; flexibility; capacity building)

- **Organisational attributes** (facilitate access to relevant services, integrated and coordinated interagency partnerships & pathways, dementia friendly & timely service provision, respect & consideration, cultural safety, address needs of people in rural & remote areas, manage risk effectively, capacity for organisational change......)
Conclusions

- Need for a coordinated entry point to services and case management / key worker approaches
- Involvement of people with YOD in service design, development & evaluation
- Raising public awareness to reduce stigma and barriers
- Genetic counselling – high risk groups
- Health promotion initiatives – alcohol and dementia
- Address research & service gaps identified (e.g. living alone)

jans@uow.edu.au