

Adults Aging with Developmental Disabilities, Perceptions of Health

Nancy Jokinen, MSW, PhD
Post Doctoral Fellow, CERAH

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Presentation

- Literature / Background
- Study: *Family Quality of Life In The Context of Aging & Intellectual Disability*
- Health-Related Findings
- Implications
- Conclusion

Literature / Background

- Adults with DD
 - 1st Cohort to Age in Significant Numbers
- Scant Canadian Research on this Group
- Other Countries
 - Leading Cause of Death - CVD
 - Some Age-related Changes
 - Syndrome Specific - Predominately DS
 - Associated Conditions
 - Little - Nutrition, Exercise, Health Promotion

REFERENCES

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- Ouellette-Kuntz, H., Garcin, N., Lewis, M., Minnes, P., Martin, C., & Holden, J. (2005). Addressing health disparities through promoting equity for individuals with intellectual disability. *Canadian Journal of Public Health, 96*(S2), S8-S22.

Family Quality of Life Study

Purpose:

To Explore & Describe Perceptions of FQoL Held by Older-Aged Family Members

- Age Criteria: Person with DD, 40+

Mixed Methods

- Interviews (19)
- Focus Groups (7)
- FQoL Survey (Brown, et al 2006) (26)

FQoL Study

Interviews / Focus Groups

- Past , Present, Future Hopes

FQoL Survey – Parents / Siblings

- 9 Domains across 6 Dimensions
- Health - Importance, Opportunity, Initiative, Attainment, Stability, Satisfaction

Data Analysis

- Qualitative / Quantitative
- Synthesis of Findings

Participants (44)

20 Parents

- 60-91 yrs; MA 76.7 (*SD* 8.80)

12 Siblings

- 43-69 yrs; MA 54.4 (*SD* 8.10)

12 Adults with ID

- 43-60 yrs, MA 49.6 (*SD* 4.98)

Living Arrangement

- Separate/Together

Abilities & Service Use

- Varied

Highlights of Health Findings

Health Considered Very Important

- Changes in health status changed family priorities / focus / arrangements

“You know with my parents aging... the emphasis is almost turning towards them and their care and their concerns.” JI3S

- Sudden Changes for Co-Resident Members

Adults with DD

- Array of Conditions

“You know you don’t know how they age. He’s 50...” IIP1

- Basic Understanding of Health

Reliance on Others

Adults with DD

- Relied on Family or Agency Staff (e.g. Access, Follow Up, Lifestyle Choices)

Parents / Siblings

- Provided Support
- Relied on Agency Staff to Monitor Health of Relative with DD

FQoL – Health Findings

- **Need for Information**
 - Family Members, Adults with DD, Agency Staff
- **Access Issues**
 - Repeat Visits
 - Unrecognized, Untreated Conditions
 - Dental Care
- **Consent for Treatment**
 - Air of Competence
- **Advance Directives / Future Planning**

Sedentary Lifestyle / Lack of Exercise

“I have numerous times suggested that somebody should be making sure these people are getting adequate exercise.” (Sibling)

Nutrition

e.g. Fast Food; Processed / Canned

Medications

“The medication he’s on, he must have a stomach of iron. They don’t seem to bother him. He’s certainly on a lot.” (Sibling)

Implications for

- Policy, Practice, Research, & Education
- Family Physicians
 - Other Healthcare Professionals
- Agency Staff
- Become familiar with DD & age-related changes
- Promote good health & best practices
- Monitor health
- Support access & provide follow-up

Conclusion

“He just might outlive all of us, the whole family” IIP9

- Emerging Population
- Many Issues & Concerns
- Critical Need for Research in a Canadian Context
 - One possible Research Tool:
Rochester Health Status Survey – IV.
Davidson et al
Used to determine & track health status and health care utilization of adults with I/DD

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