Conceptualizing Participation: Measuring More than Symptoms

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Key Papers


Presentation Objectives:
1. What is meant by participation and why should we bother measuring it?
2. Are participation measures unique? Should we be thinking about them differently?
3. How does a biopsychosocial perspective make a difference in understanding participation?

What is meant by participation and why measure it?

- “Participation” stems from the WHO’s International Classification of Functioning, Disability, and Health (ICF)
- Defined as involvement in life situations
- Problems or difficulties with this involvement are labelled “participation restrictions”
- Other terms include, “social functioning”, “life habits,” “valued activities,” “societal involvement” and “social roles” (Nagi, 1965; Nagi, 1991; Pope & Tarlov, 1991; Fougeyrollas, 1995; Badley 2008; Wilkie et al., in press; Katz & Morris, 2007; Gignac et al., 2008)
• The ICF aims to promote a common language for health and disability

• But, the distinction between “activity” and “participation” is not always clear


Acts/Tasks versus Societal Involvement

Differences In:
1) How automatic and habitual versus purposive and volitional
2) The degree to which contextual factors are important
3) The extent to which they are “social” (i.e., vary culturally, involve others).

Acts/Tasks versus Societal Involvement

• Activities and tasks have a specific, relatively narrow focus
• They are often habitual
• Activities & tasks often don’t involve others

Examples: walking, activities of daily living like dressing, eating, toileting and errands

Participation or Social Roles

• Patterns of behaviour that are taught within a socio-cultural environment
• Complex; no universal list of activities associated with them
• Shape identity; say something about who we are
• Frequently engaged in because of a sense of personal value or necessity
• Often carried out with others

Examples include being a spouse, parent, worker, and leisure roles

Social Role Participation:

• “Broad patterns of purposeful behaviour at the level of societal involvement. Roles are comprised of acts and tasks, but because of their range and diversity, cannot be defined by a universal lists of these acts/tasks. Roles are dependent upon context and because of this context and their diversity, their assessment may be largely subjective.”

A “big thinking” shift in health and disablement

Currently, the focus is:

Health, not only disease
  • Has resulted in the mainstreaming of disability
The impact of health conditions on a person’s life, not just the causes of disease and illness
  • Encourages comparative research on similar metrics (e.g., participation)
The social aspects of disability
  • Biological and medical aspects of health enhanced with the study of personal, social, and environmental factors (i.e., a biopsychosocial model)

“Tell me about yourself”

Are participation measures different or unique compared to other health outcome measures?

Potential Applications of Participation Measures:

• Individual-level applications: Aid in treatment or intervention decisions
• Group-level applications: Understand the impact of a health condition on people’s lives; Compare participation across conditions; Inform gaps in health services; Evaluate service use
• Societal Applications: Inform policy, law (e.g., eligibility for work benefits, discrimination laws, mandate changes to the built environment)

Challenges

1) Diverse items listed in participation measures
2) Variety of concepts captured in existing response keys
3) Time frames used
4) Assessing change over time
Current Participation Domains:

- Domestic life (e.g., caring for others)
- Interpersonal relationships (e.g., intimacy)
- Work and education
- Community and Social life (e.g., volunteer activities, contact with others)
- Hobbies & Leisure pursuits

Missing Data?

Not participating may reflect:

- A participation restriction related to health
- The influence of environmental factors or societal resources
- Personal factors like life stage, personal choice and preferences

The meaning of particular roles may change over time (e.g., parenting)

Response Keys Assessing Participation

- Role importance or salience
- Satisfaction with performance
- Satisfaction with time spent in the role/activity
- Performance as and when an individual would like
- Choice and control in role participation
- Role limitations
- Frequency of engagement
- Desire to change participation
- Participation compared to others/peers

Comparison of Participation Response Keys

1) Role importance/salience
2) Satisfaction with time spent in a role
3) Satisfaction with role performance
4) Role limitations

Sample:

- OA (n = 177); Healthy controls (n = 193)
- All participants aged 40 years or older
- OA (female = 70%); Healthy controls (female = 60%)
- Comparable education, income, marital status
- Recruited using community advertising, clinics; The Arthritis Society (TAS)
- Completed Social Role Participation Questionnaire (SRPQ)
Participation Study

- Role importance/salience not significantly different between the OA and healthy adult groups
- Adults with OA reported significantly greater role limitations and less role satisfaction with performance and time spent in roles

Pearson correlations among role salience, role limitations, and role satisfaction for healthy controls and adults with OA

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<th>Role Importance</th>
<th>Role Limitations</th>
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What’s the Best Time Frame For Recall of Participation?

- Some domains may not shift over the short term (e.g., salience, satisfaction)
- Need to consider both the content and the goal of the measure (e.g., eligibility for interventions)
- Time frames important to assess longitudinal changes (e.g., need to allow time for changes in role occupancy and within a role)
Why is a Biopsychosocial model important to Participation?

Age:
• Frequently a proxy for health and functioning decrements over time
• Older adults report more activity limitations and participation restrictions
• Older adults may have fewer resources (e.g., income, social support)

Life Course Changes:
• Participation will vary in its meaning; depends on what is considered normative at different phases of life
• Middle-aged adults expected to take on greatest range and amount of role responsibilities
• Expect greater participation restrictions among middle-aged adults with osteoarthritis

Role limitations

Role Satisfaction

Multivariate regression analyses examining the relationship of role participation dimensions, age, and health to stress and health-care utilization

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<th>Stress (n = 335)</th>
<th>Health Care Utilization (n = 317)</th>
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<tr>
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<td>Beta (p)</td>
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<tr>
<td>Role salience</td>
<td>0.01</td>
<td>0.12*</td>
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<td>Role limitations</td>
<td>0.24**</td>
<td>0.32***</td>
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<td>Role satisfaction</td>
<td>-0.46***</td>
<td>-0.04</td>
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<td>Age (middle- versus older-aged)</td>
<td>0.16***</td>
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<td>Health (healthy controls versus adults with OA)</td>
<td>-0.14*</td>
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Note: * p < .05, ** p < .01, *** p < .001

Summary

1) The meaning of participation may vary by life phase (also other contextual factors like gender, education, culture, etc.)

2) Participation should be examined using a range of response keys (e.g., performance, importance, satisfaction, limitations, etc.)

3) Health outcomes like depression, stress, and health care utilization may be partly explained by role participation

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