Learning Objectives

- Define social and community participation (measurement)

- Review social and community participation prevalence estimates

- Discuss current evidence on promoting participation among older adults with arthritis

- Identify and discuss gaps in the field and next steps to move the field forward
Definition: Community, Recreational and Social Participation

- Engaging in social or community associations organized by people with common interests, such as social clubs, religious entities, professional associations
- Interpersonal relationships (intimate, family, others)
- Recreational and leisure activities

Measurement: Social, Recreational and Community Participation

- Self-report
  - Performance: “how often do you do...”; “how much time do you spend”; “as and when you want”
  - Capacity: “how limited are you...”
  - Subjective/evaluative: “satisfaction,” “desire to change participation”
  - Comparative: compared to “peer norms”
Participation Measures

- Impact on Participation and Autonomy (IPA)
- Keele Assessment of Participation (KAP)
- Participation Measure for Post-Acute Care (PM-PAC)
- Participation Objective, Participation Subjective (POPS)
- Rating of Perceived Participation (ROPP)
- The Participation Scale
- Late-Life Disability Instrument (LLDI)
- SLE-FAMILY (focus family role)


Prevalence: Social, Recreational and Community Participation
**Prevalence: Social & Community Participation Restriction**

- 6% adults age 50+ in National Health Interview Survey 2002 with arthritis reported “participation restriction” vs. 3.4% total sample (Theis & Furner J Aging Res 2011)

- 41% of volunteers state that arthritis limits their involvement; among non-volunteers 27% state arthritis is the main barrier to volunteering (Theis et al. Arthritis Care Res 2010)

**Prevalence continued**

- National clinical sample of adults with rheumatoid arthritis
  - ~ 50% of subjects unable to do at least 1 valued life activity
  - 95% reported that at least one valued life activity was affected by rheumatoid arthritis
  - Activities most frequently impacted:
    - Heavy housework; minor repairs; paid work; gardening; vigorous and moderate physical activity; and hobbies

Prevalence Participation Restriction
Community Dwelling Adults Age 50+ in United Kingdom (N=7,878) 
Wilkie et al, Qual Life Res 2006

Percent Social Activities Restricted among Persons waiting for Joint Replacement (N=413) 
Social Role Salience among Older Adults with Hip or Knee OA (N=87)

5 Extremely important
1 Not at all important

Social Role Salience & Satisfaction among Older adults with Hip and Knee OA (N=87)

5 extremely important/satisfied
1 Not at all important/satisfied

Social Role Salience & Satisfaction among Older adults with Hip and Knee OA (N=87)


5 extremely important/satisfied
1 Not at all important/satisfied

Global
Relations
Physical leisure
Travel or vacation
Hobbies
Intimate...
Casual contact...
Social events
Community
Employment

- Salience
- Satisfaction with Time Spent
- Satisfaction with Role Performance

Incidence

- Multicenter Osteoarthritis-Knee Pain and Disability Study
  - ~18% of adults age 65+ with symptomatic knee pain and functional limitations without participation restriction at baseline (N=294) developed participation restriction (Late-Life Disability Instrument) at 30-months (Keysor et al. ACR/ARHP 2010)

- Community dwelling United Kingdom adults (N=6965)
  - ~30% of sample without participation restrictions at baseline developed participation restriction in at least one item on the Keele Assessment of Participation at 3-year follow-up
    - Mobility outside the home greatest incidence
Relationships Among Body Systems, Activity and Participation

Severity of physical symptoms → Activity Limitations → Participation Restriction

ICF Contextual Factors

Person Factors: Motivations, Coping, Attitude

Body Structure and Function → Activity → Participation

Environment

Adapted from WHO ICF Model, 2001
Multicenter Osteoarthritis Study: Knee Pain and Disability (MOST-KPAD) Ancillary Study

- 443 participants age 65+ with functional limitations from the MOST Study
  - MOST: Longitudinal cohort of 3026 community-dwelling adults age 50+ with symptomatic knee osteoarthritis (OA) from Alabama and Iowa City
  - Baseline MOST data collection: demographics, knee pain, x-rays, MRI, strength, function
  - Baseline and 30-month f/u KPAD data: environment (HACE); participation (Late-Life Disability Instrument)

Keysor et al., J Gerontology Med Sci 2010

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Home and Community Environment Survey (HACE)

*To what extent does your local community have....*

<table>
<thead>
<tr>
<th>BARRIER PRESENT</th>
<th>FACILITATOR PRESENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Uneven sidewalks or other walking areas A LOT/SOME</td>
<td>1. Public transportation close to home A LOT/SOME</td>
</tr>
<tr>
<td>2. Parks &amp; walking areas used for exercise NONE</td>
<td>2. Public transportation with adaptations A LOT/SOME</td>
</tr>
<tr>
<td>3. Curbs with curb cuts NONE</td>
<td></td>
</tr>
</tbody>
</table>

Keysor, Jette, & Haley (2005)
**Multicenter Osteoarthritis Study Knee Pain and Disability (MOST-KPAD) Cross-Sectional Associations (N=435)**

<table>
<thead>
<tr>
<th></th>
<th>Limitation Participation</th>
<th>Frequency Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adjusted OR (95% CI)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>2.0 (1.2-3.1)</td>
<td>1.4 (0.9-2.4)</td>
</tr>
<tr>
<td>Facilitators</td>
<td>0.5 (0.3-0.8)</td>
<td>0.8 (0.5-1.4)</td>
</tr>
</tbody>
</table>

*Adjusted age, gender, education, comorbidity body mass index, knee pain and functional limitation

Keysor et al. J Gerontol 2010

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**Self-Report Environment: Small Association**

- Community dwelling older adults: availability of transportation factors associated with increased community mobility (Wilkie et al. Arth Rehum 2007)
- 4 cross-sectional clinical samples
  - Persons s/p Stroke (Rochette A. et al. 2001)
  - Persons s/p traumatic brain injury (Whiteneck GG. et al. 2004)
  - Persons s/p spinal cord injury (Whiteneck GG et al. 2001)
  - General rehabilitation population (Keysor et al., 2010)
But does it *predict* participation?

MOST-KPAM Study Incident 30-Month Participation Restriction

294 Persons at Baseline
No/Mild Participation Restriction

240 (82%) No Participation Restriction
54 (18%) Developed Participation Restriction

Keysor et al. ACR/ARHP 2010
## Odds of Developing 30-Month Participation Restriction by Community Mobility Barriers

*Adjusted age, sex, race, education, body mass index, knee pain, walking speed, depressive symptoms and site

<table>
<thead>
<tr>
<th>Subjects Developing Participation Restriction N (%)</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted OR* (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Mobility Barriers</td>
<td>33/215 (15)</td>
<td>1.0</td>
</tr>
<tr>
<td>High Mobility Barriers</td>
<td>21/79 (27)</td>
<td>1.9 (1.1-3.7)</td>
</tr>
</tbody>
</table>

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## Odds of Developing 30-Month Participation Restriction by Transportation Facilitators

*Adjusted age, sex, race, education, body mass index, knee pain, walking speed, and site

<table>
<thead>
<tr>
<th>Subjects Developing Participation Restriction N (%)</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted OR* (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Transportation Facilitators</td>
<td>23/109 (21)</td>
<td>1.0</td>
</tr>
<tr>
<td>High Transportation Facilitators</td>
<td>31/185 (17)</td>
<td>0.8 (0.4-1.4)</td>
</tr>
</tbody>
</table>
Interventions to enhance social, recreational, and community participation among community dwelling adults with arthritis…

- Interventions (exercise, self-management, pharmaceutical)
  - Participation outcomes not primary outcomes in current literature
  - Will these approaches change participation?

Summary: Where are we?

- Conceptual definitions clearer; measurement advances
- Participation restrictions are present in the population
- People with arthritis at risk of incident participation restriction
- Limited evidence-based approached to enhance social and community participation
Where do we go next?

- Continued advances in measurement
- Establish effective approaches to promote social, recreational and community participation
- Establish effective approaches to prevent social, recreational, and community participation restriction

NIDRR PR/Award #H133B100003

Thank you!
So participation…Where are we? Where do we need to go?

Where are we?

- Gaining conceptual clarity of participation concepts (measurement advances)
- Increasing recognition that participation is an important outcome
- Some evidence that work participation interventions are effective
- Gaining perspectives on participation at the community level
Where do we need to go?

- Continued measurement advances
- Better understanding of participation outcomes and high risk groups
- Identify effective approaches to prevent and minimize participation restrictions
  - Who delivers the intervention
  - Which people are most likely to benefit
  - When do we intervene