Pain Interference Patterns

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Advocates for community participation and quality of life issues may benefit from a better understanding of how pain intensity and environmental barriers influence participation outcomes. Unfortunately, little evidence exists on how the interaction between personal factors (e.g., pain) and environmental factors (e.g., physical accessibility) influence participation. To address this gap, we studied Pain Interference Patterns (PIP) by collecting both longitudinal and ecological momentary assessment (EMA or real-time) data to explore these factors and outcomes. Through better understanding of these interactions, we hope to inform interventions, policy, and services that can promote full participation in community life. This fact sheet reports on preliminary data and analyses from this study.

Methods

We began with a population based sample of 10,000 households, randomly selected from a small city in the western United States. Household members were asked to return a postcard if they were willing to participate in the research project, were over the age of 18, and could answer “yes” to one or more of the following American Community Survey (ACS) disability screener questions.

- Do you have serious difficulty walking or climbing stairs?
- Do you have difficulty dressing or bathing?
- Do you have difficulty doing errands alone, such as visiting a doctor’s office or shopping because of a physical condition?
- Are you deaf or do you have serious difficulty hearing?
- Are you blind or do you have difficulty seeing even when wearing glasses?

From the population based mailing, we received 601 return postcards and 525 participants completed the informed consent and baseline longitudinal survey. Of the 525 enrolled study participants, 301 were between 18 and 65 years of age and 224 participants were over the age of 65. For this fact sheet, we reported baseline longitudinal survey results for working aged adults (age 18 to 65).
Measures

We collected data on participant demographics, health status, disability status, pain levels, pain management strategies, community participation, and environmental barriers. For regression models, independent variables included:

**Demographics.** Variables to control for relationship status, education, income, and employment.

**Disability Severity.** A proxy for disability severity calculated as the sum of “yes” responses across six American Community Survey (ACS) disability screener questions, including difficulty hearing or deafness; difficulty seeing or blindness; serious difficulty concentrating, remembering or making decisions because of a physical, mental, or emotional condition; serious difficulty walking or climbing stairs; difficulty dressing or bathing; and difficulty doing errands alone because of a physical, mental or emotional condition.

**Average Pain.** A single item question asking respondents to rate average pain severity over the last week, where 0 = “no pain” and 10 = “pain as bad as you can imagine.”

**Abbreviated Sum of Secondary Conditions Surveillance Instrument (SCSI-7).** A 7-item scale to assess limitations from common secondary conditions, including fatigue, physical fitness/conditioning problems, depression, anxiety, sleep problems, medication side effects, and chronic pain. Respondents rated how limited they were on a 0 to 3 rating scale where 0 = “rarely or never limits” and 3 = “limits activity 11 or more hours per week.”

**Pain Catastrophizing Scale (PCS).** A 6-item abbreviated scale to assess feelings about pain. Using a 5-point scale ranging from “not at all” to “very much,” respondents rated their feelings on the following six items: “I worry all the time about whether the pain will end,” “I feel I can’t go on,” “It’s terrible and I think it’s never going to get better,” “It’s awful and I feel that it overwhelms me,” “I feel I can’t stand it anymore,” and “There’s nothing I can do to reduce the intensity of the pain.”

**Pain Coping.** Respondents rated the number of days out of the last 30 days they used resting, guarding, ignoring, pacing, or asking others for help as a pain coping strategy. Due to very high correlations among several items we retained single items for “resting” and “ignoring” in the regression models.

**Participation Barriers Scale.** A 15-item scale used to assess environmental barriers people with disabilities may experience, including housing accessibility, curb cuts, community
safety, air quality, weather, building accessibility, transportation, assistive equipment, health limitations, thinking or concentration problems, attitudes, daily self-care, receiving needed help, and fatigue. Respondents rated how much each barrier affected their participation on a scale of never, sometimes, often, and routinely.

**Orientation to Happiness Scale.** A 6-item abbreviated scale to measure three dimensions of positive outlook, including meaning, pleasure, and engagement. Using a 5-point scale ranging from “very much unlike me” to “very much like me,” respondents rated their feelings on the following six items: “My life serves a higher purpose,” “My life has lasting meaning,” “In choosing what to do, I always take into account whether it is pleasurable,” “For me, the good life is the pleasurable life,” “Whether at work or play, I am usually ‘in a zone’ and not conscious of myself,” and “I am always very absorbed in what I do.”

**Participation in the Community**
The outcome or dependent variable was community participation. To measure this, participants indicated how many times in the last week they visited grocery stores, doctors/health care providers, pharmacies, restaurants, box stores, public parks/recreation areas, exercise facilities, and shopping malls. They also indicated how many times in the last week they participated in active recreation, socializing outside the home, religious activities, community activities, and entertainment such as going to movies or sporting events. These locations and activities were selected based on high prevalence rates on the SPARC/PARTS participation measures (Gray, Morgan, Dashner, Garrett, & Hollingsworth, 2012).

We used factor analytic methods to explore how different types of participation moved together. Figure 1 shows how participation events loaded onto three domains we describe as medical, shopping, and discretionary.
Regression Results

We constructed three regression models to predict each participation domain: medical, shopping, and discretionary. For each model, we entered all variables simultaneously. As the models show, different explanatory variables emerged as important predictors. For instance, while orientation towards pleasure (one of the happiness domains) significantly predicted discretionary participation, it was not a significant predictor for medical and shopping participation. Likewise, the sum of secondary conditions scores predicted medical participation, but did not predict shopping or discretionary participation. (See Table 1)
Discussion

Although these models are a preliminary examination of the data, they highlight the importance of exploring different domains of participation. The regression models for medical and discretionary participation were significant, while shopping participation was not. It appears that shopping (including grocery shopping, malls, and big box stores) is not sensitive to variation in personal and environmental factors. This is somewhat expected in that household shopping and in particular grocery shopping constitutes a basic need that cannot be ignored.

Medical Participation. Higher sum of secondary conditions scores were associated with increased medical participation, while higher reported pain levels were associated with reduced medical participation. This finding may reflect the debilitating nature of pain such that pain at higher levels decreases the likelihood of leaving home to access or use medical services. Interestingly, higher rates of participation barriers were associated with increased medical care use. It is possible that individuals who encounter more barriers have more limiting health conditions and the participation barriers scale is acting as a proxy for disability severity.

Respondents who were employed PT or FT engaged in significantly less medical participation. Employment may be capturing variance of a factor not specified in the model, like complexity of medical needs, which affects both employment and medical service utilization. Alternatively, it could simply reflect that employed people have less time for pursuing medical appointments.

Discretionary Participation. Interestingly, respondents who were married or had a partner participated in almost four fewer discretionary outings per week. This may indicate that single people go into the community for socialization, while couples have this need met at home. Pleasure was associated with more discretionary participation, where respondents who scored higher on the pleasure domain of the orientation to happiness scale participated in more activities.

This finding seems to reflect that people who participate more experience more pleasure. However, the opposite could also be true; individuals who experience more pleasure tend to participate more. Understanding the directionality of this result could be important for developing interventions to increase participation.

Resting for pain management was associated with reduced discretionary participation. The literature indicates that those who use resting as a coping strategy for pain management are more likely to have worse physical functioning (Jensen, Turner, Romano, & Strom, 1995). Rest may serve as a proxy variable for disability severity, which in turn acts as a mediating variable between pain management and discretionary participation.

Overall, the models highlight the need to explore specific domains of participation, as facilitators in one domain may actually serve as barriers in another. Additional participation domains likely deserve attention as well. For instance, we used employment as an independent variable for the medical, shopping and discretionary domains, but taking part in the workforce is also a participation outcome. We did not explore employment because it is typically analyzed using logistic regression and was not directly comparable to the other participation domains.

Limitations

The study has several limitations. First, all respondents live in one location and may not be representative of people in other places. Second, the measure of participation does not capture the variety of activities that constitute participation. We used high incidence activities as a proxy for all participation, but this approach misses important activities for some people. Third, the survey items were subject to recall bias. Additionally, because the reported data are cross sectional, it is not possible to establish causality in the regression models. We plan to address some of these limitations with our ecological momentary assessment (EMA) data collection.
Next Steps

These analyses set the stage for further inquiry. By looking at change scores over time with longitudinal data, we can begin to understand causal factors related to participation. These hypothesized relationships can be further analyzed among participants who also completed EMA real-time data (n = 100). EMA respondents answered six mini-surveys per day for 14 consecutive days about what they were doing, how they were feeling, and what barriers they encountered since the last data prompt (i.e., approximately over the past two hours). Recording events as they occur reduces recall bias and allows us to explore causality and patterns. For instance, high pain episodes may follow high rates of barriers encountered in the community. Likewise, participation may have lagged patterns related to changes in pain levels. How variables interact provides evidence for addressing pain and participation outcomes and can be used to inform behavioral interventions.

Citations


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