



Younger Onset Dementia: A Recent Literature Review

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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, CINAHL, 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).

YOD Literature Review (cont.)

- 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)

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