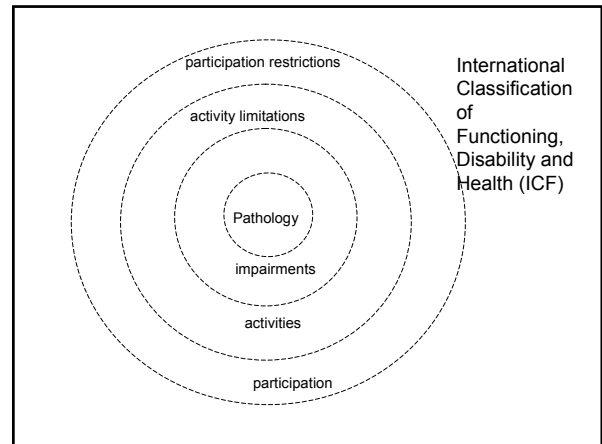


PARTICIPATION IN HOUSEHOLD AND COMMUNITY: MEASURED OBJECTIVELY, SUBJECTIVELY OR BOTH?



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International Classification of Functioning, Disability and Health (ICF)

Pathology	TBI
↓	↓
Impairment	attention deficits
↓	↓
Activity (limitation)	problems calculating
↓	↓
Participation (restriction)	loss of accountant job

Pathology	Stroke
↓	↓
Impairment	plegia left arm
↓	↓
Activity (limitation)	grasping problems
↓	↓
Participation (restriction)	stop knitting for leisure

- ### Participation: definition
- ICF: involvement in a life situation
    - Learning and applying knowledge
    - General tasks and demands
    - Communication
    - Mobility
    - Self-care
    - Domestic life
    - Interpersonal interactions and relationships
    - Major life areas (Education, Work, Economic life)
    - Community, social and civic life

### Some differences between body functions, activities and participations

	Different by age/ gender	Different by culture	Individual choice	Impact on SWB
Body functions	√	-	-	√
Activities	√	√	√	√
Participations	√	√	√	√

### More-or-less the same as participation:

- Community integration
- Social integration
- Independent living
- Handicap (ICIDH)
- Social adjustment
- Instrumental ADLs
- Extended ADLs

### Some measures of participation

- Craig Handicap Assessment and Reporting Technique (CHART)
- Community Integration Questionnaire (CIQ)
- Assessment of Life Habits (Life-H)
- Frenchay Activities Index (FAI)
- Nottingham Extended ADL
- Adelaide Activities Profile (AAP)
- Groningen Social Disabilities Schedule II (GSDS-II)

### How to measure participation

- Identify relevant items (work, leisure, volunteering, etc.)
- Develop scoring for the items (e.g. from 0=never, to 5=at least every month)
- Determine item scores for persons studied
- Add up item scores to obtain scale total score

	John	Bob
socializing	5	3
leisure	4	3
work	5	2
travel	3	1
church	2	4
	=====	=====
Total score	19	13

### Problems in measuring participation

- What items should be included? What is a normal “portfolio” of household/ family/ community activities/relationships/roles?
  - Work
  - Church activities
  - Civic participation
  - Etc.

### Problems in measuring participation

- What is normal for different age groups? Genders? Social classes? Cultural groups?
- Can we create a single scale to measure participation in all subgroups?

### Problems in measuring participation

- Should some items (work, for instance) have greater weight than others (civic activities, for instance)?
- How much more?

### Problems in measuring participation

- Should the focus be on activities or roles/relationships/statuses?
  - Roles/relationships prescribe/proscribe certain activities
  - Roles/relationships are easier to measure, but may lag behind activities

### Problems in measuring participation

- What is the appropriate metric for activities?
  - Frequency of performance
  - Share of work done
  - Hours spent on performance
  - Nature of setting and of interaction partners
  - Difficulty with performance

### Problems in measuring participation

- When can one claim that level of participation is “abnormal”?
- Participation may be lower than average due to:
  - Impairment(s) and activity limitation(s)
  - Reaction of “society” to impairments and activity limitations (discrimination, etc.)
  - Individual preferences for scope and levels of active involvement in household and community

## PART

- Participation
- Assessment with
- Recombined
- Tools

TBI model systems module project

## Research question:

- CHART, CIQ(-2), POPS, MPAI are participation measures developed by / modified by TBI MS investigators who all think their measure is “the best”
- Can we develop a new measure that
  - Combines the best of the 4 instruments
  - Is only 10-15 items long
  - Is better than any of the parent instruments

### CHART (Craig Handicap Assessment and Reporting Technique)

- Whiteneck et al., 1992
- Based on ICDH - 6 domains
- 47 items, 6 subscales: Physical Independence, Cognitive Independence, Mobility, Productive Activity, Social integration, Economic Self-sufficiency
- CHART-SF: 23 items reproducing CHART subscale scores

### CIQ: Community Integration Questionnaire

- Willer et al., 1994
- TBI MS researchers and consumers
- TBI samples
- 15 items, 3 domains: household, social, productive activities
- CIQ-2 (Dijkers): fix CIQ problems
- 36 items

### POPS (Participation Objective, Participation Subjective)

- Brown et al., 2004
- TBI samples
- 26 \* 3 items:
  - -objective: how often, how many hours
  - (-subjective: importance to life
  - -subjective: satisfaction)
- 5 ICF domains: household, transportation, major life roles, community-recreational, interpersonal

### Nature of CHART, CIQ-2, POPS questions

- How often
- How many hours
- What share of household activities
- How active
- Where work/go to school
- Number of interaction partners
- Nature of persons interacting with

### MPAI (Mayo-Portland Adaptability Inventory) Participation section questions

- How comparable to normal?
  - Productivity
  - Independent living
  - Money management
  - Etc.
- 9 questions total

### PART construction

- Combine CHART-CIQ2-POPS items
- Eliminate duplicates
- Consolidate near-duplicates
- Arrange by domain of life
- Within domain, arrange by question type

## PART data

- 400 interviews, in conjunction with 1/2/5/10<sup>th</sup> anniversary of injury follow-up
- Collapse low-frequency answer categories (>10 cases/category as standard)
- Create 4-5 categories out of continuous variables, 0=never, to 4/5=highest
- Minor major issue: what do with "NA" answers (e.g.: don't have children to take care of): code missing / code 0 / code other?

## PART results

- Item deletion based on content
  - Two CHART scales: Activity level of ICF, more than Participation level
  - CIQ-2 household participation: different conceptual basis
- "Mishmash" of items input to Rasch analysis produced 26-item instrument with:
  - Good item fit (infit, outfit)
  - Adequate person and item separation
  - Adequate item spread throughout scale
  - Very limited category disordering problems

## Standard participation measures:

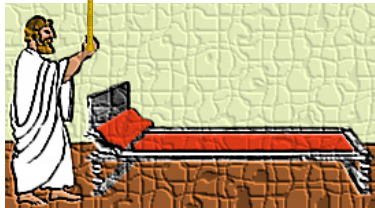
- Include:
  - What
  - How often/how long
- Omit:
  - Freely chosen, under own control?
  - Respected, treated equally?
  - Feelings of "belonging"?
  - Truly contributing?
  - Satisfactory results?
  - Etc.

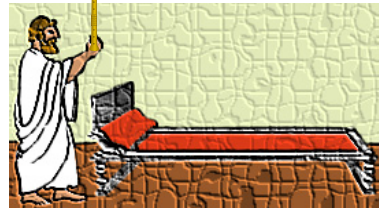
## Standard Participation inventories reflect normative view

- Participation measures are "objective" – yet reflect normative view of white middle class 20<sup>th</sup> century American proper behavior/roles
  - Work: 40 hours per week
  - Parenting: 2 children
  - Church: once per week
  - Etc.

## Standard Participation inventories reflect normative view

- Playing this role may not fit / may not bring happiness to:
  - People with disabilities
  - Other social classes
  - Other time periods
  - Even some who are 2006 US white middle class

Feels like  accommodating



Procrustes' bed

## Objective vs subjective aspects of “participation”

- Is what is done as part of participation, and how much of it is done, in accordance with person’s own values, preferences, needs?
- Does normative participation lead to quality of life (QOL)?

## Quality of life is a balancing act



Well-being, life satisfaction result from a comparison of:

STANDARDS	vs	ACTUALITY
Goals		Roles
Ideals		Relationships
Values		Settings
Priorities		Hours
Needs		

## A new old participation research area

- Subjective/evaluative aspect of participation:
  - is involvement in life situations in accord with the person’s needs, desires, wishes: what, where, with whom, how much
  - Does the person FEEL integrated, respected, valued, etc.

## Community Integration Measure (CIM) (McColl et al., 2001)

- 10 items addressing Assimilation – Support – Occupation – Independent living
- I feel that I am accepted in this community
- I can be independent in this community
- I like where I’m living now
- I know a number of people in this community well enough to say hello and have them say hello back
- There are things I can do in this community for fun in my free time
- Answers:  
always disagree - sometimes disagree – neutral - sometimes agree - always agree

## Cicerone et al., 2004: QCIQ

- Quality of Community Integration Questionnaire
- QCI: 9 questions on satisfaction with household activity / leisure & social relations / vocational situation
- N=56 persons with TBI receiving traditional vs intensive cognitive rehabilitation – post-program scores:
  - QCI unrelated to CIQ

“These findings again suggest that community functioning and satisfaction with functioning are distinct and separable aspects of participants’ experience that must be considered in the design and evaluation of rehabilitation programs for persons with TBI”.

“... the relation between objective indices of ... functional outcomes, and QOL are moderated by the subjective meanings and values assigned by patients”.

Cicerone et al., 2004

### Johnston et al., 2005: CIQ-2 additions

- N=162 persons with TBI discharged from inpatient rehabilitation (interviewed at 1 mo and at 12 months)
- For each of 47 CIQ-2 items, three questions were asked in addition to the standard one:
  - “How satisfied or dissatisfied are you with ...?” (7-point Likert) (activity satisfaction)
  - “Would like this to change?” (no; yes, want more; yes, want less; and yes, want a qualitative change)
  - “How important would this change be to you?” (5-point Likert)

### Johnston et al., 2005: CIQ-2 additions

- Median correlation between objective status and satisfaction was .17 at 1 mo, .21 at 12 mo (Kendall's  $\tau$ ); only 4 out of 94 correlations were  $> 0.40$
- Median correlation between satisfaction and desire to change (dichotomized) was -0.52 at 1 mo, -0.56 at 12 mo

“... the significance of community activities to persons served, at least in TBI, cannot be presumed or reliably inferred from scales of objective function. The person must be asked”.

“Frequency or intensity of observable community activities may be only weakly associated with individuals' need fulfillment”.

Johnston et al. 2005

### Brown et al.: Participation Objective-Participation Subjective (POPS)

- Derived from Living Life after TBI (LLATBI)
- PO: 26 objective participation items: share of (household) activities; frequency of performance per day/week/month; hours of performance per week/month

### Brown et al.: Participation Objective-Participation Subjective (POPS)

- PS: two questions for each PO item:
  - “How importance is ... to your satisfaction with life?” (5-point Likert scale)
  - “Would you say that that the amount that you do ... is satisfactory to you? Or would you like to be doing more or less than now?” (more, unchanged, less)
- Importance score is multiplied with same (+1) vs different (-1) score
- Products are added across items

### Brown et al.: Participation Objective-Participation Subjective (POPS)

- POPS administered to 454 persons with mild or moderate-severe TBI
- Correlation between PO and PS was 0.23 for the mild TBI group, 0.21 for the moderate-severe TBI group (Pearson's  $r$ )

“The POPS provides a measure of participation in community settings, while also providing a measure of the disability insider's evaluation of that level of participation. The POPS is limited in that it does not in its PS measures tap into the insider's evaluation of the *quality* of his or her participation, but does take a step in the right direction with its focus on satisfaction with quantity of engagement”.

Brown et al., 2004

## PART-OSP questionnaire

- 26 questions on **O**bjective status
- 7+7 **S**atisfaction/importance questions on Participation domains, e.g.
  - How would you rate the importance to you of socializing and making social contacts?
    - 0-10 scale
  - How satisfied are you with how often you engage in socializing and making social contact?
    - A-F scale

## PART-OSP questionnaire

- 19 statements on **P**erceptions, e.g.
  - I am able to pursue my dreams and desires
  - I can get out and about whenever I choose
  - I contribute to the well-being of others in my community
    - Nearly always
    - Sometimes
    - Seldom
    - Never

## PART-OSP cognitive interviewing

- Concerns about ability of persons with moderate-severe TBI to understand and answer PART-OSP questions:
  - Attention
  - Memory
  - Other cognitive deficits
- Goal: assess the quality of the S and P items (O was “non-problematic”)
- Rephrase/drop as necessary

## PART-OSP cognitive interviewing

- Subjects: persons comparable to TBI MS subjects: N=26, 35 interviews
- Interviewed in research office
- Question-on-a-page interview, with scripted generic and specific probes
  - “What do you think X means?”
  - “How did you get that number?”
  - “How would you ask that question in your own words?”

## PART-OSP cognitive interviewing

- Thinking aloud was requested, and training doing so provided
  - Interviewer modeled think aloud
  - Subject did a trial run
- Flexible use of think-aloud and scripted as well as ad-hoc probes
- Interviewer notes on interview pages

### PART-OSP cognitive interviewing

- Audio taping (with subject permission)
- Audiotapes listened to by at least one investigator, problems noted on special forms with problem categories listed
- Changes made in questionnaire (Phases I, II and III)

### Cognitive interviewing: Phase I

- 9 interviews
- Interview structure (7 domains):
  - O1
  - O2
  - I (domain A): 0-10 rating
  - S (domain A): A-F rating
  - O3
  - O4
  - O5
  - I (domain B)
  - S (domain B)
  - ..
  - P1-P19

### Cognitive interviewing: Phase I results

- Inability of people to weigh and rate work/school/volunteering, and household/home maintenance/parenting
- → These items split:
  - School vs work/volunteer
  - Parenting vs home maintenance/ household

### Cognitive interviewing: Phase II results

- 8 interviews
- Subjects confused importance and satisfaction
- People forgot whether “F” was for very satisfied or very dissatisfied
- → I and S items introduced after O items had all been asked
  - Only selecting as yes vs no important
  - Then rating of satisfaction on 0-10 scale

### Cognitive interviewing: Phase III results

- 18 interviews
- Forced choice between YES or NO important too difficult--not nuanced enough
- People had difficulty providing importance and satisfaction ratings for roles/relationships they are NOT active in (e.g. “school”)

### Cognitive interviewing: Phase III results

- → Three-part scheme introduced: low, medium and high importance
- Additional rephrasings of domain descriptions
- Added special elicitation of domains as important, even if satisfaction is low

### Cognitive interviewing: additional results

- Perception items:
  - Inter-subject variation in how terms were defined
    - Community (geographical vs virtual)
    - Society
  - Any restrictions/limitations reported almost incidentally seen as resulting from TBI; equally/more salient: race/ethnicity, age, being married

### Cognitive interviewing: additional results

- Other
  - Frequent errors in reporting frequencies/hours → need for interviewer vigilance
  - Participants easily overly focused on/sidetracked by a single item in a list of items → need for interviewer vigilance
  - Use of term “typical” in “a typical week” apparently is problematic for people without fixed routines
  - Many minor language changes suggested by cognitive interviewing results

### Conclusions

- Measuring participation as an objective state is difficult due to:
  - Age/gender/class/culture patterning
  - Voluntary nature of many roles and activities
  - Many alternative ways of participating

### Conclusions

- Even the best objective participation measures do not reflect the values, preferences, needs and satisfactions of individuals
- Subjective measures of participation are under development

### Conclusions

- Both the objective and subjective scales need to be used in
  - Evaluation programs
  - Researching innovative treatments for persons with ABI
  - Monitoring status of individuals with ABI?

### Conclusions

- Programs that really improve the life of individuals with ABI, and interventions that enhance functioning at the participation level, achieve:
  - Improvement on objective measures
  - High scores on subjective measures

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