Age-related vision loss: Negotiating support from others while maintaining acceptable identities

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- Department of Occupational Science and Occupational Therapy, University of Toronto
Overview

- Literature Review
- Research Objective & Question
- Methodology
- Findings
- Discussion
- Conclusion and Questions
Literature Review

- Age-Related Vision Loss (ARVL)
  - Glaucoma, diabetic retinopathy, macular degeneration, etc. (Watson, 2001)

- Affects 1 in 8 Canadians above age 75 (CNIB, 2014)

- Prevalence expected to increase (McGrath & Laliberte Rudman, 2013; Girdler, Packer, & Boldy, 2008)

Literature Review

ARVL leads to:

- Decreased ability to participate in occupations  
  (Alma et al., 2011; Moore & Miller, 2003; Law, 2002; Girdler et al., 2008; Mojon-Azzi, Sousa-Poza & Mojon, 2008)

- Increased need to rely on others  
  (McGrath & Laliberte Rudman, 2013; Laliberte Rudman et al., 2012; Brennan et al., 2001; Wong et al., 2004; Moore & Miller, 2003)

- Disruption in self-identity and social identity  
  (Laliberte Rudman, 2002; Spafford et al., 2010; Laliberte Rudman, 2006; Martin et al., 2010;; Laliberte Rudman et al., 2012; Charmaz, 2002)

Importance:

- Identity linked with well being  
  (Christiansen, 1999; Teitelman & Copilillo, 2005; Laliberte Rudman, 2002; Charmaz 1983)
Literature Review

What is missing?

Processes of negotiating assistance from informal support networks and maintaining acceptable identities
Explore the processes through which older adults with ARVL negotiate the increasing need to rely on informal support networks and maintain acceptable identities.
How do older adults with age-related vision loss (ARVL) negotiate their increasing need to rely on their informal support networks while maintaining acceptable self-identity and social identity?
Methodology

Primary Study

- “Older Adults’ Lived Experience of Age-Related Vision Loss and the Vision Rehabilitation Process: Service and Environmental Influences on Participation and Social Inclusion”
- Qualitative, constructivist grounded theory
- Completed in 2011
## Methodology

### Primary Study - Participants

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<td><strong>Mean Age at Time of Primary Study</strong></td>
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<tr>
<td><strong>Mean Age when ARVL began to Limit Function</strong></td>
<td>~70</td>
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Methodology

Current Study

- Secondary analysis
  - 62 transcripts - interviews and phone diary calls from London and Toronto, Ontario
- Constant comparison
- Memo-writing
- Modified constructivist grounded theory approach (Charmaz, 2006)

- Nvivo 10 software
Guiding Theoretical Framework

- **Symbolic Interactionism** *(Blumer, 1969)*
- Informs constructivist grounded theory
- **3 premises**
  - Human beings act towards things based on meaning
  - Meaning is created through social interaction
  - Meanings are interpreted and modified
Data Analysis

Coding process

- Initial coding
- Focused coding
- Preliminary categories
- Main categories
Data Analysis

Strategies for rigour

- Reflexive journals
- Meetings
- Triangulation
- Prolonged engagement with data
- Audit trail
Learning to live with ARVL

- Acknowledging the value of informal supports
- Maintaining continuity of roles and occupations
- Managing public perceptions

Experiencing a shift in occupational repertoire

- Facing changes in community access
- Avoiding certain situations and occupations
- Prioritizing requests for assistance

Findings

Negotiating support from others and maintenance of acceptable identities
Category 1: Learning to Live with ARVL
Findings

Category 1: Learning to Live with ARVL

I. Acknowledging the Value of Informal Support

It’s really hard, still hard uh...getting used to it a bit, but still have to have my wife do everything pretty well, like uh...sure as Hell couldn’t live by myself, so again that’s my wife that’s doing everything for me and helping me....

Mike, 74
Findings

Category 1: Learning to Live with ARVL

II. Maintaining Continuity of Roles and Occupations

So it’s, it’s, like you see in my books, I write with big letters and stuff like that...But uh...I hope I never, I, I just hope that I can always see enough to be able to write...Cause someday those kids are going to love those poems.

Deborah, 69
Findings

Category 1: Learning to Live with ARVL

III. Managing Public Perceptions

I was at a barbeque yesterday and people said, “You look dazed”. Well, I’m not dazed I’m just can’t, I said, “I’m sorry but I just can’t find where I was and it’s taking me a little of time but they don’t understand that and I think that I just try and keep educating those people and that’s not, I’m not drunk, I’m not dazed, I just don’t see what I’m looking for.

Hazel, 71
Findings

Category 2: Experiencing a Shift in Occupational Repertoire
Findings

Category 2: Experiencing a Shift in Occupational Repertoire

I. Facing Changes in Community Access

I’m scared that I’m going to bump into something….because this has happened too, I see the stuff when it’s more close to me….so I’m a little worried about that, it’s better to stay in my own places.

Denise, 83
Findings

Category 2: Experiencing a Shift in Occupational Repertoire

II. Avoiding Certain Situations and Occupations

“Well, why, why don’t you want to go?” And I said, “Well it’s because I can’t see that well” (laughs), like I get this in my head, I can’t see that well, so I won’t recognize some of the people that I should know there.

Donna, 79
Findings

Category 2: Experiencing a Shift in Occupational Repertoire

III. Prioritizing Requests for Assistance with Occupations

I try not to call them, I try to be as independent as I possibly can. I only call if it’s something I really can’t do myself...I just don’t want to be a burden you know?...When I die, I want them to say, “Well I’m sorry she’s gone”, I don’t want them to say, “Well thank God for that, she was such a nuisance”.

Marilyn, 83
Discussion
Discussion
Findings in Context of Recent Literature

- Asking for assistance is challenging (McGrath & Laliberte Rudman, 2013; Teitelman & Copolillo, 2005; Wong et al., 2004)
- Older adults are committed to maintaining independence (McGrath & Laliberte Rudman, 2013)
- Older adults limit requests for assistance (McGrath & Laliberte Rudman, 2013; Teitelman & Copolillo, 2005)
- Identity is created in a social context (Christiansen, 1999)

Negotiating support from others depends on impact on self identity and social identity
Discussion
Findings in Context of Recent Literature

- Older adults with ARVL may restrict or eliminate certain activities (Brennan et al., 2001)
- Avoidance of social occupations (Teitelman & Copolillo, 2005)
- Restrictions in community access (McGrath & Laliberte Rudman, 2013)
- Meaning emerges from occupations that are central to self-identity (Shank & Cutchin, 2010)

Maintaining acceptable self identity and social identity impacts occupational repertoire
Discussion

Implications

- Gain a deeper understanding of the processes through which older adults negotiate assistance from informal support networks and acceptable identities
- Provide clinicians and caregivers with a deeper understanding of the functional and emotional needs of older adults with ARVL
- Contribute to rich descriptions of the lived experiences of older adults with ARVL as they relate to identity maintenance
Discussion

Limitations

■ Focus of primary study
■ No member-checking
■ No access to full data set
■ Time constraints
Discussion

Relevance to occupational therapy

Findings provide occupational therapists with further insight into...

- How self and social identities are tied to occupations of older adults with ARVL
- Why older adults with ARVL accept or reject assistance from informal support networks
Discussion

Future Directions

- Explore identity and ARVL:
  - Why does identity maintenance take precedence over accepting assistance?
  - What would help them maintain satisfactory self and social identities?
- Caregiver perspectives
- Cultural considerations
- Geographical considerations
Key messages
Our findings suggest...

1. ...that adaptation to ARVL involves a complex negotiation of support from others and identity maintenance
2. ...that seeking to maintain acceptable identities takes precedence over accepting assistance
3. ...that a desire to maintain acceptable identities may result in a shrinking occupational repertoire
Conclusion

http://www.wycokck.org/uploadedImages/Departments/Health/Senior%20Women.jpg?n=1049
References


Questions?