

Participation in society

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Participation in society

In the management and rehabilitation of people with life-long disabling conditions, such as post-polio syndrome (PPS), **participation** is of central importance and often used as one overall long-term outcome

Participation in society

Being able to **participate** in society is thought to be related to a high level of life satisfaction, hence, one main goal of all PPS rehabilitation is to enhance **participation**

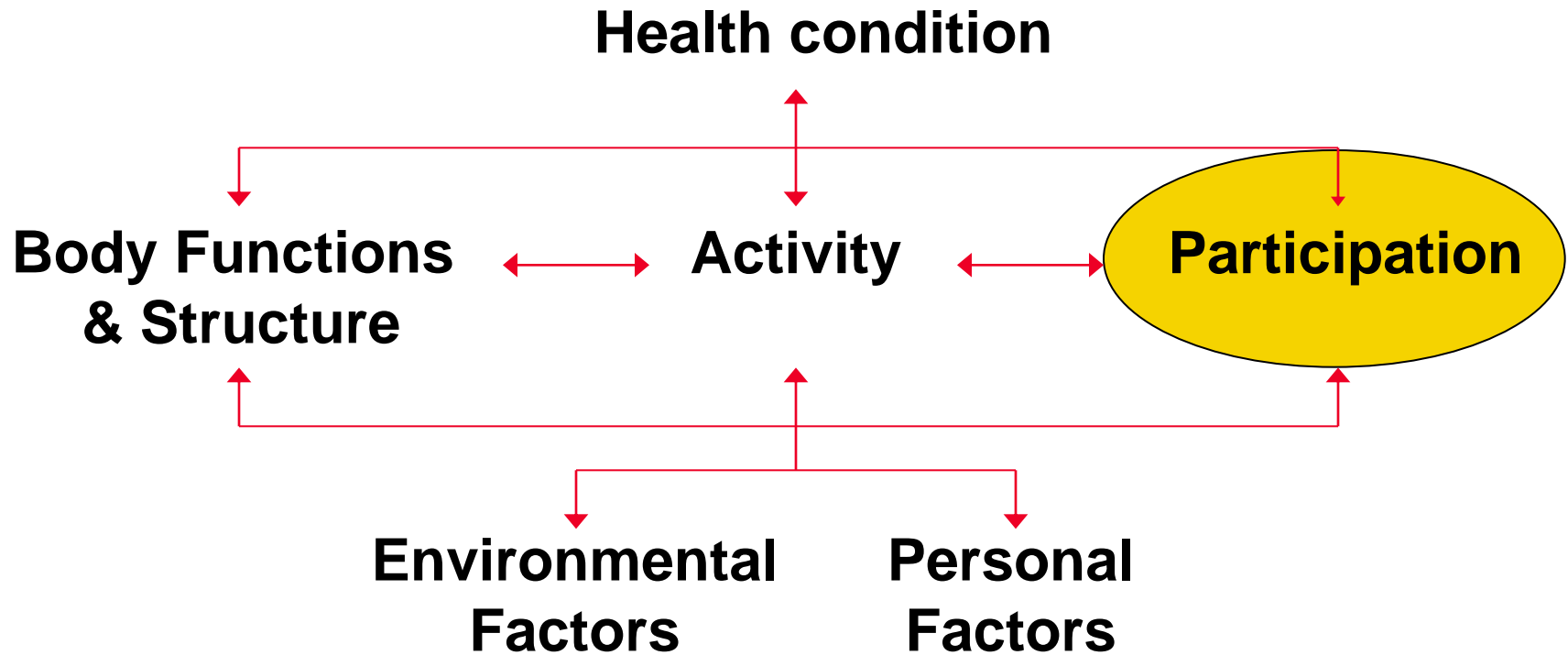
Participation in society

However, our knowledge of **perceived participation** in people with PPS is very limited, and factors that influence **participation** have not been determined

Participation in society

- How is participation defined?
- How can we measure it?
- How is participation perceived by people with PPS?
- How is participation related to other factors in people with PPS?

ICF



WHO International Classification of Functioning, Disability and Health (ICF)

Participation – ICF

...an individual's subjective experiences of involvement in life situations

(the lived experience of people in the actual context they live, and accordingly disabled person's own perceptions of their life situation)

Measuring participation

- Assessment tools based on the definition of participation are now available
- Perceived participation as well as perceptions of problems with participation can now be measured

Impact on Participation and Autonomy

- IPA addresses
 - Perceived participation in 31 items in the domains of
 - autonomy indoors, family role, autonomy outdoors, social relations, work and education
 - Perceived problems with participation in 8 items/areas

Cardol et al. 2001

Impact on Participation and Autonomy

- The items for perceived participation have 5 response options:
 - very good; good; fair; poor; very poor.
- The 3 response options for perceived problems with participation are:
 - no problems; minor problems; severe problems.

Cardol et al. 2001

Impact on Participation and Autonomy

- Autonomy indoors
 - Getting around indoors where one wants
 - Getting around indoors when one wants
 - Washing, dressing, grooming the way one wants
 - Washing, dressing, grooming when one wants
 - Going to bed when one wants
 - Going to the toilet when one needs
 - Eating and drinking when one wants

Cardol et al. 2001

Participation and PPS

- Swedish version of the IPA
- 160 men and women with PPS
 - Mean age 68 years; previously completed a period of interdisciplinary rehabilitation
- Questions about
 - marital status, vocational status, self-estimated walking ability and use of mobility aids, and instrumental support

Larsson Lund & Lexell. Perceived participation in life situations in persons with late effects of polio. J Rehab Med, 2008; 40: 659–664.

Participation and PPS

- Participation was perceived as sufficient in items addressing mobility indoors and self-care, communication, relationship and respect from other people as well as helping and supporting other people

Larsson Lund & Lexell. Perceived participation in life situations in persons with late effects of polio. J Rehab Med, 2008; 40: 659–664.

Participation and PPS

- Less sufficient participation was perceived in the items for heavy housework, repairs and upkeep of the home, going on trips and holidays, getting or keeping a job, getting a different job and, finally, getting training and education

Larsson Lund & Lexell. Perceived participation in life situations in persons with late effects of polio. J Rehab Med, 2008; 40: 659–664.

Participation and PPS

- A large majority of the respondents perceived no or minor problems with various aspects of participation
- A smaller proportion (4–22%) reported severe problems in the 9 items addressing problems with participation

Larsson Lund & Lexell. Perceived participation in life situations in persons with late effects of polio. J Rehab Med, 2008; 40: 659–664.

Participation and PPS

- Reports of insufficient instrumental support were associated with perceived severe problems with participation
- Being male was also associated with the presence of severe problems with participation, whereas age, marital status and the need for mobility aids were not

Larsson Lund & Lexell. Perceived participation in life situations in persons with late effects of polio. J Rehab Med, 2008; 40: 659–664.

Participation and life satisfaction

- Impact on Participation and Autonomy (IPA)
- Life Satisfaction Questionnaire (LiSat-11)
 - level of global satisfaction and level of domain specific satisfaction in 10 items (vocation, economy, leisure, contacts, sexual life, family life, ADL, partner relationship, somatic health and psychological health)

Larsson Lund & Lexell. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. Disabil Rehabil, 2009; 31:1592–1597.

Participation and life satisfaction

- Perceived participation in the IPA-S was significantly correlated with satisfaction with life as a whole and with most of the 10 domains of life satisfaction
- Severe problems with participation corresponded with low levels of life satisfaction

Larsson Lund & Lexell. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. Disabil Rehabil, 2009; 31:1592–1597.

Participation – environmental barriers

- Impact on Participation and Autonomy (IPA)
- Craig Hospital Inventory of Environmental Factors (CHIEF-S)
 - instrument designed to describe peoples' subjective perceptions of the occurrence, frequency, and magnitude of 25 environmental barriers that can restrict them from doing what they need or want to do

Larsson Lund & Lexell. Associations between perceptions of environmental barriers and participation in persons with late effects of polio. Scand J Occup Ther, 2009; 16: 194-204.

Participation – environmental barriers

- Craig Hospital Inventory of Environmental Factors (CHIEF-S)
 - attitudes and support barriers
 - barriers to assistance and services
 - physical and structural barriers
 - policy barriers
 - barriers at work and school

Larsson Lund & Lexell. Associations between perceptions of environmental barriers and participation in persons with late effects of polio. Scand J Occup Ther, 2009; 16: 194-204.

Participation – environmental barriers

- A majority of the persons with PPS encountered environmental barriers, but most only encountered a few, and the magnitude of the barriers was relatively low

Larsson Lund & Lexell. Associations between perceptions of environmental barriers and participation in persons with late effects of polio. Scand J Occup Ther, 2009; 16: 194-204.

Participation – environmental barriers

- The barriers identified in the physical/ structural subscale were most strongly related to problems with participation
- A high frequency of never encountering environmental barriers were significantly related to more reports of good participation

Larsson Lund & Lexell. Associations between perceptions of environmental barriers and participation in persons with late effects of polio. Scand J Occup Ther, 2009; 16: 194-204.

Summary

- People with PPS can perceive sufficient participation with no or minor problems in various aspects of participation
- Support from other people is an important factor for their perception of severe problems with participation

Summary

- Perceived participation and problems with participation in life situations:
 - are determinants of life satisfaction
 - are influenced by the perception of environmental barriers encountered

Conclusion

PPS rehabilitation programs need to focus on areas of participation that are perceived as a problem and promote access to a supportive environment to enhance participation in society and thereby a high degree of life satisfaction