

Use of Automated Electronic Diaries to Explore Sleep and Other Symptoms Among Persons with Multiple Sclerosis – A Pilot Study

Pamela Newland, RN, PhD, CMSRN, '10 NRSA Fellow, Assistant Professor; Mary Bordner, JD, RN, BSN, MSNc, Goldfarb School of Nursing at Barnes Jewish College, St. Louis, MO;

Marguerite Riley, RN, PhD, CMSRN, CNE, Associate Professor, Southern Illinois University Edwardsville, IL; Rebecca Lorenz, RN, PhD, Associate Professor, Saint Louis University School of Nursing, St Louis, MO

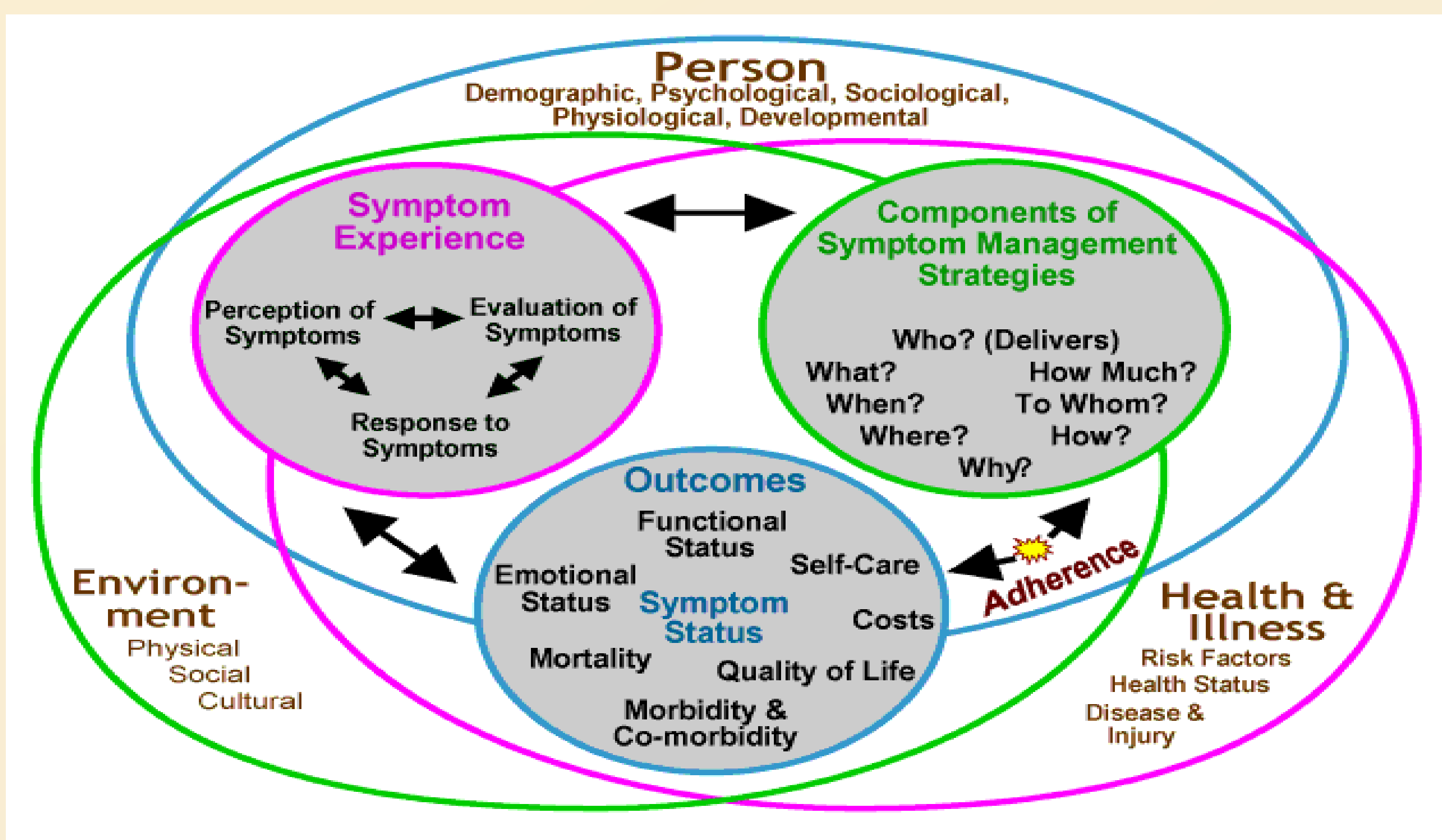
Background

- Multiple sclerosis (MS), an inflammatory neurodegenerative disease, afflicts over 400,000 people in the U.S.
- Poor sleep quality among people with multiple sclerosis (pwMS) may be related to depression, anxiety, drug effects, neurogenic bladder, and poor sleep hygiene.
- Consequences of poor sleep quality include heart disease, stroke, cognitive decline, and accidents.
- Capturing self-report symptoms in real-time is an innovative method that will lead to improved interventions for person-centered care.

Objectives

- The **overall objective** in this pilot, mixed method, descriptive, repeated measures study was to examine sleep quality using automated electronic diaries.
- We also examined the impact of other symptoms on sleep in pwMS.

Model Framework



Funding

- Research Grant Award from Academy of Medical Surgical Nurses and Phillips Healthcare.

Method

- Five narrative questions adapted for a web-based sleep diary regarding sleep and other symptoms.
- Subjects received the symptom/sleep diary daily for seven days via email using REDcap data capture software and again for another seven days approximately eight weeks later.
- The Sleep Visual Analog Scale (VAS) was used for reporting sleep quality, which is scored between 0 (very poor) and 100 (extremely good).

Sample Characteristics

- This convenience sample of pwMS included relapsing-remitting (RRMS) MS and secondary progressive (SPMS) MS.
- There were a total of 28 pwMS, comprised of mainly of RRMS.
- The majority were women (89%), who were white (86%) and average age of 44 years old.
- The mean time since diagnosis in years was 12 (SD = 7.6) and the mean EDSS-P was 3.8 (SD = 1.8).

Results

- The median sleep quality VAS was 73 (extremely good), but two participants scored their experience on two nights as “1” and “9”(extremely poor) (Figure 1).
- Pain was expressed in the diaries as the most common barrier to sleep (n = 10).
- Participant entries were “*Severe leg cramps that woke me early....I was awakened by leg pain and leg cramps.*”.
- Another participant wrote “*Ankles bothered me and had sharp pain in “legs”, with pins and needles.*”.
- Poor sleep illustrated distress as follows: “*I really wish I could just go to sleep like most people and just stay sleeping all night*”.

Disclosures

- Drs. Newland, Riley, Lorenz, and Ms. Mary Bordner have no disclosures to report.

Comparison Sleep Visual Analog Scale

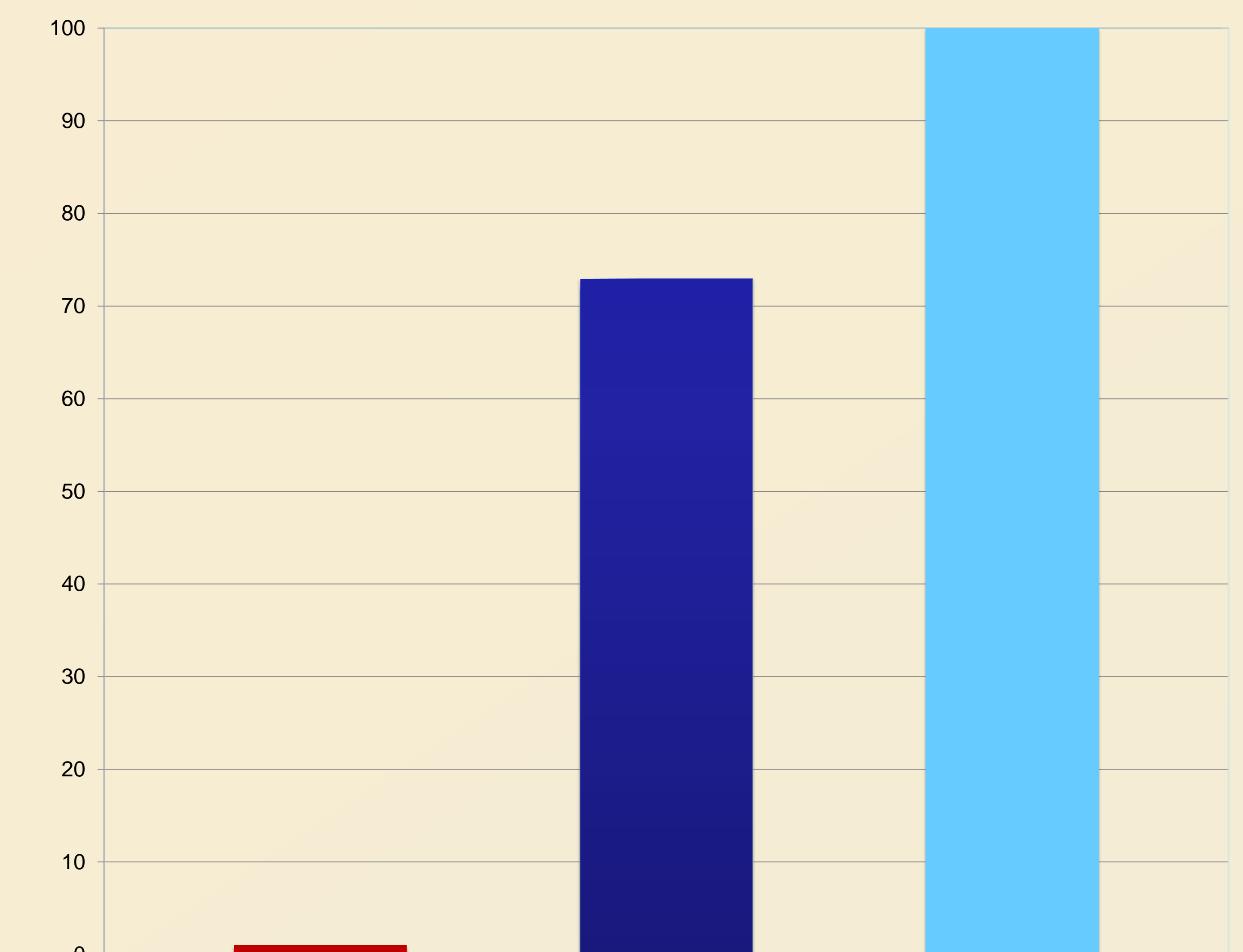


Figure 1. Range and Median Sleep Quality. The red bar indicates the low range score of 1; the dark blue bar indicates the median of 73; and the turquoise bar indicates the high range score of 100.

Conclusions

- These findings suggest that sleep quality may vary dramatically between nights of the week.
- Problems with sleep, accompanied by other symptoms, especially pain, are not uncommon.
- For pwMS in this sample, weekly recalled sleep and other symptoms might be more useful as a data collection method.
- The **VAS** may not be a sensitive enough tool to differentiate pwMS with lower EDSS scores.
- Identification of risk factors may facilitate interventions to improve sleep and other health outcomes.