Understanding the social implications of Dual Sensory Impairment in the older Australian: through the eyes of the carer

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Dual Sensory Impairment (DSI)

‘Deafblindness (or dual sensory impairment) is a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation, mobility and daily living’

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<tr>
<th><strong>DSI current research</strong></th>
<th><strong>Reference</strong></th>
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<tr>
<td>High prevalence of DSI in older Australians, particularly &gt;80 years; growing ageing population- national and global</td>
<td>Caban, 2005; Schneider et al., 2011; Swenor et al., 2013; Rooth, 2017; Lehane, Dammeyer &amp; Wittich, 2019.</td>
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<td>Notable increase of depressive symptoms in presence of DSI; impact of DSI on cognitive function; association with dementia</td>
<td>Heine &amp; Browning 2014; Hatfield et al., 2013; Chin et al., 2006; Lin et al., 2013</td>
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<td>Strong association of DSI with social isolation. Negative consequences for family/carers</td>
<td>Heine and Browning, 2004; Chia et al., 2006; Tay et al., 2007; Kricos 2007; Brennan and Bally, 2007; Arndt and Parker, 2016; Hovaldt, Lund, Lehane and Dammeyer, 2019</td>
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<td>Impact on carers</td>
<td>Lehane, Dammeyer &amp; Elsass, 2017</td>
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Social implications of DSI: what the literature tells us

- Increasing isolation
- Reduced social participation
- Cognitive decline
- Depression

DSI
The study

Research Questions

• How do older Australians with DSI and their family carers manage the challenges of maintaining and adapting their social networks and roles?

Participants

• With DSI (N=15)
• Carers (N=8)
• Criteria: >60 years; reduced visual acuity; self reported hearing loss

Methods

• Qualitative study (Grounded Theory Methodology)
• Face to face interviews (N=23)
• Thematic analysis
Key themes: Carers

Social effort
- One sided conversation
- Social cues
- Trying to engage
- Social facilitation
- Social protector
- Carer fatigue

Changing relationships
- Maintaining self identity
- Co-dependence
- Feeling trapped; close proximity
- Unintended hurt
- Balance and negotiation
Social Effort: key points

- Social facilitation: loss of social confidence
- Carer as ‘eyes and ears’
- Invisible Disability >>Social discomfort
- Prioritising other ‘needs’ over social needs
DSI impact on carers: Social effort

“it's hard to meet new people and it's hard to form friendships with them because Ruth* can't see who she's talking to and she kind of loses interest in that”

“I have noticed over the time that Clive’s* had a sight impairment that people [get –] are introduced and that's fine, as soon as they've been introduced, they kind of move away, it's like someone who's got leprosy or something, you know”
Changing relationships: key points

- Fractured communication
- Demands and expectations
- Forced proximity & low perception of control
- Ability (or inability) to maintain self identity in the relationship
- Adaptation and acceptance
DSI impact on carers: Changing relationships

“You seem to be stuck, and the more you are stuck the more you become just sort of dead, you know you lose interest in everything. But I would like us to be more - do things or something...but we can’t”

“I think the companionship, it’s not there anymore. Lots of things, we tend to argue a bit now, I think its frustration”
DSI: Policy priorities

- **National**
  - Acknowledge DSI as separate & unique disability; National Research Priority; Co-ordination: Australian Hearing/Vision Australia
  - Transition from NDIS to Aged Care

- **International**
  - UN Disability Rights: WHO Ageing well International definition; Research; Look at international experience

- **Community: service delivery**
  - Case management; defining DSI; clear guidelines re informed consent; multidisciplinary approach; service delivery; care for carers; interpretation; associated costs
Acknowledgements

Primary Supervisor: Associate Professor James Gillespie
Associate Supervisor: Associate Professor Heather McKenzie
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Staff at Vision Australia
All study participants

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References


References


