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Patient-Reported Outcomes

Deriving Meaningful Aspects of Health Related to Physical Activity in Chronic Disease: Concept Elicitation Using Machine Learning-Assisted Coding of Online Patient Conversations



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ABSTRACT

Objectives: Clinical outcome assessment (COA) developers must ensure that measures assess aspects of health that are meaningful to the target patient population. Although the methodology for doing this is well understood for certain COAs, such as patient-reported outcome measures, there are fewer examples of this practice in the development of digital endpoints using mobile sensor technology such as physical activity monitors. This study explored the utility of social media data, specifically, posts on online health boards, in understanding meaningful aspects of health related to physical activity in 3 different chronic diseases: fibromyalgia, chronic obstructive pulmonary disease, and chronic heart failure.

Methods: We used machine learning and manual coding to summarize the content of posts extracted from 4 online health boards. Where available, patient age and sex were retrieved from post content or user profiles. We utilized analytical approaches to assess the robustness of findings to differences in the characteristics of online samples compared to the true patient population. Finally, we assessed concept saturation by measuring the convergence of autocorrelations.

Results: We identify a number of aspects of health described as important by patients in our samples, and summarize these into concepts for measurement. For chronic heart failure, these included purposeful walking duration and speed, fatigue, difficulty going upstairs, standing, and aspects of physical exercise. Overall and age-adjusted results did not differ considerably for each disease group.

Conclusions: This study illustrates the potential of performing concept elicitation research using social media data, which may provide valuable insight to inform COA development.

Keywords: concept elicitation, electronic clinical outcome assessment, endpoint development, machine learning, physical activity, social media.

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Introduction

Debilitating symptoms and impaired functional capacity in persons with diseases such as fibromyalgia, chronic obstructive pulmonary disease (COPD), and chronic heart failure (CHF) can place limitations on patients' abilities to do the types of things that bring meaning to their lives. Specific symptoms of CHF, for example, shortness of breath, chest pain, and fatigue, are contributing factors to reduced activity and limitations on patients' abilities to perform activities of daily living and their associated quality of life.¹ In general, patients with COPD and CHF are relatively inactive, with steps per day reported to average 2237 and 4342, respectively, compared with healthy adults who typically take between 4000 and 18000 steps per day.² Fatigue associated with fibromyalgia is reported to be the greatest factor influencing inactivity.³

Although research studies have been conducted to measure activity levels in persons with these diseases, few studies have first sought to determine the aspects of physical activity that are meaningful or important to patients with these conditions before determining measures of physical activity. For example, in their review of the use of activity monitors in patients with COPD, Byrom and Rowe⁴ reported over 80 different endpoint measures used across 76 research studies, with no studies consulting patients first to explore the aspects of physical activity most meaningful from their perspectives.

In response to the 21st Century Cures Act,⁵ the US Food and Drug Administration is in the process of developing a guidance series on patient-focused drug development to ensure that meaningful patient and caregiver input can be included to inform medical product development and regulatory decision making. The first of these guidance's was published in June 2020.⁶

Fundamental to this guidance is the requirement to understand what is important to patients and determine how this can be measured and assessed most appropriately within interventional clinical trials.

There are numerous ways that patient input can be collected during the development of appropriate measures and endpoints for use in clinical trials. Most common, for example, are qualitative interview methodologies that seek to elicit a minimal set of concepts that are meaningful and discrete in characterizing aspects of health status most relevant to the disease. Concept elicitation studies are typically conducted in relatively small groups of patients (eg, 40–60 patients),⁷ with final sample size often determined with reference to the reaching of concept saturation (ie, the point at which additional patients fail to add new concepts).^{8,9} Nevertheless, the increasing use of social media for the purposes of sharing personal health information, in particular the use of online health boards (OHBs—web-based, asynchronous, text-based discussion forums dedicated to personal health), presents an opportunity to also gain unsolicited insights from patients that may help inform concept elicitation. The first Food and Drug Administration guidance document on patient-focused drug development,⁶ for example, states that “social media tools (eg, medical community blogs, crowdsourcing, or social media pages) may include information on patients’ perspectives regarding symptoms and impacts of a disease or condition” and that “targeted social media searches may be useful during the preliminary stages of a study to complement literature review findings, inform the development of research tools (eg, qualitative study discussion guides), or as a supplement to traditional research approaches (eg, literature, one-on-one interviews, focus groups, or expert opinion).”

In this work, we explore the use of social media data in understanding aspects of physical activity most meaningful and important to patients living with fibromyalgia, COPD, and CHF. The aim of this work is to provide valuable input to the development of pertinent and meaningful patient-oriented physical activity endpoints using activity monitors in clinical trials. At the time of writing, this is a novel approach and we are not aware of other published works using social media data to understand meaningful aspects of physical activity in these, or other, conditions.

Methods

Post identification, cleaning, and coding activity were conducted using technology supplied by Mebomine (Mebomine Ltd, London, UK). Posts in which patients reported their experience of 1 of the 3 conditions (fibromyalgia, COPD, and CHF) in relation to aspects of physical activity were identified using Mebomine’s OHB search engine, configured to return results from HealthBoards,¹⁰ HealthUnlocked,¹¹ Patient.info,¹² and Inspire.¹³ These OHBs were chosen because of their size, in terms of number of posts and users, and their coverage of multiple conditions. Users posting to these OHBs are almost exclusively from the United States, United Kingdom, and Canada. Most write in English, but US-based OHBs, such as Inspire, also contain a significant number of Spanish language posts.

The Mebomine OHB search engine used keywords for the conditions of interest and their synonyms to return a filtered list of posts containing only those including personal experiences (ie, spam, news items, and general disease information was discarded). We focused on English language posts.

Post and user data were cleaned and standardized, including automated structuring and deduplication of the data. Post data were linked at the level of threads and individual users. Where

available, patient age and sex were retrieved from post content or user profiles—the later requiring determination of the relationship between the user and patient from post content.

Mebomine’s coding interface was used to code posts according to the impacts they were associated with. We followed a thematic analysis approach whereby 3 coders performed an initial evaluation to develop sets of high-level impacts for each disease. These were consolidated into a single codebook by the authors so that a common coding approach could be applied across the 3 conditions. This approach identified a set of 17 impacts (Table 1), and coding was manually assigned by 2 independent coders. Discrepancies were adjudicated by a third coder, where necessary. Subsequently, the subset of CHF posts assigned the impact “exercise” were further sub-coded using a more specific set of impacts that was accrued during the coding process. Impacts were aggregated over all posts for each user to avoid overrepresentation of impacts reported multiple times by the same user. Pseudonymization and paraphrasing of post content was used to protect privacy in reported results.

To account for differences in the demographics between the OHB-derived samples and the patient population, impacts were also weighted according to patient age. The adjustment was performed on data from individuals for whom age could be identified, by fitting a polynomial to the age distribution of OHB users as sampled, and calculating the ratio of this to the general patient population distribution (obtained from prevalence distributions reported in the literature^{14–16}) as a function of age. Age-adjusted results were scaled to provide a relative frequency, where an impact would have a value of 100% if it was mentioned by all patients for which age could be determined.

Concept saturation was explored for the CHF data by investigating the convergence of autocorrelations between impact frequencies across the sample. Autocorrelation is a common method for identifying convergence in many tasks, such as machine learning, but to our knowledge, its application to identify saturation in concept elicitation from social media is novel.

Results

Chronic Obstructive Pulmonary Disease

The search strategy surfaced 425 posts related to challenges with physical activity from 315 individuals living with, or caring for an individual with, COPD (Table 2). Eighty-four percent of individuals ($n = 262$) were identified as patients, with a further 16% ($n = 50$) as caregivers. Two individuals could not be coded as either patient or caregiver (Table 2). Sex could be established for almost 25% of patients (female: 19.4%, male: 5.4%). Age could be determined for 130 patients (41%), and ranged from 24 to 90 years (mean [SD]: 62.1 [12.5] years).

Of the 315 individuals inspected, the most common high-level labels identified were exercise (34%), fatigue (19%), chores (18%), mood (17%), self-care (12%), lack of sleep (11%), and diet adjustments (11%) (Fig. 1A). Among the cohort of patients for whom age could be derived (130/315, 41%), applying age-adjustment weightings to map to the true prevalence age distribution of patients,¹⁴ showed little difference in the findings compared with the overall unadjusted dataset (Fig. 1A). The most frequently reported impacts, and their ranking, remained consistent with the unadjusted data.

Fibromyalgia

Three hundred and 4 posts were identified related to challenges with physical activity from 244 individuals living with, or

Table 1. High-level impact categories used in initial coding phase.

| Impact | Description |
|------------------------|--|
| Exercise regimen | Difficulties or an inability with following an exercise regimen that was advised by a doctor or physical therapy, cardio/pulmonary rehabilitation. |
| Exercise | Difficulties or an inability with any form of exercise, including walking. |
| Self-care | Difficulties or an inability with typical self-care activities, such as cooking, getting dressed, and bathing or showering. |
| Stairs | Difficulties or an inability with going up stairs. |
| Falling | Experienced falling. |
| Getting up | Difficulties or an inability with getting up from a bed or chair. |
| Chores | Difficulties or an inability with doing chores, including household and garden chores. |
| Fatigue | Fatigue affected ability to perform a specific activity. |
| Lack of sleep | Difficulties or an inability with sleeping. |
| Mood | Changes in mood or mental health affecting ability to perform a specific activity. |
| Diet adjustments | Difficulties or an inability with following a prescribed diet. |
| Sickness (time off) | Taking time off, leaving or retiring from work because of illness. |
| Productivity | Difficulties or an inability with being productive at work, conducting hobbies, and in day-to-day life. |
| Social | Difficulties or an inability with social interactions between family members, friends, and partners. |
| Travel | Difficulties or an inability with traveling, including trouble driving or traveling on private and public transport. |
| Going out of the house | Difficulties or an inability with going out of the house, eg, visiting restaurants. |
| Caring for others | Difficulties or an inability with caring for others, including children, parents, and other family members. |

caring for an individual with, CHF (Table 2). Ninety-six percent of individuals were identified as patients, with a further 4% as caregivers (Table 2). Sex could be established for around 46% of patients (female: 40%, male: 6%). Age could be determined for 83 patients (34%), and ranged from 16 to 69 years (mean [SD]: 37.8 [14.4] years).

Of the 244 individuals inspected, the most common high-level labels identified were lack of sleep (40%), exercise (39%), fatigue (39%), productivity (28%), getting up (26%), mood (23%), sickness/time off (19%), chores (19%), and going out of the house (17%) (Fig. 1B). Applying age-adjustment weightings (ages available for 83/244, 34% of patients) based on the true prevalence age distribution of patients,¹⁵ showed little difference in the findings compared with the overall unadjusted dataset (Fig. 1B). The most frequently reported impacts remained consistent, with a small difference in ranking. Lack of sleep slipped from first to fifth most frequently cited impact, with the same top 5 impacts.

Chronic Heart Failure

The search strategy surfaced 383 posts related to challenges with physical activity from 271 individuals living with, or caring for an individual with, CHF (Table 2). Over 80% of individuals (n = 219) were identified as patients, with a further 19% (n = 52) as caregivers (Table 2). Sex could be established for around 56% of patients (female: 53%, male: 3%). Age could be determined for 209 patients (77%), and ranged from 20 to 96 years (mean [SD]: 53.6 [14.9] years).

Of the 271 individuals inspected, the most common high-level labels identified were exercise (48%), lack of sleep (19%), chores (16%), fatigue (16%), sickness/time off (15%), self-care (14%), productivity (14%), and stairs (13%) (Fig. 1C). Among the cohort of patients for whom age could be derived (209/271, 77%), applying age-adjustment weightings to map to the true prevalence age distribution of patients¹⁶ showed little difference in the findings compared with the overall unadjusted dataset (Fig. 1C). The most

frequently reported impacts remained consistent with the unadjusted data, with small differences in the ordering. Age-adjusted relative frequencies showed self-care move from sixth to second in the order of most frequently reported impacts and chores from third to seventh.

Detailed evaluation: exercise-labeled posts identified for the CHF evaluation

Evaluating the posts labeled as related to exercise in more detail by sub-coding these to establish the aspect of exercise described, 12 aspects of health were identified (Table 3).

Walking-related aspects of health were reported by 66.9% of individuals, with 45.8% of individuals reporting being unable to walk a very short distance without resting. One individual stated (this quote and all that follow have been paraphrased as described in Methods) "I could not walk the 3 blocks from the car park to my workplace," and a further individual stated, "I feel queasy and short of breath even when trying to walk a short distance like 50 meters." Individuals also identified being able to walk for various distances or times: 8.5% could walk 10 to 20 minutes without a rest, 9.9% for half an hour or 1 to 2 miles, and a further 1.4% could walk up to 10 kilometers.

Aspects of health related to intensity of exercise were reported by 16.2% of individuals. Eleven individuals (7.7%) reported using cardiovascular gym equipment or outdoor cycling. Eight individuals (5.6%) reported having to move more slowly than before, for example 1 individual writing "It makes me so upset because I cannot keep up the pace anymore – my children have to keep stopping and waiting for me."

Smaller numbers of individuals reported aspects of health related to strength and flexibility (eg, yoga or lifting weights, 3.5%), difficulties sitting or lying (4.9%), or related to balance (0.7%).

Activity-labeled posts also contained details of challenges with self-care. Four individuals (2.8%) reported difficulties showering or

Table 2. Summary characteristics of participants analyzed.

| Characteristic | COPD (N = 315) | Fibromyalgia (N = 244) | CHF (N = 271) |
|-----------------------|-------------------|------------------------|-------------------|
| Type of participant | | | |
| Patient | 262 (83.2%) | 234 (96%) | 219 (80.8%) |
| Caregiver | 50 (15.9%) | 10 (4%) | 52 (19.2%) |
| Unknown | 2 (0.6%) | 0 | 0 |
| Sex of patient | | | |
| Female | 61 (19.4%) | 98 (40%) | 145 (53.5%) |
| Male | 17 (5.4%) | 15 (6%) | 8 (3.0%) |
| Unknown | 237 (75.2%) | 131 (54%) | 118 (43.5%) |
| Age of patient | | | |
| n (%) | 130 (41%) | 83 (34%) | 209 (77%) |
| Mean [SD] | 62.1 [12.5] years | 37.8 [14.4] years | 53.6 [14.9] years |
| Range | 24-90 years | 16-69 years | 20-96 years |
| Total number of posts | 425 | 304 | 383 |

CHF indicates chronic heart failure; COPD, chronic obstructive pulmonary disease.

bathing, with one writing “I need to allow about 45 minutes to have a bath and get my clothes on.” Difficulties dressing or undressing were reported by 2 individuals (1.4%).

21.8% of individuals reported aspects of health related to activities of daily living. Nine individuals reported difficulties with household chores, one stating “Doing small household chores have become huge tasks that take all my energy and oxygen, even to do in a half-assed manner.” Twelve individuals (8.5%) reported difficulties going upstairs (“I get short of breath going up steps.”). A further 6 individuals (4.2%) reported difficulty standing for periods of time (“I need to leave others in the queue at the shops, as standing and waiting really kills me”), and a further 4 individuals (2.8%) reported difficulties lifting or carrying things (“I don’t carry a bag now, I don’t have it in my arms and legs to do this”).

Fatigue-related aspects of health were reported by 22.5% of individuals, one writing “I am tired, so tired, all the time.”

Posts for almost 5% of individuals (n = 7) reported fear of exercise or certain activity because of their CHF. One individual wrote “I’m scared of doing anything that might trigger a shortness of breath episode.”

Smaller numbers of individuals reported aspects of health related to pain when exercising (3.1%, n = 2), limitations on their sex life (0.7%, n = 1), and difficulty dealing with high outdoor temperatures (2.1%, n = 3).

Age adjustment of these data yielded the same key aspects of activity as most important (Table 3), with minor changes in the relative frequency of reporting of certain aspects of activity. Walking-related aspects of health showed increased frequency of reporting difficulties walking short distances and less reporting of the other distance/time categories. The use of home gym equipment was also associated with a lower relative frequency compared with the unadjusted data.

Saturation analysis for CHF analysis

Saturation analysis showed asymptotic growth in identified concepts during the coding process, but correlation between the overall frequency distribution of concepts from post to post began to stabilize after the first 30 posts, and continuing to code beyond the first 90 posts had negligible impact on the overall findings (Fig. 2). Although the results shown are for the sequence in which posts were coded in this study, analysis of 100 different permutations of this sequence demonstrated the general trends are independent of the order in which posts were coded.

Endpoint development considerations: exercise-labeled posts identified for the CHF evaluation

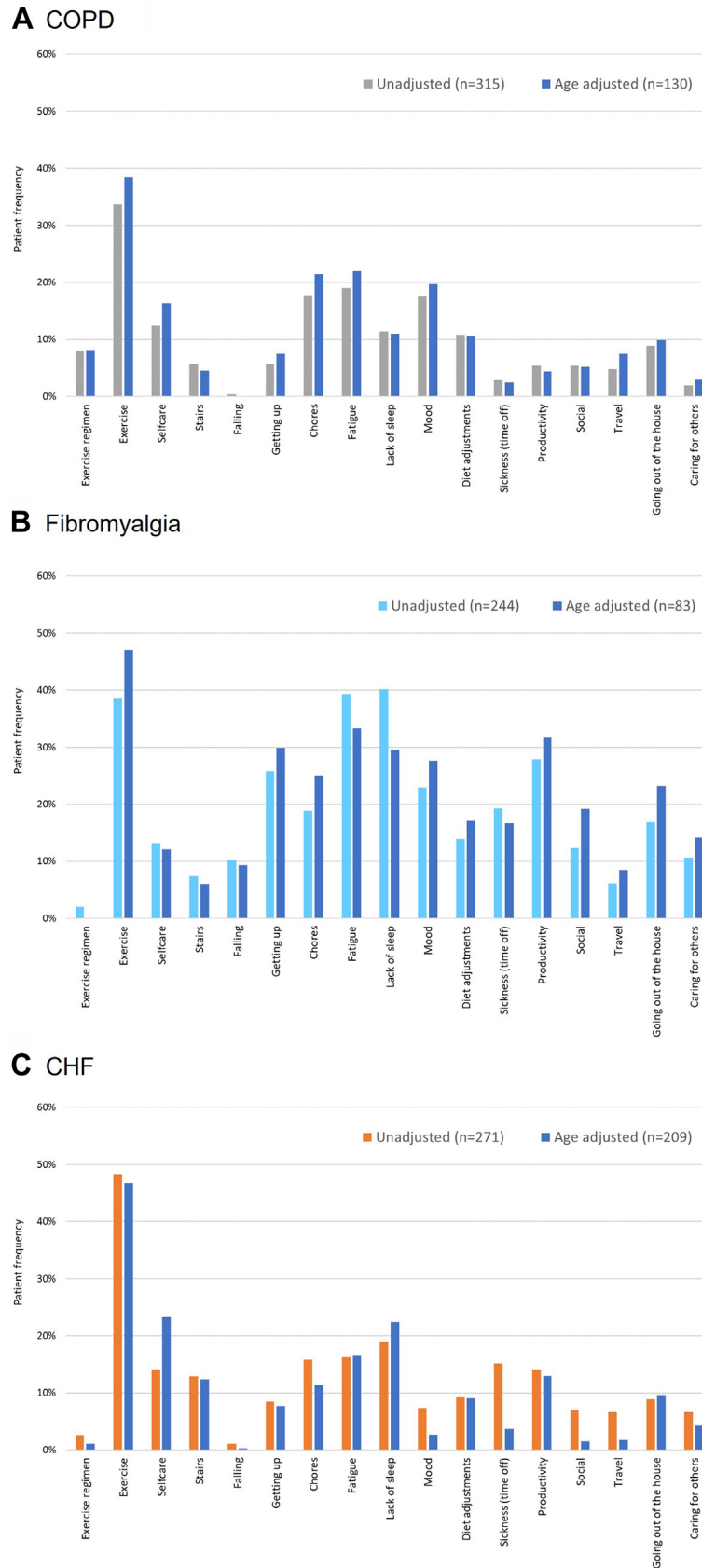
Taking the most frequently reported items extracted from the OHB posts related to exercise for patients with CHF, a number of distinct constructs were suggested to be the most meaningful to patients (Table 4^{4,17,18}). Based on these, we identified a number of measures that might be most suited to activity monitor evaluation (purposeful walking episodes, speed of walking), patient-reported outcome measure evaluation (fatigue, difficulty climbing stairs, cardiovascular exercise, difficulty doing household chores, speed of movement, fear of exercising, and difficulty standing), and performance outcome measures (difficulty climbing stairs, cardiovascular exercise, and difficulty standing).

Discussion

Social media data may offer a different approach to the collection of patient perspectives on disease and its treatment. Uniquely, the data obtained from social media, such as that posted on OHBs, offers an unsolicited insight into living with disease in comparison with prospective study approaches, such as those using pre-defined questioning based on an interview guide. Online, patients discuss the aspects of health that are most meaningful and impactful to them, which provides a valuable perspective to outcome measure developers and those seeking to understand the impact of the disease. At a minimum, information gathered from social media can be used to inform the development of interview guides for conventional studies to ensure that questioning covers the topic areas most important to patients. Nevertheless, this study has shown that social media data may provide valuable insights that can form the starting point for endpoint developers (Table 4^{4,17,18}).

The high-level themes identified most frequently in all conditions were exercise, fatigue, lack of sleep, and difficulties performing chores. This is consistent with what is already understood about these diseases. For example, a qualitative study in patients with CHF reported housekeeping and walking among the 3 most reported difficulties of activities of daily living¹⁹; and fatigue and difficulty sleeping have been identified as common concerns in fibromyalgia²⁰ and COPD.²¹ Further, changes in mood or mental health affecting activity was identified frequently in the COPD and fibromyalgia cohorts. This is consistent with literature reports in

Figure 1. Frequency of individuals providing activity-related posts: unadjusted and age-corrected frequencies.



CHF indicates chronic heart failure; COPD, chronic obstructive pulmonary disease.

Table 3. Aspects of health related to physical activity derived from online health board posts for patients with congestive health failure (n = 142).

| Item | Frequency (%) | Age-adjusted relative frequency % | Example quote (paraphrased) | Measure |
|---|---------------|-----------------------------------|--|-------------|
| Aspect of health: walking related (n = 95/142, 66.9%) | | | | |
| Unable to walk very short distance without resting | 65 (45.8%) | 67.4% | "I could not walk the 3 blocks from the car park to my workplace" "I feel faint and weak, my heart pounds, I get red in the face, and I feel queasy and short of breath even when trying to walk a short distance like 50 meters" | AM |
| Only able to walk 5 minutes before resting | 6 (4.2%) | 0.7% | "I need to stop and catch my breath when I walk for 5 minutes" | AM |
| Only able to walk 10 to 20 minutes before resting | 12 (8.5%) | 1.1% | "I need to sit and take a rest once I have walked for 15 minutes" | AM |
| Able to walk for half an hour or a couple of miles a day | 14 (9.9%) | 3.6% | "Before CHF I would run 5 miles a day, now I can walk a couple of miles a day" | AM |
| Able to walk up to 10 k | 2 (1.4%) | 0.8% | "On a flat route, I am now able to walk 10 km" | AM |
| Unable to walk by the end of the day | 1 (0.7%) | 0.2% | "It is difficult to walk towards the end of the day as my feet become swollen" | AM |
| Unable to walk without a support | 3 (2.1%) | 1.4% | "I need a walker to go more than 20 steps or so" | PROM |
| Able to walk unlimited with/without support | 2 (1.4%) | 0.3% | "With a support, I can walk most of the day" | AM |
| Difficulty walking on an incline | 2 (1.4%) | 0.9% | "Even at my new slow pace, it's difficult for me to go up even the slightest inclines" | PROM |
| Need oxygen to walk | 2 (1.4%) | 0.9% | "I depend on oxygen to move and stand – I need at least 15 liters when walking, 10 liters when doing things in the house like standing to cook, and 6 liters when sitting or sleeping" | PROM |
| Aspect of health: intensity of exercise (n = 23/142, 16.2%) | | | | |
| Have to move more slowly than before CHF | 8 (5.6%) | 2.2% | "It makes me so upset because I cannot keep up the pace anymore – my children have to keep stopping and waiting for me" | AM, PROM |
| Able to do cardio on home gym equipment or outside, run/bicycle or other intense exercise | 11 (7.7%) | 1.1% | "I use various cardio fitness machines at home – an old rowing machine, an elliptical, and a stationary bike, for cardio and flexibility" "Before starting treatment he was unable to walk even a block without becoming breathless, now he is able to cycle for 8 miles and feel fine" | AM, PROM |
| Limitations on intensity of workouts | 2 (1.4%) | 1.0% | "I can workout, but not at the high intensity I was able to" | AM |
| Cannot do more than light walking | 2 (1.4%) | 0.2% | "I get breathless and faint, so I can't do more than light walking" | AM |
| Get dizzy exercising | 1 (0.7%) | 0.0% | "Every time I try to exercise I get really dizzy" | PROM |
| Aspect of health: strength/flexibility (n = 5/142, 3.5%) | | | | |
| Able to do Yoga | 3 (2.1%) | 0.4% | "I do yoga stretching exercises on my bed" "I do yoga and I find that this helps with my breathing" | PROM |
| Able to lift light weights | 2 (1.4%) | 0.0% | "To help with muscle tone and flexibility I lift lighter weights" | PERFO, PROM |
| Aspect of health: sitting and lying (n = 7/142, 4.9%) | | | | |
| Difficulty sitting upright | 4 (2.8%) | 0.5% | "I find it difficult to sit upright for long" "I can hardly sit up" | PROM |
| Difficulty lying flat or lying without propping head | 3 (2.1%) | 0.7% | "I needed to prop my head when lying" "Sometimes she would sleep in an armchair at night as she found it too difficult to breathe lying flat" | PROM |

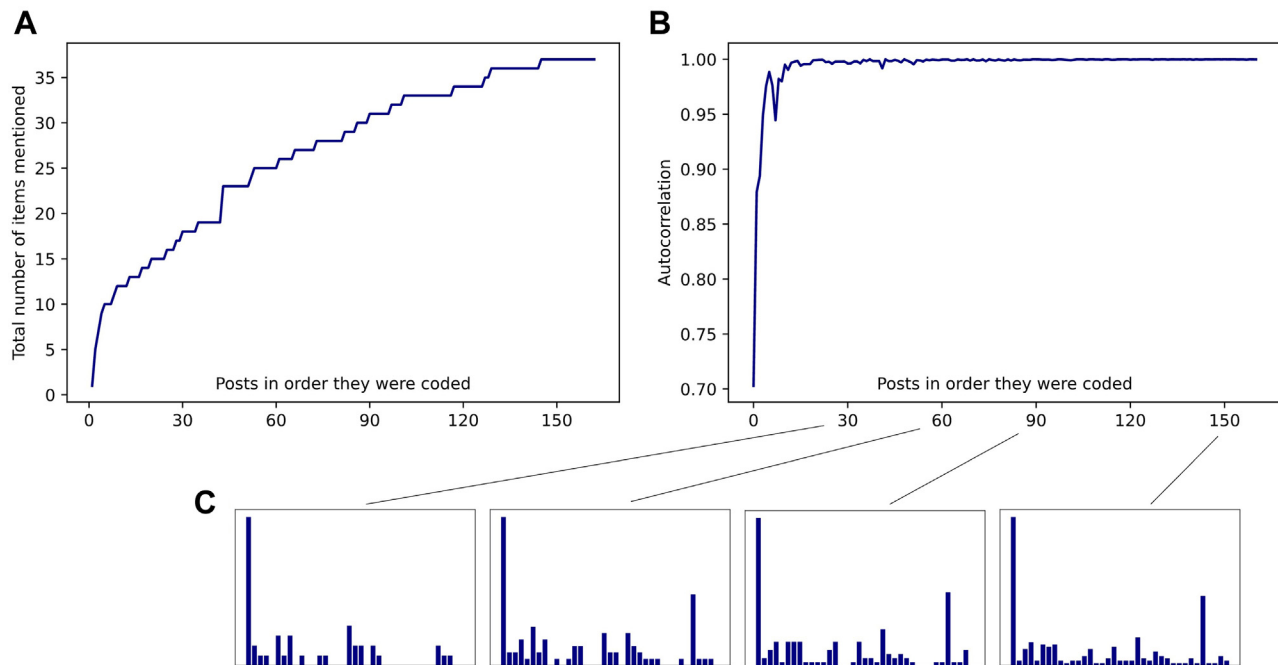
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Table 3. Continued

| Item | Frequency (%) | Age-adjusted relative frequency % | Example quote (paraphrased) | Measure |
|--|---------------|-----------------------------------|--|-------------|
| Aspect of health: balance related (n = 1/142, 0.7%) | | | | |
| Unsteady when walking/fear of falling | 1 (0.7%) | 0.0% | "I can see that he has become more and more unsteady when he walks. He's afraid of falling over" | PROM |
| Aspect of health: self-care (n = 5/142, 3.5%) | | | | |
| Difficulty showering or bathing | 4 (2.8%) | 3.8% | "Trying to have a shower has become an ordeal" "He is now unable to shower, or move around through the house" | PROM |
| Difficulty dressing/undressing | 2 (1.4%) | 0.2% | "I need to allow about 45 minutes to have a bath and get my clothes on" | PROM |
| Aspect of health: activities of daily living (n = 31/142, 21.8%) | | | | |
| Difficulty doing household chores | 9 (6.3%) | 7.0% | "Doing small household chores have become huge tasks that take all my energy and oxygen, even to do in a half-assed manner" "I get short of breath when doing household chores" "I need to sit for 30 minutes after folding a load of laundry" | PROM |
| Difficulty going up stairs | 12 (8.5%) | 7.6% | "I get short of breath going up steps" "I still can't walk up a flight of stairs without getting exhausted" | PERFO, PROM |
| Difficulty bending | 3 (2.1%) | 0.7% | "I could not bend over due to swelling up from the waist down" | PERFO, PROM |
| Difficulty raising arms/limited upper body strength | 2 (1.4%) | 0.6% | "Raising my arms to a certain point really gets me" | PERFO, PROM |
| Difficulty standing for periods | 6 (4.2%) | 0.6% | "I need to leave others in the queue at the shops, as standing and waiting really kills me" | PERFO, PROM |
| Difficulty getting up from a chair | 2 (1.4%) | 0.0% | "I can't easily get up from a chair without some help" | PERFO, PROM |
| Driving is an effort | 1 (0.7%) | 0.2% | "I find driving tough now, but I am able to do it" | PROM |
| Difficulty lifting/carrying | 4 (2.8%) | 0.2% | "I don't carry a bag now, I don't have it in my arms and legs to do this" "I can't lift more than 10 kg" | PERFO, PROM |
| Aspect of health: fatigue related (n = 32/142, 22.5%) | | | | |
| Able to be active/work, but hit by occasional days of fatigue | 4 (2.8%) | 0.6% | "Every month or so I just get wiped out and need a day off work to recover" | PROM |
| Chronic fatigue | 28 (19.7%) | 23.0% | "I am tired, so tired, all the time" | PROM |
| Unable to exercise at all on bad days | 1 (0.7%) | 0.2% | "I can't exercise on my bad days" | AM, PROM |
| Aspect of health: fears (n = 7/142, 4.9%) | | | | |
| Afraid to exercise or do certain activities | 7 (4.9%) | 1.7% | "I'm scared of doing anything that might trigger a shortness of breath episode" | PROM |
| Aspect of health: pain (n = 3/142, 2.1%) | | | | |
| Pain when exercising | 3 (2.1%) | 0.2% | "He really gets a lot of pain when he walks" | PROM |
| Aspect of health: sex-life related (n = 1/142, 0.7%) | | | | |
| Limitations on sex life | 1 (0.7%) | 0.0% | "I rarely have sex now. I tell my partner that if it kills me, at least I'd go out happy!" | PROM |
| Aspect of health: temperature related limitations (n = 3/142, 2.1%) | | | | |
| Difficulty dealing with high outdoor temperatures | 3 (2.1%) | 1.4% | "I find hot weather really troublesome" | PROM |

AM indicates activity monitor; PERFO, performance outcome measure; PROM, patient-reported outcome measure.

Figure 2. Saturation analysis for activity-related CHF posts showing (A) cumulative increase in number of items as posts were coded and (B) correlation between overall frequency distribution of items from one post to the next. Example frequency distributions are shown in (C) to illustrate convergence to the final result.



CHF indicates chronic heart failure.

which depression and anxiety have been identified as key contributors to quality of life in fibromyalgia²² and depression associated with reduced physical activity in COPD.²³ Our study identified difficulties with self-care in the CHF and COPD cohorts, in line with literature reports of difficulty bathing/showering and dressing.^{24,25} Productivity and time off because of sickness were identified in the fibromyalgia and CHF cohorts, which may reflect the higher proportion of patients of working age in these cohorts (Table 2). Stair climbing also was identified as a key theme in the CHF cohort, which is consistent with the study of Dunlay et al,¹⁹ which identified this as the most problematic of 9 activities of daily living in this patient population.

In the detailed analysis of patients with CHF, we identified a number of meaningful aspects of health important to patients which have good face validity with what is already known about this disease.^{19,24} Alongside each, we identified possible measurement approaches, ranging from patient-reported outcomes (eg, difficulty doing household chores), performance outcomes (eg, difficulty going up stairs), and measurement using a wearable activity monitor (eg, ability to walk a short distance without stopping).

Similar use of social media data has been reported by other researchers. One study, using social media listening as a source of patient experience data reported greater understanding about patient experiences and unmet treatment needs in dry eye disease.²⁶ Freeman et al²⁷ reported an analysis of 5663 social media posts sourced from open blogs on health boards published by patients with COPD and used a neural network approach to generate a dictionary of words and phrases used by patients to describe their symptoms. This study successfully provided insights into symptoms and the impact of the disease. Their analysis was limited by the inability to extract demographic features associated with the patient sample, such as age and sex. Wolffsohn et al²⁸

used social media data to provide insights into the impact of presbyopia (age-related deterioration of near vision) on quality of life. They concluded that the robustness and relevance of their findings should be confirmed with prospective qualitative research. A limitation in the use of social media data is the inability to explore concepts in greater depth than the posts themselves provide. For example, in our study, it was not possible to probe more deeply to understand how long/intensive a meaningful walking episode should be. This makes social media insights at least a valuable starting point for qualitative research.

McCarrier et al²⁹ performed a feasibility study recruiting patients with leukemia from an online health community to answer online questionnaires and telephone interviews to generate concept elicitation data to support patient-reported outcome measure development. Although the study illustrated the potential of using social media platforms as a vehicle to recruit patients for concept elicitation studies, it was noted that the participants tended to be younger and had a higher proportion of females than expected in the patient population as a whole. This same phenomenon was also noted in our work and is a likely consequence of the demographic of OHB users. Nevertheless, because demographic information was accessible for many of the individuals included in our study (particularly for the CHF patient sample), we were able to apply weightings to adjust our sample to mirror the expected age distribution of the true patient population. Interestingly, this approach delivered the same key aspects of health, although the ranking of each in terms of frequency did change. For fibromyalgia, for example, lack of sleep moved the highest to the fifth ranked impact. In this case, many of the top impacts had similar frequencies, and this change in rank is likely a feature of this and the small sample for whom age could be derived. Nevertheless, both adjusted and unadjusted data identified lack of

Table 4. Endpoint development considerations for aspects of health related to physical activity derived from online health board posts for patients with congestive health failure (n = 142).

| Aspect of health | Items included | Endpoint considerations | Measurement approach |
|---|---|--|---|
| Purposeful walking | <ul style="list-style-type: none"> • Unable to walk very short distance without resting • Only able to walk 5 minutes before resting • Only able to walk 10 to 20 minutes before resting • Able to walk for half an hour or a couple of miles a day | <ol style="list-style-type: none"> 1. Definition of purposeful walking, for example, walking at a regular cadence or speed without taking a significant break in stepping.⁴ 2. Definition of a pertinent length of purposeful walking episode to be meaningful (eg, 5, 10, 30 minutes).⁴ | Wearable activity monitor able to measure steps and stepping rate. |
| Fatigue | <ul style="list-style-type: none"> • Able to be active/work, but hit by occasional days of fatigue • Chronic fatigue | Qualitative measurement of fatigue. | Patient-reported outcome measure, for example, PROMIS Fatigue short form. ¹⁷ |
| Difficulty going upstairs | <ul style="list-style-type: none"> • Difficulty going up stairs | Qualitative or quantitative measurement of stair climbing capability. | Patient-reported outcome measure, or performance outcome measure such as a short stairclimbing test. ¹⁸ |
| Cardiovascular exercise | <ul style="list-style-type: none"> • Able to do cardio on home gym equipment or outside run/bicycle or other intense exercise | <ol style="list-style-type: none"> 1. Qualitative or quantitative measurement of cardiovascular exercise capability. 2. Is it important to capture what the patient elects to in real life, and/or what the patient is capable of doing? | Patient-reported outcome measure, or performance outcome measure such as a 6-minute walking test or treadmill/cycle test. |
| Difficulty doing household chores | <ul style="list-style-type: none"> • Difficulty doing household chores | Qualitative measurement. | Patient-reported outcome measure. |
| Speed of movement | <ul style="list-style-type: none"> • Have to move more slowly than I have done before CHF | Qualitative or quantitative measurement of walking speed. | Wearable activity monitor able to measure speed or stepping rate, or patient-reported outcome measure. |
| Fear of exercising | <ul style="list-style-type: none"> • Afraid to exercise or do certain activities | Qualitative measurement. | Patient-reported outcome measure. |
| Difficulty standing for periods of time | <ul style="list-style-type: none"> • Difficulty standing for periods | Qualitative or quantitative measurement. | Patient-reported outcome measure, or performance outcome measure. |

CHF indicates chronic heart failure; PROMIS, Patient-Reported Outcomes Measurement Information System (PROMIS Health Organization, River Forest, IL, USA).

sleep as a meaningful aspect of health. We recommend inspection of both unadjusted and adjusted data in drawing conclusions. The more detailed coding of activity of CHF exercise-related impacts showed a shift toward lower intensity/duration—for example a higher relative frequency reporting difficulties walking a short distance, with lower relative frequencies of reports of walking for longer times/distances. This seems to have reasonable face validity given that the age adjustment will have applied a lower importance to the posts of younger individuals in our sample.

Although useful to assess the robustness of findings, a limitation of such straightforward mathematical adjustment of the demographic distribution from social media samples is that we may rely too heavily on a few samples in under-represented areas of the age distribution—for example, the older users. This can be mitigated, as we propose, by considering both the adjusted and unadjusted findings when drawing conclusions. Alternatively, extracting social media data samples large enough to improve coverage and/or applying debiasing techniques may similarly mitigate this potential issue, even in the case that the true age distribution of the disease is unknown.³⁰ Although the ages of patients could only be derived for a small proportion of patients in the fibromyalgia sample, overall and age-adjusted results did not differ considerably for each disease group. A further limitation of

our work is that we adjusted only for age and not for other demographic factors measured, such as sex. If adjusting for multiple demographic factors, dealing with the limitations of missing data would need to be considered, as described above. Furthermore, our choice of language and OHBs limited us to English speaking patients from the US, UK, and Canada; therefore, our findings should be considered within that context.

Confirmation of diagnosis is a limitation of studies relying on social media data. Conventional concept elicitation studies prospectively recruit patients, during which diagnosis and severity of the condition can be accurately identified. In our study, it would have been valuable, for example, to explore whether differences in volunteered meaningful aspects of health derived from the CHF sample exist between severity groups based on New York Heart Association class, but along with diagnosis confirmation, these data cannot be established credibly from OHB data. Other studies cite this limitation, for example, Farrar et al,³¹ in their study of patient perspectives of tardive dyskinesia using social media data. Proactive outreach to OHB users in the sample, as described by McCarrier et al²⁹ may mitigate this, but it may be impractical and subject to low response rates.

In our approach we used machine learning to aid the initial identification of pertinent posts, by removing inappropriate and

duplicate posts automatically. This approach was effective in significantly reducing the need for manual coding without losing pertinent information. We also used our data to train machine learning algorithms to perform the more detailed coding activity, and although we did not benefit from this in this study, we anticipate efficiency gains in similar future studies resulting from this activity. This would enable coders to spend more time curating, and less time manually coding, individual posts.

Finally, although social media data samples are often much larger than those achieved in cognitive interview studies, the question of whether concept saturation has been reached remains important. We used autocorrelation between concepts identified over time to measure the convergence of findings as an approach to objectively quantifying concept saturation, which we feel is an important methodological approach when analyzing social media data in this way.

Conclusion

We have demonstrated that social media data can provide valuable, unsolicited information related to meaningful aspects of health in patients with a variety of chronic health conditions. This information may be valuable to inform further concept elicitation work and clinical trial endpoint development.

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