Current status of participation measures

Dr Ross Wilkie
Research Fellow in Epidemiology

Key papers


Content

- Social participation in community-dwelling older adults with joint pain
  - prevalence
  - potential determinants of restriction
  - implications for practice
- Review of instruments

Part 1: Epidemiology of social participation

Disclosure

- No commercial interests to disclose

Where is Keele?
Development of the KAP

- Systematic review: no existing instruments could measure participation restriction exclusively* 
- Keele Assessment of Participation (KAP) was developed**
- Qualitative and quantitative testing of the psychometric properties of the KAP**

** Wilkie et al., Qual Life Res 2005;14:1889-99

Keele Assessment of Participation: Mobility outside the home

During the last 4 weeks, I have moved outside my home, as and when I have wanted?

All the time Most of the time Some of the time A little of the time None of the time

Participation Participation restriction

Wilkie et al., Qual Life Res 2005;14:1889-99

Prevalence of restriction

No joint pain (n=1762) Knee pain (n=4060)

0 restriction 1-3 restrictions 4-6 restrictions 7-11 restrictions

Prevalence of restriction

No joint pain (n=1762) 1 joint pain (n=1796) 2 joint pains (n=1652) 3 joint pains (n=1297) 4 joint pains (n=898)

0 restriction 1-3 restrictions 4-6 restrictions 7-11 restrictions
Prevalence of any participation restriction for those with knee pain

- **Age band (yrs)**: 50-59, 60-69, 70-79, 80+
- **Prevalence (%)**:
  - Men: 70-80
  - Women: 70-80

Prevalence of restriction for those with knee pain aged 50 and over (n=4060)

- **Percentage (%)**:
  - Mobility: 0-5%
  - Self-care: 0-5%
  - Looking outside the home: 0-5%
  - Interpersonal: 0-5%
  - Managing: 0-5%
  - Work: 0-5%
  - Education: 0-5%
  - Social: 0-5%
  - Home: 0-5%
  - Home belongings: 0-5%
  - Dependents: 0-5%

Prevalence of restriction for those with knee pain aged 50-59 (n=1235)

- **Percentage (%)**:
  - Mobility: 0-5%
  - Self-care: 0-5%
  - Looking outside the home: 0-5%
  - Interpersonal: 0-5%
  - Managing: 0-5%
  - Work: 0-5%
  - Education: 0-5%
  - Social: 0-5%
  - Home: 0-5%
  - Home belongings: 0-5%
  - Dependents: 0-5%

Prevalence of restriction for those with knee pain aged 80 and over (n=534)

- **Percentage (%)**:
  - Mobility: 0-5%
  - Self-care: 0-5%
  - Looking outside the home: 0-5%
  - Interpersonal: 0-5%
  - Managing: 0-5%
  - Work: 0-5%
  - Education: 0-5%
  - Social: 0-5%
  - Home: 0-5%
  - Home belongings: 0-5%
  - Dependents: 0-5%

Determinants

- 712 (32%) indicated that they were restricted in their mobility outside the home in the knee pain group.
Potential determinants

- Condition specific characteristics
- Physical limitation
- Psychological factors
- Demographic
- Socio-economic factors
- Environmental factors

Univariate associations
Knee pain severity

Potential determinants

- Over 80
- Cognitive impairment
- “Underweight”
- Depression
- Difficulty walking half a mile
- Difficulty climbing one flight of stairs
- Requirement of aids/assistance
- Poor access to public transport

Adj. OR (95%CI)

- Over 80 3.2 (1.9, 5.3)
- Cognitive impairment 1.6 (1.1, 2.3)
- “Underweight” 3.1 (1.4, 6.8)
- Depression 3.3 (2.0, 5.5)
- Difficulty walking half a mile 6.3 (3.9, 10.0)
- Difficulty climbing one flight of stairs 4.1 (2.5, 7.0)
- Requirement of aids/assistance 2.6 (1.9, 3.7)
- Poor access to public transport 2.1 (1.3, 3.4)

Adj. OR (95%CI)

- Over 80 3.2 (1.9, 5.3)
- Cognitive impairment 1.6 (1.1, 2.3)
- “Underweight” 3.1 (1.4, 6.8)
- Depression 3.3 (2.0, 5.5)
- Knee stiffness severity 1.8 (1.0, 3.3)
- Difficulty walking half a mile 6.3 (3.9, 10.0)
- Difficulty climbing one flight of stairs 4.1 (2.5, 7.0)
- Requirement of aids/assistance 2.6 (1.9, 3.7)
- Poor access to public transport 2.1 (1.3, 3.4)

Restriction increases over time with increasing pain

<table>
<thead>
<tr>
<th>Change in pain intensity</th>
<th>Regional pain (n=2188) RR (95%CI)*</th>
<th>Widespread pain (n=1260) RR (95%CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change/decrease</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>One unit increase</td>
<td>1.7 (1.6, 1.8)</td>
<td>2.6 (2.3, 2.9)</td>
</tr>
<tr>
<td>Two unit increase</td>
<td>3.6 (3.5, 3.7)</td>
<td>6.0 (5.7, 6.4)</td>
</tr>
</tbody>
</table>

* adjusted for all fixed (gender and baseline measures of age, education and occupational class) and time dependent factors (BMI, physical function, cognitive impairment, financial strain, social network, number of health conditions, number of impairments, anxiety & depression)

Contribution of multiple peripheral joint pain to participation restriction

Potential determinants: Psychological status

- Over 80
- Cognitive impairment
- “Underweight”
- Depression
- Knee stiffness severity
- Difficulty walking half a mile
- Difficulty climbing one flight of stairs
- Requirement of aids/assistance
- Poor access to public transport

Adj. OR (95%CI)

- Over 80 3.2 (1.9, 5.3)
- Cognitive impairment 1.6 (1.1, 2.3)
- “Underweight” 3.1 (1.4, 6.8)
- Depression 3.3 (2.0, 5.5)
- Knee stiffness severity 1.8 (1.0, 3.3)
- Difficulty walking half a mile 6.3 (3.9, 10.0)
- Difficulty climbing one flight of stairs 4.1 (2.5, 7.0)
- Requirement of aids/assistance 2.6 (1.9, 3.7)
- Poor access to public transport 2.1 (1.3, 3.4)
### Socio-economic factors: Income adequacy

- **Income adequacy**

  - **Perceived adequacy of income**
    - Odds Ratio
    - Comfortable
    - Little difficulty
    - Some difficulty
    - Little adequacy

### Potential determinants: Environmental factors

- **Requirement for aids/assistance**
  - No: 1
  - Yes: 15.2 (11.9, 19.4)

- **Poor access to public transport**
  - No: 1
  - Yes: 11.7 (8.3, 16.5)

- **Poor access to a car**
  - No: 1
  - Yes: 1.8 (1.4, 2.2)

### Pathways

- **Knee pain** → **Difficulty walking half a mile** → **Restricted participation**

### Factors linked with restricted participation in older adults with knee pain

- **Comorbidity**
  - Difficulty walking
  - Participation restriction

- **Age**
  - Requirement for aids/assistance
  - Poor access to public transport
  - Poor access to a car

- **Wilkie et al., Arthritis Rheum 2007**

### Prevalence of adults participating “as and when they want”

- **Difficulty walking half a mile**
  - Yes, a lot of difficulty
  - Yes, a little difficulty
  - No difficulty

- **Prevalence (%)**
  - Good access
  - Poor access
To assist the selection of an instrument to measure participation and social function in clinical practice or research

Selection of instruments
- Two observers reviewed all instruments for inclusion in the review
- Instruments were included if they
  a. were developed to measure participation or social function in adult populations
  b. did not include items to measure additional constructs to participation/social function
  c. could be easily obtained and did not require purchase
  d. had published evidence of psychometric testing

Review of instruments
Each instrument was reviewed by two observers (three pairs)
- Origins
- Applicability
- Psychometric properties
- Quality of psychometric testing
  (using the COSMIN checklist (Mokkink et al., 2010))
- Appraisal of its value to musculoskeletal clinical practice or research

Method
- Literature search of MEDLINE & EMBASE
- Search terms – participation, social, adaptation, community integration
  - combined with questionnaire, interview, measure, measurement, instrument, evaluation, survey, assessment, scale, index, impact, rating and profile
- First search – Review papers
- Second search – New instruments
Results

- 37 instruments were identified by searches
- 28 instruments were excluded because they included items that did not measure participation or were not freely available.
- 3 were removed, as at the time of the review investigation of psychometric properties had not been published as peer-reviewed articles
- 6 instruments had undergone sufficient psychometric testing to assess their applicability in clinical practice or research

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Definition of participation?</th>
<th>Administration</th>
<th>Number of items</th>
<th>Evidence for use in clinical practice/research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on Participation and Autonomy (Goddard et al., 2001)</td>
<td>Choice and control</td>
<td>Self-complete questionnaire</td>
<td>23</td>
<td>Clinical practice &amp; research</td>
</tr>
<tr>
<td>Keele Assessment of Participation (Wike et al., 2005)</td>
<td>Performance “as and when you want”</td>
<td>Self-complete questionnaire</td>
<td>11</td>
<td>Research</td>
</tr>
<tr>
<td>Participation Measure for Post-Acute Care (PitPAC) (Gardite et al., 2007)</td>
<td>Limitation</td>
<td>Interview</td>
<td>51</td>
<td>Clinical practice (although difficult to interpret scores)</td>
</tr>
<tr>
<td>Participation Objective, Participation Subjective (Brown et al., 2004)</td>
<td>Frequency Satisfaction</td>
<td>Self-complete questionnaire or interview</td>
<td>78</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>Rating of Perceived Participation (ROPP) (Sandstrom &amp; Lund-Olsson, 2007)</td>
<td>Perceived and desire to change</td>
<td>Self-complete questionnaire</td>
<td>60</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>The Participation Scale (Brook et al., 2008)</td>
<td>Compared to a “peer norm”</td>
<td>Interview</td>
<td>18</td>
<td>Clinical practice</td>
</tr>
</tbody>
</table>

POPS

- 5 domains
  - domestic life (8 activities)
  - interpersonal interaction (8 activities)
  - major life (8 activities)
  - transportation (2 activities)
  - community/recreational and civic life (5 activities)

- There are 3 questions for each activity
  1. frequency of engagement (objective)
  2. how important engagement in the activity is (subjective)
  3. would you like to change the current level of engagement (subjective)

ROPP

- 9 domains covered
  - personal care, mobility, communication, social relationships, domestic life and caring for others, education, work and employment, economic life and social and civic life

- Total of 22 statements
- Each statement has 3 questions
  - perceived participation/restriction
  - satisfaction
  - need for support to change participation level

Instruments

- Impact on Autonomy and Participation
- Keele Assessment of Participation
- Participation Measure for Post-Acute Care
- Participation Objective, Participation Subjective
- Rating of Perceived Participation
- The Participation Scale
- Social Role Questionnaire
- Valued Life Activities Questionnaire
Factors linked with restricted participation in older adults with knee pain

- Comorbidity
- Knee Pain severity
- Depression
- Underweight
- Cognitive impairment

Requirement for aids/assistance
- Poor access to public transport
- Poor access to a car

Age

Restricted mobility outside the home

Wilkie et al., Arthritis Rheum 2007

Summary

- Participation restriction is common in older adults with joint pain
- Participation restriction is multiply determined through health, socio-demographic and environmental factors
- Participation can be maintained even in the presence of impairments and activity limitation
- Demographic, socio-economic and environmental factors are important

Assessment of participation restriction

- Keele Assessment of Participation (Wilkie et al., Qual Life Res 2005;14:1889-99)
- Social Role Participation Questionnaire (Gignac et al., J Rheumatol 2008;35:1655-36)
- Disease Repercussion Profile (Carr, Br J Rheumatol 1996;35:921-32)
- Impact on Participation and Autonomy (Cardol et al., Clin Rehabil 1999;13:411-9)
Area-level measures

- Index of Multiple Deprivation: 7 domains
  - Income deprivation
  - Employment deprivation
  - Health deprivation and disability
  - Education, skills and training deprivation
  - Barriers to Housing and services
  - Living environment deprivation
  - Crime

(Office of the Deputy Prime Minister, 2004)

- 34,482 areas in England: mean population = 1500
- 99 local areas were included in this analysis

Onset of work restriction

- 493 adults aged 50 to 59 with lower limb joint pain who remained in employment
- 81 (16.4%) indicated work restriction at three years

Individual factors: Multivariate analysis

<table>
<thead>
<tr>
<th>Factor</th>
<th>Adj. OR (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comorbid pain</td>
<td>3.0 (1.1, 8.0)</td>
</tr>
<tr>
<td>Aged 55-59</td>
<td>2.1 (1.2, 3.8)</td>
</tr>
<tr>
<td>Depression</td>
<td>2.2 (0.9, 5.1)</td>
</tr>
<tr>
<td>Requirement for aids/assistance to mobilise</td>
<td>2.0 (0.4, 9.0)</td>
</tr>
<tr>
<td>School education only</td>
<td>1.6 (0.8, 3.5)</td>
</tr>
<tr>
<td>Severe lower limb joint pain and disability</td>
<td>1.5 (0.8, 2.7)</td>
</tr>
<tr>
<td>Underweight</td>
<td>1.4 (0.2, 13.3)</td>
</tr>
</tbody>
</table>

Area-level factors: Multivariate analysis

Employment deprivation

<table>
<thead>
<tr>
<th>Deprivation Level</th>
<th>Adj. OR* (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Least deprived</td>
<td>1</td>
</tr>
<tr>
<td>Mid</td>
<td>1.5 (0.7, 3.3)</td>
</tr>
<tr>
<td>Most deprived</td>
<td>1.8 (0.7, 4.6)</td>
</tr>
</tbody>
</table>

*Adjusted for health, demographic, socioeconomic and environmental factors

Interactions: Age & Employment deprivation

<table>
<thead>
<tr>
<th>Age Group &amp; Deprivation</th>
<th>Adj. OR* (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-54 &amp; Least deprived</td>
<td>1</td>
</tr>
<tr>
<td>50-54 &amp; Mid deprived</td>
<td>3.5 (0.8, 16.0)</td>
</tr>
<tr>
<td>50-54 &amp; Most deprived</td>
<td>3.5 (0.7, 18.8)</td>
</tr>
<tr>
<td>55-59 &amp; Least deprived</td>
<td>4.5 (0.9, 24.3)</td>
</tr>
<tr>
<td>55-59 &amp; Mid deprived</td>
<td>5.3 (1.2, 23.9)</td>
</tr>
<tr>
<td>55-59 &amp; Most deprived</td>
<td>6.1 (1.2, 31.2)</td>
</tr>
</tbody>
</table>

*Adjusted for health, demographic, socioeconomic and environmental factors