



## Research Paper

## Why stay home? Temporal association of pain, fatigue and depression with being at home

Craig Ravesloot, Ph.D.<sup>a,\*</sup>, Bryce Ward, Ph.D.<sup>b</sup>, Tannis Hargrove, M.A.<sup>a</sup>, Jennifer Wong, M.A.<sup>a</sup>,  
Nick Livingston, M.A.<sup>a</sup>, Linda Torma, Ph.D.<sup>c</sup>, and Catherine Ipsen, Ph.D.<sup>a</sup>

<sup>a</sup>The Rural Institute on Inclusive Communities, USA

<sup>b</sup>The Bureau of Business and Economic Research, USA

<sup>c</sup>Montana State University, School of Nursing, USA

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**Abstract**

**Background:** Community participation is important to most people with disabilities despite the fact that common secondary conditions like pain, fatigue and depression may increase the difficulty of leaving home. Despite decades of research on these secondary conditions, little is known about how they are associated with being at home.

**Objective:** We used Ecological Momentary Assessment data to examine within subject fluctuation in these secondary conditions to examine their effect on the likelihood that participants remain at or return home.

**Methods:** Participants ( $n = 139$ ) were recruited from a population based sampling frame to complete an Ecological Momentary Assessment that queried their location and experience with secondary conditions six times a day for two weeks.

**Results:** Between subjects secondary condition ratings averaged across time periods indicated that pain and depression were associated with the share of measurement periods that respondents reported being at home. Within subject results indicated that a standard unit increase in pain, fatigue and depression was associated with being home one to two days later. Within day results indicated that increases in pain and fatigue were associated with increased likelihood of being home later, but increases in depression were associated with lower likelihood of being home later.

**Conclusion:** These results suggest there may be a complicated relationship among these secondary conditions and community participation with effects observed both across and within days. One interpretation suggests that secondary condition severity is tempered by adjusting participation. These results may have implications for intervening on these secondary conditions. © 2015 Elsevier Inc. All rights reserved.

*Keywords:* Participation; Pain; Fatigue; Depression; Measurement

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For most people, participation in daily life involves leaving home. People leave home to work, recreate, socialize, and shop, among other things.<sup>1</sup> For people with disabilities, participation is a complex personal choice that is valued for many reasons.<sup>2</sup> Secondary conditions like pain, fatigue and

depression may limit people's engagement in activity outside the home. Existing studies of these secondary conditions have focused little attention on their impact on daily life. Thus, the impact of these secondary conditions on daily life remains largely unknown.

We address this gap in the literature. We obtained data from a mixed impairment sample using a longitudinal electronic diary technique known as Ecological Momentary Assessment (EMA). Using these data, we describe the relationship between pain, fatigue, depression and time spent at home. We examine these relationships both between subjects and within subjects over time.

Pain is a secondary condition associated with a variety of primary disabling conditions including spinal cord injury (SCI),<sup>3</sup> multiple sclerosis (MS),<sup>4</sup> arthritis,<sup>5</sup> traumatic brain injury (TBI),<sup>6</sup> amputation<sup>7</sup> and cerebral palsy.<sup>8</sup> Self-report measures of pain interference among people with disabilities indicate that pain can affect social activities, recreation,

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\* Corresponding author. Rural Institute, 52 Corbin Hall, University of Montana, Missoula, MT 59812, USA. Tel.: +1 406 243 2992.

E-mail address: [craig.ravesloot@mso.umt.edu](mailto:craig.ravesloot@mso.umt.edu) (C. Ravesloot).

mood, work, self-care, communication, learning new information/skills, and enjoyment of life.<sup>9,10</sup> Not surprisingly, pain is associated with lower life satisfaction, poorer physical and mental health and level of handicap.<sup>11,12</sup>

Fatigue is also a common secondary condition reported by people with MS,<sup>13</sup> stroke,<sup>14</sup> arthritis,<sup>15</sup> Parkinson's disease,<sup>16</sup> TBI<sup>17</sup> and SCI.<sup>18</sup> It is associated with a reduction in daily activity engagement, including social and recreational activities,<sup>19–21</sup> but may not be associated with engagement in major life activities like employment and education.<sup>22</sup>

Depression is a secondary condition that affects people diagnosed with diabetes related disability,<sup>23</sup> Parkinson's disease,<sup>24</sup> epilepsy,<sup>25</sup> SCI,<sup>26</sup> MS,<sup>27</sup> as well as those who have experienced a stroke.<sup>28</sup> Endemic to depression is the effect it has on engaging in activity and, not surprisingly, depression is associated with a decrease in participation.<sup>23,29</sup>

When people make the decision to leave home, they consider the costs and the benefits of going out. For people experiencing pain, fatigue or depression the relative benefits and costs of leaving home may change. To go out, among other things (e.g., money), people need sufficient time, energy and motivation to engage in the planned activity. Pain, fatigue, or depression may decrease the resources available and make it more challenging to leave home. For instance, these conditions may increase the time and effort to complete self-care activities, and thus reduce the resources available to pursue activities outside the home.<sup>30</sup> Alternatively, pain, fatigue, or depression may increase the "price" of activity outside the home. For instance, it may take more time and effort for someone with these conditions to complete the same activity.<sup>31</sup> In either case, individuals experiencing greater pain, fatigue, or depression face more constraints to engaging in activities outside the home.<sup>32</sup>

Cross-sectional studies are inadequate for understanding the relationship between pain, fatigue, depression and community engagement. Standard between subjects analyses cannot rule out the possibility that unobserved characteristics drive observed correlations between pain, fatigue, or depression and one's propensity to remain home. Between subjects analyses also ignore within-person fluctuations in pain, fatigue, or depression. Within person fluctuations matter. They may drive an observed between subject relationship. Furthermore, they can illuminate whether people go home when they experience an increase in pain, fatigue, or depression. To develop the most effective interventions to increase community engagement, researchers need longitudinal data that is sensitive to daily fluctuations and individual differences.

Ecological Momentary Assessment (EMA), a technique subsumed under Experience Sampling Methodology, collects data *in situ*, which facilitates investigation of status fluctuations and individual differences.<sup>33,34</sup> It typically uses electronic devices to collect data in the person's usual environment. It is a reliable and valid method for collecting data on a variety of variables (e.g., pain and emotional state) and reduces retrospective recall bias

associated with autobiographic recall errors.<sup>34,35</sup> The aim of the current study was to use EMA to explore the within-person temporal relationship between pain, fatigue, and depression on the amount of time people with impairments spend at home.

## Methods

### Participants

We recruited 525 participants in a small Western US city from an initial pool of 10,000 randomly selected households to complete a paper-and-pencil survey. Invitation letters and pre-coded, anonymous, postage paid post-cards were sent to each household. Interested participants who returned the post card and met inclusion criteria (i.e., endorsed one or more American Community Survey [ACS] questions)<sup>36</sup> were sent a survey using Dillman's procedures for materials development (e.g., cover letter content) and follow up.<sup>37</sup> We recruited 149 of the survey respondents to complete the EMA by telephoning all individuals who gave permission on the survey to contact them for another study. The current study sample included 139 participants who responded to at least half of the 84 scheduled EMA prompts over the 14 day study period. Data were collected in 2013 and 2014.

Respondents included in the current analytic sample were between the ages of 19 and 75 ( $M = 55.7$ ,  $SD = 11.2$ ) and were predominantly female (61.8%), Caucasian (97.1%), and college educated (73.3% reported some college or more education). The majority were not employed (64.5%) and reported median household income between \$20,000 and \$30,000 (Table 1).

### Measures

We used the paper-and-pencil survey to collect a standard set of demographic variables including age, gender, income, employment status and educational attainment. We also collected the six American Community Survey (ACS) disability screener questions and the type of adaptive equipment respondents normally use.

We collected the EMA data using four-inch touch screen tablet computers (i.e., Samsung Galaxy Player 4.0) that were programmed to prompt participants using a random schedule within 2-h intervals (delivered between 9:00 am and 9:00 pm), six times daily, for 14 consecutive days. At each EMA prompt, participants reported where they were (e.g., at home), what they were doing (e.g., watching television), and questions about their experience in the moment (e.g., who they were with, how satisfied they were with the activity, their pain level). To indicate the level of pain they were experiencing, they used a 10-point rating scale anchored at each end (0 = No pain, 10 = Pain as bad as you can imagine). Respondents used a five-point rating scale (i.e., 0 = Not at all, 1 = A little, 2 = Somewhat,

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