

Aging with long-term physical impairment: The significance of social support
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Abstract:

As the population ages more people are reaching old age having lived with a long-term physical impairment. This vulnerable group of people has specific needs that are often different from those of someone who reaches old age without a pre-existing physical impairment. This paper focuses on the significance of social support in ameliorating the aging experience when living with long-term physical impairment. It is based on a qualitative study of the aging experiences of eight men and women living in Ontario, Canada who were between the ages of 50 and 65 and had lived with their physical impairment for more than 10 years. Two participants had impairments on account of multiple sclerosis, two on account of rheumatoid arthritis, one had loss of limb, one had muscular dystrophy, one had hip deterioration from age 12, and one had polycystic kidney disease. Data were gathered through in-depth, semi-structured interviews. The findings suggest that coping with long-term physical impairment may be a lonely experience when the person lacks a strong network of family and/or friends to offer emotional support as they deal with the constant changes that can occur. Participants felt their experiences of aging with long-term physical impairment were improved when they shared their thoughts, feelings and problems with others. The paper also discusses the significance of gender and marital status with regard to access to social support.

Keywords: aging, disability, impairment, social support, gender

Aging with Long-Term Physical Impairment: The Significance of Social Support

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Questions Guiding the Research: Do community-dwelling, middle-aged people with long-term physical impairments/chronic illness feel that they have access to adequate social support? Are there gender differences?



Literature on Physical Impairment and Social Support

- ◆ Significant numbers of people are growing older with pre-existing impairment, and this population continues to increase
- ◆ Easy access to social support helps people cope with physical impairments
- ◆ As people age they are often more willing to accept support from family and friends
- ◆ Evidence suggests that people between 50-65 are especially likely to have inadequate access to social support
- ◆ Problems occur if people do not feel as though they are in a reciprocal relationship
- ◆ Gender differences regarding who people turn to for support:
 - ◇ Women more likely to share feelings with non-family members
 - ◇ Men more likely to rely on family rather than friends
- ◆ We cannot assume that all marriages are supportive
- ◆ Support groups can be beneficial but not all people are interested or have access

Methods

- ◆ Based on qualitative research
- ◆ Purposive sampling design
- ◆ Eight participants aged 50 to 65 who had been living with a long-term physical impairment for over 15 years
- ◆ Each participant interviewed once using a semi-structured, in-depth interview guide

Participant Characteristics

- ◆ 4 women (1 single, 1 widow, 2 married) and 4 men (all married)
- ◆ 7 participants have children
- ◆ Age Range: 51-65 (M=58)
- ◆ Women - Types of impairments/chronic illness: 2 with Rheumatoid Arthritis, 2 with Multiple Sclerosis
- ◆ Men - Types of impairments/chronic illness: Muscular Dystrophy, Polycystic Kidney Disease, Legg-Calvé Perthes Syndrome and Amputated arm



Findings – The Importance of Family and Friends for Women

Women's Experiences

- ◆ Despite having spouses, children, family members and friends, women often feel lonely and rely more on friends than their spouses for support
- ◆ Dorothy (single) attributes her high quality of life to a supportive network of family and friends
- ◆ Carol's husband is deceased but she never relied on him for support. She relies primarily on her sons, mother, siblings who live nearby and personal support workers
- ◆ Victoria and Karli – both married – commented on feeling alone
 - ◇ Victoria felt that she could talk to no one except her internist:
He listens to what you have to say. But to just sit and talk to somebody, I don't talk really to anyone about my health
 - ◇ Karli's husband didn't understand her need to talk to family members who live in the United States
- ◆ Karli received some assistance from community agencies, but not enough. She was not eligible for more assistance because she was married, even though her husband was unable to provide adequate physical support
- ◆ Karli is often unable to leave the house, yet maintains numerous friendships over the telephone and the Internet



Findings – The Importance of Family and Friends for Men

Men's Experiences

- ◆ Unlike the women, the men could rely – without exception – on their spouses for emotional support
- ◆ David, who rarely left his house, praised his wife and worried about her ability to cope
- ◆ Jake tried hard not to rely on anyone and was worried about becoming a burden:
I have often told my wife and son, if something happens that I have to end up in a wheelchair and you have to look after me, then that's the end. No more dialysis. I don't want you to spend the rest of your life looking after me.
- ◆ Mark worried about the strain his impairment had on his wife:
my wife, she was always been strong but I could tell there were times when emotionally she was drained to the max.
- ◆ John tried not to take up too much of his wife's time:
I don't feel like I can say, come here and do this with me every morning. ... she is not here just to serve my needs.
- ◆ John was the only man to speak about relying on his friends for support



Findings – Support Groups – Are they relevant?



- ◆ Only 3 participants had experience with being members of a support group:
 - ◇ John was heavily involved in a support group and spoke about the benefits
 - ◇ Dorothy used to attend an arthritis support group and enjoyed hearing about other people's experiences, but had to quit going because it was too difficult to get there
 - ◇ Karli started a group where she used to live, but she can no longer get out to a group. She participates in online discussion boards relating to her interests
- ◆ Other participants were aware of support groups but didn't believe they would be beneficial for them.

Take-Home Messages



- ✓ Men are more likely than women to turn to a spouse for support
- ✓ Not everyone feels willing or able to ask for help from a spouse. The assumption that spouses can be relied upon for support can lead to community-dwelling individuals having unmet support needs
- ✓ Individuals aging with impairments are immersed in and wish to maintain reciprocal relationships. They do not want to be a burden on family and friends. To maintain independence they will seek assistance from paid support workers
- ✓ Support groups can be helpful but not everyone is able or willing to join a support group. Women are more likely than men to participate in a support group
- ✓ Without a strong network of family and friends, aging with a long-term physical impairment can be lonely