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Distributed Knowledge in an Online Patient Support Community: Authority and Discovery

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ABSTRACT

Amyotrophic Lateral Sclerosis (ALS) is a progressively debilitating neuro-degenerative condition that occurs in adulthood and targets the motor neurons. Social support is crucial to the well-being and quality of life of people with unpredictable and incurable diseases such as ALS. Members of the PatientsLikeMe (PLM) ALS online support community share social support but

also exchange and build distributed knowledge within their discussion forum. This qualitative analysis of 1000 posts from the PLM ALS online discussion examines the social support within the PLM ALS online community, and explores ways community members share and build knowledge. The analysis responds to three research questions: RQ1: How and why is knowledge shared among the distributed participants in the PLM-ALS threaded discussion forum?; RQ2: How do the participants in the PLM ALS threaded discussion forum work together to discover knowledge about treatments and to keep knowledge discovered over time?; and RQ3: How do participants in the PLM-ALS forum co-create and treat authoritative knowledge from multiple sources including the medical literature, health care professionals, lived experiences of patients and "other" sources of information such as lay literature and alternative health providers? The findings have implications for supporting knowledge sharing and discovery in addition to social support for patients.

INTRODUCTION

Social support is crucial to patients' well-being and overall quality of life. It plays an important role in reducing stress, increasing access to emotional and tangible support, and improving medication adherence and compliance with treatment plans (Cohen et al., 2007; Griffiths, Calear, Banfield, & Tam, 2009; Shigaki et al., 2008; Wright & Bell, 2003). Widespread access to social support is facilitated by a growing number of web-based platforms such as social networking sites (e.g., Facebook) and blogs in addition to more traditional approaches like discussion forums and listservs. The ability to participate in supportive communications is particularly valuable for individuals suffering from chronic diseases that may not be widely understood or for which a cure is not yet available (Coulson, Buchanan, & Aubeeluck, 2007; Davison, Pennebaker, & Dickerson, 2000; Lasker, Sogolow, & Sharim, 2005; Mo & Coulson, 2008). As the patient's disease progresses, these opportunities for peer-to-peer knowledge sharing and building are just as important for their caregivers who become increasingly involved in their patient's care and their day-to-day living.

To date, the corpus of research on online social support groups has focused on examining the effects of online social support on the psychosocial functioning and well-being of patients as well as on the types of information exchanged within these networks. In contrast, the current study examines participation in online supportive communications from the perspective of knowledge sharing and creation. Patients and their caregivers play critical roles in building the knowledge base

about day-to-day and caregiving experiences that might not be adequately discussed or discovered in clinical encounters.

The study specifically examines a socially supportive online community of individuals touched by Amyotrophic lateral sclerosis (ALS), including patients, their caregivers, and clinicians. Also known as Lou Gehrig's disease, ALS is a progressively debilitating neuro-degenerative condition that occurs in adulthood and targets the motor neurons. This article explores the ways that members of this community, who are distributed across space and through time, share and build knowledge about this rare and fatal disease whose causes and treatments are largely unknown. Unlike traditional online social support systems, PLM provides formalized mechanisms for members to find other patients like themselves and share their medical data and information about their treatments. In addition, it has the ability to aggregate and visualize this data, which in turn becomes a valuable tool for evaluating the effects of various medications and treatments on patient-reported outcomes (Wicks et al., 2010; Wicks, Vaughan, Massagli, & Heywood, 2011). This unique collaborative sharing environment makes it particularly appropriate for exploring PLM as a locus for knowledge building.

This study examines knowledge-building processes in the PLM-ALS community through the lens of two concepts closely tied to distributed knowledge: *undiscovered public knowledge* and *authoritative knowledge*. The discovery of *public knowledge* is important in communities like PLM-ALS where related information about causes, treatments, symptoms, and co-occurring conditions is not always stored together or clearly linked. It explores the key roles patients and their caregivers play in filtering information, creating knowledge and discovering existing-but-hidden knowledge as their disease progresses; sharing information from multiple sources, people, and systems; and helping one another manage the sometimes complex relationships of authority and expertise among patients, caregivers, health care professionals, and others who provide treatments to people with rare diseases like ALS. And because these exchanges are based on patients' lived experiences, it has become an important resource for understanding this rare disease with implications for the discovery of better treatments and potentially, a cure.

To explore those aspects in the PLM-ALS community, this analysis posed the following research questions:

RQ1: How and why is knowledge shared among the distributed participants in the PLM-ALS threaded discussion forum?

RQ2: How do the participants in the PLM ALS threaded discussion forum work together to discover knowledge about treatments and to keep knowledge discovered over time?

RQ3: How do participants in the PLM-ALS forum co-create and treat authoritative knowledge from multiple sources including the medical literature, health care professionals, lived experiences of patients and "other" sources of information such as lay literature and alternative health providers?

Answering these questions will help us understand how to support knowledge sharing and discovery among distributed groups of patients – particularly, how to help make their knowledge public and maintain it over time. The findings may lead to a better understanding of "authoritative knowledge" and how patients' experiences, knowledge, and opinions are important for the creation of a mutually-agreed upon treatment plan that in turn can improve compliance and enhance the therapeutic alliance between patients and their doctors. Finally, these findings will have implications for designing and for improving systems (such as PLM) in order to better facilitate knowledge sharing while minimizing the chances for misinformation. This in turn may facilitate the discovery of better treatments for this rare and debilitating disease and help improve patients' quality of life.

BACKGROUND

PatientsLikeMe and ALS

PatientsLikeMe (PLM; http://www.patientslikeme.com/) is an online community that uses various technologies including social media and user-generated content to facilitate the exchange of social support. The site couples the functionality of online discussions with tools to report and review patients' medical histories (Wicks et al., 2010). Symptoms, treatments and outcomes are charted on individual profiles and aggregated into interactive reports. On PatientsLikeMe, patients can review and respond to changes in their own medical history, use the records of these changes when interacting with their physicians, find other people similar to themselves, and hold data-centered discussions of health. The website offers free membership and supports more than 175,000

(as of January 2013) patients with rare illnesses such as Amyotrophic Lateral Sclerosis, Multiple Sclerosis, and Parkinson's Disease.

The current study focuses on a qualitative analysis of the Amyotrophic Lateral Sclerosis (ALS) community within PLM. ALS is a rare and incurable disease affecting approximately 30,000 Americans (Wijesekera & Leigh, 2009). This fatal, neurodegenerative disease attacks the nerves and muscles, resulting in the progressive loss of voluntary motor function which eventually leads to difficulties in speaking, swallowing, and breathing. While ALS contributes to the weakening of voluntary motor functioning and eventual paralysis, most patients can still think clearly and rely on various assistive technologies to aid in communication. The ability to communicate with others is an important aspect of patients' ability to cope with their disease and remain active participants in their own care.

As in the case of other rare, incurable diseases, ALS patients live with great uncertainty. In the majority of cases, onset occurs in the limbs where it causes spasms and loss of manual dexterity, muscular atrophy, weakness and finally, paralysis (Wijesekera & Leigh, 2009). In ALS, the paralysis progresses leading to respiratory failure and death within 2-3 years for bulbar onset cases and 3-5 years for limb onset cases (Wijesekera and Leigh, 2009). Riluzole is currently the sole FDA-approved drug for the treatment of ALS, but it only increases median survival by two to three months (Miller, Mitchell, & Moore, 2012) and costs $12,000 per patient (Messori, Trippoli, Becagli, & Zaccara, 1999). Clinical guidelines for the treatment of ALS lack empirical evidence and there is little ongoing research that might improve them. The guidelines that do exist rely on minimal evidence and small studies conducted with only 5 to 20 patients per trial arm (Miller et al., 2009). Of the few trials conducted between 1998 and 2007, only one was a Class I randomized controlled trial rigorous enough to inform treatment recommendations.

Without substantive research, clinical guidelines remain vague and many aspects of the condition remain understudied. As a result, there is great need for additional information on how to best care for people with ALS. Spurred by this challenge, brothers Benjamin and Jamie Heywood founded PatientsLikeMe in 2004 in response to the lack of treatment and care options for their brother, Stephen. Since then, PatientsLikeMe and its members have conducted studies about several aspects of ALS to fill gaps in medical research – e.g., patient preferences in the treatment of cognitive decline in ALS (Wicks & Frost, 2008), the prevalence of depression in ALS (Wicks et al.,

2007), and the efficacy of an experimental treatment, Lithium, on clinical outcomes (Wicks, et al., 2011). While these are not randomized controlled trials, these studies provide empirical evidence about otherwise understudied issues related to ALS. PLM members associate the routine use of the site with improved quality of life and care in several areas including: learning about symptoms, understanding the side-effects of treatment, and improved treatment outcomes for particular conditions (Wicks, et al., 2010). Knowledge sharing within online social support groups like PLM is crucial for helping improve the day-to-day quality of life of patients and, possibly, hasten improvements in the treatment of rare diseases like ALS. This is also particularly important in situations where healthcare providers and clinical experts do not have all the answers. The following section explores knowledge creation among members of this community through processes associated with the concept of distributed knowledge – specifically, the exchange of undiscovered public knowledge and authoritative knowledge related to ALS.

Distributed Knowledge within the PLM/ALS Community

Participants in the PLM-ALS discussion forum co-create knowledge about ALS and how to manage their disease trajectories by sharing information related to their diagnosis, symptom management, and drug and other treatments (Beaudoin & Tao, 2007; Berkman, 1995; Israel, 1985; Leimeister, Schweizer, Leimeister, & Kromar, 2008). As with other online communities, individuals participating in the PLM/ALS discussion board are not physically co-located and their interactions are asynchronous. The knowledge they build together is created through processes that are mainly made visible to us through the central hub of the online discussion. Less obvious in these forums are the contributions to knowledge building by other actors who do not directly contribute to the discussion (for example, the medical professionals who treat the ALS patients, their caregivers, the creators of literature they read, and others to whom they turn for advice, support, and information). Halpern and Moses (1990) describe such phenomena as distributed knowledge, "knowledge that is distributed among the members of the group, without any individual agent necessarily having it" (Halpern & Moses, 1990, p. 550). In other words, "a group has distributed knowledge of a fact φ if the knowledge of φ is distributed among its members, so that by pooling their knowledge together the members of the group can deduce φ, even though it may be the case that no member of the group individually knows φ" (Fagin, Halpern, Moses, & Vardi, 2003, p. 3).

Distributed knowledge *processes* occur when multiple actors are engaged in building, distributing, storing, using, or otherwise interacting with knowledge. Distributed knowledge processes can occur among multiple people and among different and disparate systems (computer systems, institutional systems, etc.) (Haythornthwaite, 2006). In such cases, physical distance (O'Leary & Cummings, 2007; Olson & Olson, 2000), cultural differences, and differences in practice (Haythornthwaite, 2006) affect these knowledge processes and what is built, discovered, re-discovered or "lost" over time. From this perspective, temporal or chronological differences are also important, and vary from short term ones such as time-zone differences affecting collaborative knowledge work (Cummings, 2011) to long term ones in which what is known does not persist across time. A tragic yet apt example of knowledge becoming "unknown" over time is that of the volunteer who died at Johns Hopkins University in 2001 after inhaling hexamethonium as part of a research study, because even though:

> [T]he supervising physician, Dr. Alkis Togias, made "a good-faith effort" to research the drug's adverse effects, his search apparently focused on a limited number of resources, including PubMed, which is searchable only back to 1966. Previous articles published in the 1950s, however, with citations in subsequent publications, warned of lung damage associated with hexamethonium. (Perkins, 2001, n.p.)

Distributed knowledge is thus not only distributed among members of a group or social world but is distributed across time and subject to decay as a result (Cramton, 2001). Knowledge can be distributed across multiple people within a social world but also across multiple social worlds, making it difficult to keep knowledge "known" (Haythornthwaite, 2006). Over time, the amount of useful knowledge held by individuals in distributed groups may decrease as they increasingly rely on information that is centrally stored (Griffith, Sawyer, & Neale, 2003).

Distributed knowledge processes tend to occur particularly in health-related arenas. For example, medical knowledge is typically fragmented across different disciplines, specialties and systems making it difficult to recognize meaningful connections between disparate sources of evidence (*undiscovered public knowledge*). Moreover, that which patients may accept to be meaningful medical knowledge (*authoritative knowledge*) requires thoughtful consideration of information from multiple sources and individuals with different perceived levels of expertise.

Undiscovered Public Knowledge

In framing the concept of undiscovered public knowledge (UPK) Swanson (1986, p. 103) wrote: "independently created pieces of knowledge can harbor an unseen, unknown, and unintended pattern." What is known and generally accepted—that is, *public*—in one place, group, discipline, or arena may have a relationship with knowledge from another arena, but these connections can remain undiscovered by people in either arena. Moreover, knowledge in one area may reinforce or refute what is known elsewhere or it may fill in a gap elsewhere. For example, those in one area (Arena A) may know they have a knowledge gap but do not know how to fill it, whilst those in another area (Arena B) may have a piece of knowledge that could fill a gap existing elsewhere (Swanson, 1986, p. 109). There may be a "missing link in the logic of discovery" (Swanson, 1986, p. 110) where a known relationship between A and B, held separately from a known relationship between B and C, makes it difficult to discover a relationship between A and C. Or, what may be hidden is the "cumulative strength of individually weak tests" (Swanson, 1986, p. 111), where what is known on the basis of relatively small studies or samples in disparate settings or disciplines could be combined to form a more persuasive aggregate finding. In all cases, the important factor is that the knowledge is simultaneously public, in the sense that it is accessible to people and to information systems, and also undiscovered, in the sense that the salient relationships or mechanisms that would render the knowledge usable remains hidden.

The literature provides examples of salient characteristics of UPK in medical settings with most of this research focusing on information retrieval systems: developing systematic approaches to drug repurposing using various information retrieval techniques to extract UPK from the biomedical literature (Andronis, Sharma, Virvilis, Deftereos, & Persidis, 2011); building systems to support drug discovery by extracting, associating, and storing chemical terms from MEDLINE records (Baker & Hemminger, 2010); building systems to reveal UPK that lies hidden in the literature on bioterrorism (Dang et al., 2009); and using UPK to test a knowledge discovery system in MEDLINE (Koike & Takagi, 2007) and vice versa—using a knowledge discovery system in MEDLINE to test UPK (Gordon & Lindsay, 1996).

Conversely, some research acknowledges the potential social aspects of discovering public knowledge where knowledge discovery also relies on interpersonal interactions and emotional negotiations. For example, social information foraging (Chi, Pirolli, & Lam, 2007; Pirolli, 2009) uses UPK as an informing concept to add "social dimensions to how people both use and create information in decentralized information systems" (Wohn, Lampe, Vitak, & Ellison, 2011, p. 1).

Authoritative Knowledge

Authoritative knowledge is "that knowledge taken to be legitimate, consequential, official, worthy of discussion and useful for justifying actions by people engaged in accomplishing a given task" (Suchman & Jordan, 1997, p. 98). Jordan stresses, " By authoritative knowledge I mean…the knowledge that participants agree counts in a particular situation, that *they* see as consequential, on the basis of which *they* make decisions and provide justifications for courses of action. It is the knowledge that within a community is considered legitimate, consequential, official, worthy of discussion, and appropriate for justifying particular actions by people engaged in accomplishing the tasks at hand." (Jordan, 1997, p. 58)

Authoritative knowledge is socially co-constructed by members of a community, and is not defined by hierarchies of power or authority. It is something to be built, rather than sought, and includes contributions of opinion, emotion, bodily experience, and social experience. Jordan writes that "By authoritative knowledge I specifically do *not* mean the knowledge of people in authority positions" (Jordan, 1997, p. 58). Authoritative knowledge is both situated in a community and is "assembled … from a shared history and from the experience of those present" and involves input from participants of varying "ranks" as seen from the outside (e.g., the patient, family, medical professionals, lay caregivers, and others) but who, within the specific situation, all contribute to a "shared store of knowledge" (Jordan, 1997, p. 60).

Conflicts arising during the construction of authoritative knowledge can occur when patients' knowledge (i.e., their experience) contradicts that held by medical professionals, or when multiple experts consider contradictory "facts" to be "known" (Kingfisher & Millard, 1998). In both cases, conflict arises when multiple parties do not share an understanding of what knowledge is meaningful in their setting, regardless of the perceived “authority” of experts conferred on them by virtue of their role or educational attainment (Kingfisher & Millard, 1998).

Processes governing the construction of authoritative knowledge are demonstrated not only when people are making decisions about medical treatments but also when they are making or justifying claims related to their knowledge about the efficacy of such treatments (Oliphant, 2009). For example, making decisions about treatments requires resolving conflicts among published and established knowledge in the medical literature, clinical experience of health care professionals, "other" sources of information (such as lay literature and alternative health providers) whose

authority may be questioned within the framework of established medical practice, and lived experiences of patients (McCoyd, 2010). Treatment decisions, which ideally should be mutually developed and agreed upon by patients and their doctors, may in reality reflect uneven power relationships, and their application (by the health professional) or uptake (by the patient) may not match the knowledge-based expectations of all those involved (see, e.g., Kingfisher & Millard, 1998).

PLM provides a platform where participants can socially construct their own authoritative knowledge, that is, the knowledge considered to be authoritative within that community based on their shared way of seeing the world. It exists apart from the enforced hierarchy of the clinical setting, a separation that allows the community freedom about what knowledge they can consider to be legitimate. But, as will be seen in the following data analysis, it does not exist in a vacuum, nor does it involve a complete rejection of publicly accepted forms of clinical knowledge embodied in medical literature and disseminated by healthcare professionals. Instead, those become part, but not all, of the basis for the knowledge collaboratively built within the PLM ALS group.

METHODS

Data Source: PLM/ALS Discussions

The current study focuses on a qualitative analysis of the ALS community within PLM. The PLM-ALS community allows its members to interact and discuss various topics associated with ALS, and participate in research studies (Bedlack, Wicks, Heywood, & Kasarskis, 2010; Turner et al., 2011; Wicks, Massagli, Wolf, & Heywood, 2009; Wicks, Vaughan, Massagli, & Heywood, 2011). Through research collaborations, PLM also permits analysis by researchers to uncover new findings that would be difficult to explore in traditional research studies (Frost, Okun, Vaughan, Heywood, & Wicks, 2011). This study analyzes a snapshot of data from PLM's ALS threaded discussion board, including 1000 messages randomly selected from a total of 2500 messages posted between February 2006 and November 2008. This time period coincides with the initial launch of the PLM-ALS community and represents a time when more active and concentrated knowledge sharing about this rare disease first took place among ALS patients and their caregivers on the web. Five coders coded 200 posts each from the full data set using initial codes created through an iterative and inductive process described in more detail in the next section. The data are characterized in Table 1.

[INSERT TABLE 1 HERE]

Qualitative Data Analysis

This project applied an inductive thematic analysis method to examine messages posted to the PLM-ALS discussion forum (Charmaz, 2006; Schrire, 2006; Strauss & Corbin; 1998). Codes for the data, used to describe the content, purpose, and context of each individual post, were developed through an inductive analysis of randomly-selected posts (Dickey, Burnett, Chudoba, & Kazmer, 2007). The authors developed the codes closely following procedures described by Dickey et al. (2007, p. 53): To begin, five coders individually examined 25 randomly-selected posts from the dataset without setting pre-defined categories. The authors then used an inductive, iterative process of discussion and additional coding to develop a list of codes to guide coding of the full set of posts. This ongoing process was also used to resolve disagreements about coding (Ahuvia, 2001) resulting in one consistent corpus of coded data (Bradley, Curry, & Devers, 2007; Steinke, 2004). Table 2 lists the final code categories and sub-categories that were developed through this process.

[INSERT TABLE 2 HERE]

*To save space, the full list of 117 codes is available on request from the corresponding author; the subsequent discussion takes into account the specific codes that were relevant to the conceptual lenses brought to this analysis.

The concepts associated with distributed knowledge, undiscovered public knowledge, and authoritative knowledge were examined by focusing on interactions where participants were asking or answering questions for one another (distributed knowledge); where the level of authority held or perceived to be held by various people or information sources were different (authoritative knowledge); and/or where discussions occurred about topics that overlapped unexpectedly, where different posts shared content-related codes, or when the conversation had included a connection between the topics in a way that revealed knowledge that was previously undiscovered. This theory-driven approach to purposeful sampling of the data (Coyne, 1997; Patton, 2002) did not force a theoretical framework onto the data; rather, it allowed a means of access to a large dataset using codes that were based exclusively on the content of the posts.

Knowledge shared across multiple participants (RQ1) was indicated by posts coded using the "purpose" codes listed in Table 3. Posts indicating authoritative knowledge and undiscovered

public knowledge literature (RQ2 and RQ3) were coded with "content" codes. The exchange of undiscovered public knowledge was reflected in the data through a set of codes that included 13 codes associated with drugs and non-drug treatments (see Table 3). Similarly, authoritative knowledge phenomena were examined through a set of codes created for data mentioning care providers (also seen in Table 3). Additional combinations of codes indicated by the literature on AK and UPK were also examined. For example, co-occurrences of any other care provider code with neuro[logical] specialists were examined for their possible relation to AK, because neurological specialists have a high level of outwardly-perceived authority. Two codes to indicate cognate conditions that occur with ALS and that were broached as possible causes of ALS were used to examine aspects of UPK in posts focused on symptoms and pulled from threads related to drug and non-drug treatments.

[INSERT TABLE 3 HERE]

The codes were not used as restrictive criteria to determine which posts could and could not be examined. Neither did we cherry-pick only those posts and threads that seemed interesting, because all threads referenced by the codes listed above were examined. Rather, the coded posts were used as an entree to whole threads, and the content and coding of those threads led to the examination of related threads that also had distributed knowledge features. This illustrates the use of a second stage of purposeful (snowball) sampling through the data. The shift in unit of analysis at this point was intentional; while the data were originally coded at the level of the post, this analysis is explicitly at the level of the thread, allowing an examination of distributed knowledge across time and among multiple people.

FINDINGS

The findings are organized by the research questions posed above. Related phenomena identified in the background section are also explicated and supported by specific threads from the PLM-ALS discussion board. All posts are presented as originally written, including spelling, punctuation, and spacing; these "errors" in posts were common in the threads as PALS (persons with ALS) have varying symptoms that can make it difficult to type accurately, or they may use speech-to-text devices to produce their posts, which can also increase "errors." Individuals' names have been redacted and threads are identified by researcher-assigned letters for ease of reference.

Distributed Knowledge in the PLM ALS forum

RQ1 asked: How and why is knowledge shared among the distributed participants in the PLM ALS threaded discussion forum? To address this question, we examined threads whose content was coded in ways indicating that knowledge was intended to be created and shared among multiple members of the community (see Table 3). A brief thread (seven posts over two days), Thread F, serves as a short and straightforward exemplar of distributed knowledge. It has the subject line "Loss of appetite from taking scopolamine," and includes contributions from five unique posters, all patients (rather than caregivers, family, etc.). This thread focuses on loss of appetite as a side effect of this medication. The original poster notes a loss of appetite after 5 weeks of scopolamine, and the thread focuses on resolving this side effect via the use of various cannabinoids (3 are discussed). In Thread F, the weight of the collective evidence from multiple users of different cannabinoids is brought together when one participant asks a question about loss of appetite.

Knowledge can also be distributed: (1) across threads, as contributors refer to other relevant threads; (2) across participants with different roles (such as caregivers and patients); and (3) across time, as different threads are re-visited by new participants. An example of all three activities is found in Thread A, which has the subject line "Alternative – No Drugs." A caregiver begins Thread A, which comprises 10 posts, including contributions from nine different patient posters. The thread originally included four posts in three days and is re-visited by new participants eight months later. One poster connects the knowledge shared here across threads by pointing to related discussions elsewhere within PLM about "zero meds" and "not taking anything."

The subsequent sections discuss knowledge building processes within the PLM-ALS community that are associated with undiscovered public knowledge and authoritative knowledge.

Undiscovered Public Knowledge in the PLM ALS Forum

RQ2: How do the participants in the PLM ALS threaded discussion forum work together to discover knowledge about treatments and progress in symptoms and to keep knowledge discovered over time? To address this, we examined posts focusing on treatments, symptoms and disease progress, specifically those referring to drugs and non-drug treatments, and to cognate conditions co-occurring with ALS or broached as possible causes of ALS (Table 4). These posts (and their threads) demonstrate some phenomena of UPK not exclusively related to discoveries from published medical literature.

[INSERT TABLE 4]

Discovering public knowledge about ALS

UPK phenomena were indicated in these posts by knowledge shared or created that reinforces or refutes other knowledge or that fills an expressed gap in knowledge, and that posters co-created out of their individual experiences. In Thread C a PALS asks about the relationship between anti-depressants and insomnia, acknowledging a gap in her knowledge that she hopes can be filled by others in the community:

> I have had ALS for 2 years now.[...] I have been trying to avoid an anti depressant but am changing heart. A week ago I got a prescription for Celexa and after one day stopped because I could not sleep. I took the Celexa in the morning but I still could not sleep. I will try again but does anyone have any suggestions?

A PLM staff member responds that insomnia is "a known side effect of this drug" and recommends that the original poster talk to her doctor about other drug treatments for her depression, but adds: "It's quite possible that thinking about the effects of the drug lead to you being anxious, leaving you unable to sleep. I wouldn't have thought a single dose could have such an effect." The original poster responds explaining that for her, an anti-depressant is not worth increased insomnia because since her ALS diagnosis she has had insomnia that she treats with supplements (melatonin and valerian) and sleep positioning (hospital bed and pillows). She again asks specifically for input from other patients (rather than PLM staff), saying "I was curious to what other PALS take and if the insomnia was common for them and if it subsided after taking it for a while?" Contributions from PALS in the subsequent conversation include information about alternative anti-depressants and separate medications to fight insomnia; reinforcement of the knowledge that ALS often co-occurs with insomnia anyway; and that "older" anti-depressants and relaxants can be viable options to newer drugs. A brief dialog between two PALS explores the possibility of finding an anti-depressant that does not interfere with lithium: one PALS says "I take effexor without it Iam a real fu**ing jerk.they just make thinks easyer. but when i was onn lithium the lithium made the effexor not work so i stopped lithium wish find something that worked together", and another responds "I take Lexapro long with Lithium, have no side effects!" Throughout this thread multiple PALS work to discover possible solutions for "known" problems,

that is: that insomnia co-occurs with ALS; that depression co-occurs with ALS; and that anti-depressants can cause insomnia.

In Thread D, five PALS share their individual experiences with Baclofen, which is used to treat spasticity. The thread demonstrates how they work together to sort out contradictory and complex interactions between the side effects and delivery mechanisms of this drug. The original poster summarizes his experience and explicitly seeks experiences from other PALS:

> I was put on baclofen 1 pill a day.. Symp. got worse. Doc upped to 3 a day...worse yet..Doc upped to 5 a day.. I could not breath, walk, and weak as hell.. Wife cut back to 1 a day.. all symp. went away but the ache in my legs.. I thought it was the als.. It was the damn baclofen..Anyone else have this?

The second poster responds by indicating that the reaction described by the original poster is "known" to her, sharing her own experience with baclofen and another anti-spasticity drug: "I have heard of this reaction before. [...]Talk to your doctor. I tolerate baclofen very well and I am taking around 90 mgs. a day. It helps with the pain and spasticity in my legs. I also take Zanaflex which helps the best in addition to the baclofen." The third poster offers his individual piece of knowledge, saying, "It made me feel the same as you. I took it a few days and stumbled around, slurred speech even more, just a general feeling of increased weakness all over. If you think about it, it makes since. Baclofen is a muscle relaxer." The fourth poster adds another piece to the knowledge mosaic, suggesting that an alternative delivery mechanism (pump rather than oral delivery) might have "far less if any at all side affects." The final poster adds the last piece in direct contradiction to the previous post in favor of the pump. This leaves an overall impression regarding the lack of consensus in the available public knowledge about this treatment. The sharing of these individual cases illustrates the discovery of public knowledge but also demonstrates the complexity and non-absoluteness of knowledge" about treatments:

> Hi,I had a horrible reaction to the baclofen pump!! I walked in the hospital using a walker the day of surgery and I could get up from a sitting position. After surgery I came home that night I couldn't move my legs at all[...]. Off to the ER[....] After 16 hours the pump was turned off, 10 days flat on my back with the worst headache ever, 4 months of PT, I used a walker about a year afterwards. I never was able to get up from sitting again and 6 years later the pump is still in me not running. Beware of the pump!!!!!!!

Thread D (above) illustrated how discovering knowledge is not always a straightforward, linear process. Knowledge can remain undiscovered for various reasons even though it is likely to exist elsewhere or knowledge can be discovered by accident. Two more threads, both of which deal with the topic of frontotemporal dementia (FTD), demonstrate these features of knowledge discovery. Thread L begins with a PLM staff member posting the abstract of an article called "A screening assessment of cognitive impairment in patients with ALS." The thread takes a turn when several patients bring up the issue of their lack of access, or perceived lack of access, to the medical research literature (due to cost and language/writing/jargon). The PLM staff member subsequently posted: "You can subscribe to the jounral here [hyperlink provided in original] but it is nearly $300 a year and is of course written in scientist language. Much of the most interesting ALS research is press-released by ALSA/MNDA/MDA/TDI anyway in much more accessible language." In response, a PALS writes, "I would politely dissent a bit on the value of the journal (expensive as it is) for non-scientists. Some of the articles on psychology and the emotional health of patients are easy enough to understand and the abstracts and discussion sections in most of the higher levels articles can be grasped by laypeople." This thread provides several examples of, and possible reasons for, a known lack of discovery. PALS indicate a shared understanding that cognitive impairment co-occurs with ALS for some patients. However, research on cognitive impairment among PALS lags because most are focused on causes and treatments of ALS; because screening is more difficult (for example, as explained by the original poster, because "cognitive problems are clouded by communications problems,"); and because some findings about the brain (for example about proteins in the brain) are based on post-mortem pathology rather than on "collecting samples from recently diagnosed patients to ensure we're getting proteins from around the time of clinical presentation" (see also Wicks & Frost, 2008).

Analysis of Thread K echoes what was discussed in Thread L (above) -- that the manifestation of FTD in PALS remains largely undiscovered. The original poster, a PALS, shares coping strategies, information on the medications he/she uses, and an outside source (web site) on FTD. The second poster asks: "i wonder if, once you have FTD, you can objectively diagnose yourself"? This post is misunderstood as a joke that is making fun of the original poster and the member who asks the question returns to say, "i AM asking a serious question! will we know when we have it?" Despite the misunderstanding and the resulting 6 posts in which participants do the emotional work of settling the conflict, the thread opens up a discussion about FTD and its co-

occurrence with ALS. A final poster ends by saying: "Thanks for giving an insight into your situation and opening a very neglected area."

Thread K also demonstrates how a piece of public knowledge unrelated to FTD is discovered through the conversation. In the third post in the thread a PALS responds, "I laughed so hard reading this that I spit out the beer I was drinking and nearly peed my pants! Why don't you post the questionnaire for FTD so we can all self diagnose - then, we'll get back to you (or, not)." The problem of incontinence, expressed however facetiously in this post, results in a backchannel private message communication -- the poster subsequently makes public the resulting knowledge discovery by editing their post: "**update: I was just advised via pm [private message] that FDS [feminine deodorant spray, http://www.fds.info/faq/] will help with peeing pants. I didn't know what that was. It's "female deodorant spray"."

Maintenance of discovered knowledge

Two short threads exemplify the challenges of keeping public knowledge discovered within the PLM-ALS community. Thread P illustrates what happens when knowledge discovered is not discussed or evaluated by the community. In essence, the value of this discovered knowledge remains unknown if it is not accepted by the community through use and preserved (in the case of PLM, the official PLM list of ALS symptoms serves as a proxy for this representation and preservation of discovery). The original poster in Thread P thinks his front teeth are eroding but is not certain. Several follow up posts share potential causes (sweet drinks, hard straw, grinding/clenching, teeth-shift caused by ALS) but no solutions, and the original poster never returns to the thread to clarify or verify symptoms. The idea that teeth shifting may be part of ALS is evidently a discovery, at least for this subset of the community. But unlike most other threads, there is no resolution, no concrete suggestion, no reference to the literature, and no suggestion of adding a symptom to PLM's official ALS symptom list – so the discovery is not preserved.

Thread B exemplifies a situation in which public knowledge that is already known to be discovered has trouble staying discovered. The original poster experiences itching and wants to know if it is normal for ALS. Subsequent posts by other PALS and PLM staff imply that itching as a symptom of ALS is public knowledge in this community but the original poster points out, "I am writing about itching because i don't see the itching in the <symptoms>." A PLM staff person responds that one can search the "symptoms" *discussion* and find information about itching.

However, its absence on the list of symptoms demonstrates that itching has not (yet) been codified as an official symptom within this community and therefore still requires “discovery” by members not familiar with this.

Authoritative knowledge in the ALS forum

RQ3 asked: How do participants in the PLM-ALS forum co-create and treat authoritative knowledge from multiple sources including the medical literature, health care professionals, lived experiences of patients, and "other" sources of information such as lay literature and alternative health providers? To address this question, we examined posts that include or refer to the opinions of individuals with 'externally-perceived high authority' (neurological specialists) and individuals with 'externally-perceived low authority' (alternative and natural medicines), and that include references to other resources pointed to as providing or proving authority of knowledge (Table 5). This approach is not meant to assert an objective view of authority that reflects the opinion of the researchers or the PALS, but instead refers to Jordan's (1997) original formulation of authoritative knowledge where there is an understood hierarchy that is not necessarily accepted within a specific setting.

[INSERT TABLE 5]

Co-constructing authority by collecting personal experience

Three threads (N, G, and M in Table 5) help to demonstrate this community's preference for personal experience as evidence in their co-construction of authoritative knowledge, and what happens when personal experience interacts with other forms of knowledge considered in society (and particularly by health care professionals) to be "authoritative."

The topic of Thread N is IVIGlobulin therapy, and it begins with a brief query: "Has anyone participated in IVIGlobulin Therapy and if so, has there been any improvement from this treatment?" The remaining posts of the thread work together to paint a coherent picture of IVIG as an effective treatment for multi-focal motor neuropathy (MMN) but not ALS. MMN can be difficult to distinguish diagnostically from ALS in its early stages. The efficacy or non-efficacy of IVIG can be used diagnostically; if it is not effective, then the diagnosis is more certainly ALS and not MMN, as demonstrated by this post: "My first dx [diagnosis] was Multifocal Motor Neuropathy (MMN)

and I did 5 days straight of IVIG. When nothing happened, my doc reconsidered my dx and changed it to ALS."

This thread illustrates how experience and medical literature offer different forms of evidence when building authoritative knowledge in this community. As noted in the thread about no-drug approaches to ALS (Thread A), personal experience (as distinct from opinion) is a form of knowledge that this community has mutually constructed as being authoritative. This was also demonstrated from the opening of this Thread N, which begins "Has anyone participated...." Five PALS who had tried IVIG provide answers, and three of them post again to share more details of their direct experiences. Six posts by one individual (who is not a PALS and who otherwise does not participate in the thread) referred largely to outside authority, citing medical research articles and attempting to provide additional contextual authority for the medical research articles by including their PubMed ID numbers and full citations. This contributor does not interact directly with any PALS in the discussion and the discussion among the PALS begins again three months later with another set of four posts. These latter posts do not refer to the six medical research posts but start by sharing more personal empirical experience: "I've had four courses of IVIG, and it seems to help. I had my best reaction to the first round. I was diagnosed with ALS, but after a spinal tap and the IVIG, I've got two neurologists saying that I don't have ALS, and that I probably have MMN." In addition, this set of posts revisits the role of IVIG as a diagnostic indicator, where the treatment's efficacy is indicative of MMN rather than ALS. The shift back to personal experience posts without any reference to or acknowledgement of the six mid-thread medical literature posts should not be taken as an indicator that outside medical authority is entirely meaningless to these posters. It does imply that it is of less importance to the community's construction of authority compared to the knowledge embodied in personal experience. In fact, the second post in the third group includes this passage in which the poster refers to the existence of a hierarchy of authority: "My treatments did absolutely nothing for me and gave my doc his first suspicion of ALS. I'm no doc but, if you got results from IVIG, you don't have ALS." It is not possible to tell from this passage whether the poster truly believes his/her knowledge is less authoritative than that of a physician, as it could be *interpreted* in several possible contradictory ways. Nevertheless, inclusion of the clause "I'm no doc" alludes to the shared understanding that a hierarchy exists, although it is less meaningful within this community than it is outside.

Thread G also demonstrates this community's preference for personal experience as evidence. Thread G begins with a request from a PALS for PLM to develop a "rated list of MDs"; the initial post goes on to say:

> It would be a valuable service if this forum could legally compile a listing of MDs rated by whether they are willing to "aggressively" treat ALS, or whether they stick to the Rilutek cookbook, or whatever other adjectives you might choose. Proactive MDs are needed who will prescribe off-label (but still do all the monitoring, etc.). A lot of neuro's become irrelevant to a large degree once a dx is made if all they do is prescribe Rilozole and "manage the disease's progress". Given the internet and forums like this, most PALS know as much as their neuros, at least as far as knowing the CAUSE, the CURE, and the TREATMENTS. If MDs expect to be part of the solution, they need to try new approaches and stop just waiting for the researchers to discover THE pill.

As a side note, this post also highlights a common theme in medical support groups, that "expert patients" often know as much as their specialist physicians do about their conditions (Brownstein, Brownstein, Williams, Wicks, & Heywood, 2009; Hartzler & Pratt, 2011). The remainder of the thread focuses on whose knowledge about the MDs is considered authoritative within this community. It suggests that in this community the patients are the ones with that knowledge: as the thread originator says in a subsequent post, "it's about personal experience - no one else could do it [rate the MDs] but the 'user'." It is agreed throughout the thread that this knowledge needs to be shared anonymously because the same power structure that affords MDs more outwardly-perceived "authoritative knowledge" than lay experts also makes the patients vulnerable to negative consequences. None are explicitly listed in this thread but possible negative consequences include the MD losing trust in the patient, the patient/MD relationship suffering, or the MD refusing to treat the patient further (Brody & Haut, 2009; Wright, Nyland, Carnevale, & Gros, 2010).

Thread M, although brief, serves as a good example of how members value personal experiences as evidence while not wholly dismissing the knowledge of health care providers. In the first 10 posts, different PALS indicate that they had no experience with the specific type of "colon cleanse" that is mentioned in the original post. In the eleventh post, another contributor indicates her willingness to be a "guinea pig" and try the colon cleanse program, saying "I will update here."

After three months, a new contributor asks, "Just wondered how your cleansing went. Did everything come out OK?" The PALS who volunteered to do the cleanse responds: "I didn't do the cleansing. I emailed my GP and he said the most the cleanse would do is give me diarrhea. Getting to the toilet is hard enough as it is, let alone having diarrhea too." The remainder of the thread includes it getting "bumped" (a common mechanism in discussion boards used to maintain knowledge among the group by moving an existing thread into the current, active discussions) and then two new posters ask: "has anyone tried this?" and "Holy crap! Has anyone tried this particular program? If I have anything like that in me, I want it out! Seriously, I think colon cleansing sounds like a good idea for anyone. I would like to know what products or ingredients have been used and how well did they work." There are no subsequent posts, but the desire for personal evidence is clear throughout the thread. It is also clear that the poster who volunteered to test the cleanse, and provide the personal experience so valued by this community in their constructions of authoritative knowledge, relied on knowledge from her GP to make the decision not to test the cleanse.

Co-constructing authoritative knowledge by seeking widely-varying outside sources

There is no generally-accepted known cause of ALS, but the topic is sometimes discussed in the PLM-ALS community. This is one topic where direct experience (normally considered so important in determining authoritative knowledge in this community) is of less importance because no one person has the answer. Close examination of three threads (Threads H, J, and E in Table 5) provides multiple examples of how members work to co-construct authoritative knowledge by seeking evidence from various sources with different perceived kinds and levels of "authority." In Thread H, the original poster asks, "With all this floundering about for decades on the cause of ALS, why isn't it understood that the most likely cause of a neurological disease is a neurotoxin?" The poster has framed the post as a question, but is presenting an opinion (that ALS, being a neurological disease, is most likely caused by a neurotoxin) and is tacitly asking the group why that opinion is (a) not more widely held and (b) not being pursued by medical researchers. The second poster responds with an acknowledgement but also a hedge against the absoluteness of the neurotoxin hypothesis: "I have to agree with you. Neurotoxin and metabolism unique to a particular person." The original poster responds:

> So, if that's a given and it's strongly suspected that some forms of als have environmental triggers, then why aren't neurotoxins being looked at more closely along with their presence

> in the body and our ability to rid ourselves of them? A lot of what's being studied is in my opinion the downstream results of neurotoxins and Phase 2 being out of ratio with Phase 1. I mean, just mention something as simple as Phase 1 or 2 detox pathways and eyeryone says "Huh?" Could it be as simple as that? Am I not making sense here? I'm just a simple guy but Yikes!

This response demonstrates authoritative knowledge concepts in several ways. The poster uses the word "everyone" to lend authority to his hypothesis -- bringing in the collective weight of a number (rather than the status) of unspecified others. The poster also uses words ("I'm just a simple guy") whose explicit meaning downplays his own authority but carries weight in this community, which values the authority of the layperson. The remainder of the thread brings in more possible causes of ALS, and different kinds of references to authoritative sources to give weight to the shared knowledge and to buttress different suggested causes (e.g., "articles I have read," an MD by name, a Google search, and the BBC news). Posters provide a wide variety of answers supported by a wide range of "authoritative" sources making this thread different from other topics discussed in this community where authoritative knowledge is normally co-constructed out of personal experiences and (to a much lesser extent) from medical research and specialists.

A similar process is seen in a related (not explicitly linked) thread, Thread J. The original poster asks others to share "what you think is the most likely trigger of your ALS? Even if there is no obvious trigger, please state that too" and indicates their own alignment with an (as of yet) unspecified hypothesis that head trauma can cause ALS:

> I think my onset is 2 months after I was "hit" on the back of the head/neck using cupped hand repeatedly (about 30 times) by my massage therapist, supposedly to release tension. He used the force about the same as clapping hands. I did not feel much pain. That is the closest "head trauma" that I can think of.

The original poster, later in the thread, provides support for the head trauma hypothesis by sharing a news story (published in a mainstream newspaper) that explicitly links one person's death from ALS to a specific head trauma. Other PALS resist this hypothesis and respond by posting things such as: "Dont search for a trauma, for me its the genetic"; "Wouldn't there be a more medically recognizable connection?"; "it's easy to look back and find suspicious incidents in anyone's past...I give my history to my doctors and other researchers and let the professionals try to

figure it out while I get on with enjoying the heck out of life"; "a world-renowned expert in ALS, said the link between trauma and the onset of the disease may be 'tenuous,'"; and "My specialist said that the trauma of prostate cancer in june 2004 could have triggered ALS" (which aligns with a trauma hypothesis but not specifically head trauma). The latter four of these excerpts explicitly rely on medical professionals to lend externally-perceived authority to the as-yet-undetermined causes of ALS. Interwoven in the discussion are posts from long-term PALS providing their own authoritative knowledge (authority earned by the length of time they have lived with the disease) about the futility of a lay approach to a search for causes and the need to focus on enjoying life while letting researchers solve the problem. This viewpoint is both tacitly and explicitly indicated in posts such as these: "After 21+yrs with ALS I don't even bother myself worrying about what triggered mine. I just take one day at a time and try to make every day special in some little way"; "I refuse to dwell on it, or have self pity. I try hard to live as normal as possible. My husband thinks I'm in denial, and it drives me insane! After 10 yrs of this, there is no denying"; and "I have no concrete explanation for my having ALS. It may have been the massive dosages of chemotherapy I received 15 years ago. It may have been the back trauma I suffered in years prior, or environmental exposures. Whatever the causes, the point is to make the most of what we have now."

Another thread that seeks authority from a wide variety of outside sources is Thread E, which discusses a potential and controversial treatment for ALS involving glutathione (an antioxidant normally used as a supplement rather than a medication). The original post is long (484 words), and the poster supports his pro-glutathione content by drawing explicitly on the authority vested in: his personal experience with therapy with glutathione (a lack of ALS progression when he was taking it and a return of progression when he stopped taking it), published literature on ALS, his own physician, his naturopath, German colleagues of his naturopath and the experiences of their patients, and God. The next eight posts are a dialogue between the original poster and one other PALS, who expresses his belief that money (which carries its own authority) is an important factor in determining which potential treatments are and are not pursued by medical researchers: "it's logical for there to not be much interest in this line of thought. Not that Doctors and drug companies aren't well meaning, but lets face it, the almighty dollar drives everything." The tenth post in the thread is from a PLM staff member asking any PALS with experience with glutathione to share those details within the PLM site. This demonstrates an attempt to derive authority using a more "standard" research approach, that is, to establish reliability across a larger "n" and through use of a

standard rating scale: "If anyone else is taking it then please enter your details onto your profile and in future I may be able to find out if it is having any sort of consistent effect." The relative weight of different personal experiences is brought into play when another PALS finds a way to tacitly contradict the original poster without arguing with him but rather by bringing the authority of their own experience: "My experience with IV Glutathione was far from what you are experiencing. I was in a safety trial with 4 other PALS. We took it IV twice a week for 4 months. I felt no difference, better or worse."

DISCUSSION

The online discussion among members of the PLM-ALS community demonstrates various phenomena associated with distributed knowledge, undiscovered public knowledge, and authoritative knowledge. While it exists as a support group for people who share a medical condition, PLM is also intended to be a rich arena for knowledge creation, sharing, and preservation. As this analysis indicates, members of this online community engage in the construction of distributed knowledge in order to better understand their disease and to find better ways to cope. PALS come together to provide collective evidence, mostly from personal experience, and to help each other to understand these important issues. Users also create connections from thread to thread in order to facilitate the discovery of knowledge for the group, particularly as topics often need to be re-established when new users join the group.

With regard to undiscovered public knowledge, varying bounds of what can be defined as discovered are also indicated by these data. Knowledge can be discovered locally rather than universally; for this group, discovery within the context of the PLM/ALS environment is often sufficient for their personal purposes. The discussions show that knowledge does not have to end up residing with one person to be discovered, a distinction that means persistently distributed knowledge can then be considered discovered. When people who are not co-located interact online, knowledge is not only distributed across space, it is also distributed across time as discussions are conducted asynchronously. Our analysis shows that knowledge is also distributed across time in a much broader sense; this is how knowledge is maintained and refreshed in the long term. When new members join the community, they not only bring new knowledge, but they introduce gaps in their knowledge that may have already been previously filled and addressed within the online community. Part of keeping knowledge discovered is to bring new people into the group and

facilitate their acquisition of existing knowledge. This can be difficult because it is not reasonable to expect them to "just read the whole archive" because there is too much material there, not everything is relevant over time, and some knowledge evolves because accepted knowledge (see also authoritative knowledge) changes. For any new member, then, there is a process of what knowledge needs to come forward, when, and in what context. This is partly decided by people -- generally those who have been there longer (participants or administrators) or who have some important kinds of knowledge (i.e., content knowledge previously discussed, location knowledge of where it is and how to find it, and the understanding of the timing and flow of the community to know when it needs to be moved forward again). It is also partly decided through technical affordances of the system that allow people to manipulate knowledge through time: search capabilities, the ability to "bump" older threads into the active discussion, and the ability to generate lists of symptoms and treatments maintained by PLM. When all of this works well, knowledge gets distributed across "long time" (as distinct from the "short time" distribution during the life of a thread), thus maintaining the knowledge of the community in important ways: knowledge is less likely to get lost; experienced users are less likely to get frustrated by the repetition of existing discussions; and old discussions can be refreshed purposively and when needed rather than occurring automatically and in a contextual vacuum.

Authoritative knowledge (AK) is constructed by members of the PLM-ALS community by navigating between the authority claimed by PALS based on their lived experience and that of medical providers and researchers whose authority is externally vested on them by their positions, medical credentials and other evidence of their expertise or areas of specialty. Medical professionals have the knowledge that "counts"—what is generally accepted as true—and what is considered actionable in terms of what is acceptable to say in public, and what allows one to legitimate actions, such as taking medication, selecting assistive devices, filing insurance claims, and so on. The concept of the expert layperson is important here because many ALS patients become experts in the disease or in aspects of it that affect or are of interest to them. No matter how much knowledge they develop over time, it will not be authoritative if the group does not define it as actionable or acceptable. Shared knowledge by multiple people, especially those with personal experience, lends the weight of collective evidence.

In an ill-defined knowledge area such as that surrounding ALS, where causes and treatments are unknown and imperfect, efforts to share, discover and create knowledge rely on evidence for

authority as well as more traditional hierarchies and accepted values of knowledge. Even if a cause (or partial cause) of ALS is discovered (e.g., Siddique & Ajroud-Driss, 2011) this finding is relevant for the many diseases whose causes remain unknown; the activity of seeking causes among fellow patients, even if it does not generate a factual result, fills a need and provides patients the opportunity to share knowledge and to share emotional support.

LIMITATIONS

A few limitations of this study must be noted. The researchers were granted access to a randomly-selected subset of threads from the PLM-ALS community. While the sample size was large and allowed the researchers to examine complete threads, we could not realistically examine if threads were revisited after the sampling frame, and it would not have been possible to compare the content of the analyzed posts with those of other communities, or over a longer period of time. The data collected were created at a specific moment in time soon after PLM first went online, when knowledge discovery and authority construction were new in the community. Technologies used by PALS will change over time, but the findings here are focused on knowledge creation and discovery rather than technology use.

Second, the data received from PLM were de-identified in order to protect their users. Generally this was not an issue in coding data for this study but user expertise in the form of educational or work background could not be examined (data which PLM was not capturing at the time of data export anyway). It was possible that a user could be a PALS yet also be a member of the medical community. Although this information was not crucial to analyzing authoritative knowledge, it may have been helpful for understanding the community more.

A third limitation is that it is very difficult to assess undiscovered public knowledge because it is just that, undiscovered. Although the threads indicate that as users share new information with each other based on their own experiences or acquired knowledge, without the input of an expert it is hard to make the leap from true undiscovered public knowledge to a known truth.

CONCLUSIONS AND IMPLICATIONS

The focus of this study was to examine distributed knowledge-building within the PLM-ALS community -- an active and engaged community with a shared interest in understanding a rare, progressively debilitating, and currently incurable disease. The unconstrained ability of distributed

participants to post to the online community at any time of day allows for the examination of knowledge building processes in a setting that has few bounds of time or space. The PLM-ALS community is an ideal arena to examine the phenomena associated with distributed knowledge building and specifically related to the subcategories of undiscovered public knowledge and authoritative knowledge within a health context.

We coded and analyzed 1000 posts from PatientsLikeMe, an online community of patients, caregivers and others touched by ALS. In addition to being a source of social support, the site provides a forum for users to share information, discuss ALS, and build knowledge of the disease so that they can make better informed choices about their treatment, lifestyle, and future plans. We examined this data from the lens of distributed knowledge concepts, leading to insights about how members of the community co-construct knowledge, the processes undergirding their discovery of knowledge related to ALS, and their experiences navigating the complex knowledge environment of the patient and medical infrastructure.

The strength of this study lies in its implications for theory and research. The analysis provides evidence that patients and their caregivers use online tools to build and discover knowledge about a shared medical condition, seeking and providing answers and benefiting from the personal experiences of many other patients while giving comfort to others touched by the same medical ailment. Features of online support groups that allow sharing of knowledge across time and space can facilitate knowledge building and discovery but can also pose challenges for "preserving" these discoveries. For example, the analysis indicates that as more members are added to a group or as more information is shared over time, the discovery of public knowledge is not only enhanced but it can also be hindered without processes in place to help participants make connections between disparate pieces of knowledge. Moreover, the findings indicate that discovering knowledge does not appear to be as difficult as keeping it discovered.

The study sheds light on how patients' perceptions and practices about evidence and authority behind knowledge can affect their treatment decisions. The study reveals that people seek out not only understanding and support from those who share their illness, but also authoritative knowledge from experts or others deemed more knowledgeable than themselves. The findings suggest that PLM-ALS members provide information that complements knowledge gathered from a wide variety of sources. At the same time, the analysis indicates that authority is claimed and vested

through different mechanisms but most prominently, in this environment, through personal experience. Patients develop expertise (Hartzler and Pratt, 2011) about daily treatment practices through trial and error and can therefore share valuable information and actionable advice based on their lived experiences, thus co-contructing authoritative knowledge among the patient community. This is particularly valuable in areas where there is limited empirical evidence and when many aspects of disease treatment and management are still poorly understood.

While past research has connected distributed knowledge building to information retrieval systems (see, for example, Hoadley & Kilner, 2005), this paper was not specifically focused on the design of online community systems. However, this is an area of interest and the findings of this study do have implications for system design and can provide guidance for future research. For example, researchers in this area may want to look closely at how system design influences distributed knowledge, and how system features can provide support for discovering the undiscovered, navigating the complex area of authority, and keeping knowledge discovered over time and across people. As such, the findings may be used to inform future efforts to design more effective online health communities, encourage experts to join online health communities and stay active in the group, as well as motivate users to seek and post information from other sources (online and offline).

Overall, these results indicate some of the practices employed by online community members to build shared knowledge of their disease. Results from this study provide theoretical support for research on distributed knowledge and inform builders of online health communities about how to better support knowledge sharing among its members. Alternatively, tools for streamlining these knowledge-sharing processes may help hasten the discovery of treatments or better ways to help patients manage their conditions and alleviate stressors associated with rare diseases.

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Table 1. Posts per individual and per thread in the 1000 posts analyzed.

Posts per individual (n=241 individuals)		
Range	Median	Mean
1-76	2	4.3
Posts per thread (n=85 threads)		
Range	Median	Mean
3-48	7	12.2

Table 2. Final code categories and sub-categories used for all coding*.

# of codes	Within the Category	Divided into Subcategories		
15	"Purpose"	Help self	Help others	
		Referring to PLM	Misposted/empty post	
18	"Miscellaneous"	Signatures	Language use	Topic drift
84	"Content"	Equipment	Drugs	
		Treatments (non-drug)	Activity	
		Policy	Experience with ALS	
		Care providers	Emotions	
		Coping mechanisms	Other content	

Table 3. Existing codes used to begin the purposeful data sampling process.

RQ1: "Purpose" codes	**Example threads/quotes**
1. Ask a question	Thread F: "You drink pot? What are you taking?"
2. Answer a question	Thread A: "I'm not on any Rx right now. I don't necessarily go out of my way to avoid them. I also do not like that “drugged" feeling."
3. Supply factual information	Thread H: "Neurotoxins are cause by Microorganisms. I have read articles that said that 90% of the neurotoxins come from the food we eat. In 2000 a Dr. Ritchie Shoemaker MD. come up with a Visual Contrast Sensitivity Test to reveal the presence of neurotoxin in a patients system. The test only takes 5 minutes."
4. Direct users to PLM resources	Thread E: "FYI, click here to find out more about this treatment. If anyone else is taking it then please enter your details onto your profile and in future I may be able to find out if it is having any sort of consistent effect."
5. Direct users to other resources	Thread N: "Here is some info on this topic. Note this passage:"... IVIG was not recommended for 8 conditions including adrenoleukodystrophy, amyotropic lateral sclerosis, autism, critical illness polyneuropathy, inclusion body, myositis, intractable childhood epilepsy, paraproteinemic neuropathy (IgM variant), and POEMS syndrome." Transfus Med Rev. 2007 Apr;21(2 Suppl 1):S57-107."
RQ2: "Content" codes	**Example threads/quotes**
1. Prescribed drugs	Thread C: " I take 40 mg. of Celexa and it is of great assistance in keeping me balanced emotionally. The "start-up" period for many antidepressants can cause side effects, for me the only bad start-up side effect I got from Celexa was nausea, which disappeared after a few days. The main side effect with SSRI's is loss of sexual libido. I also have had problems with insomnia, dating way before I was diagnosed with ALS. An antidepressant I've been given which is very sedating is Remeron (mirtzapine), however this drug has a side effect of weight gain. I've also taken Ambien and Lorazepam (Ativan) on occasion."
2. Over-the-counter drugs	Thread B: "My wife found an anti-itch ointment at Target that helps."
3. Drug trials	Thread E: "My experience with IV Glutathione was far from what you are experiencing. I was in a safety trial with 4 other PALS. We

	took it IV twice a week for 4 months. I felt no difference, better or worse. This was back in 03 and I think I'm the last of the 4 of us still kicking."
4. Alternative medicines/natural remedies	Thread C: "I am also taking Melatonin and Valerian (an herbal sleep rejuvenating sleep supplement)."
5. Supplements	Thread S: "Hello pals,I noticed several of us are taking Coq10, fishoil, grape seed extract and creatine. I recently started taking Coq10 and I was very dismayed at the steep prices of these supplements at GNC. I wanted to know if anyone taking these thinks if they're doing any good. I know in theory they're suppose to. I feel the Coq10 has helped me, but that might be psycological. I would appreciate any input. Thankyou."
6. Drug side effects	Thread D: "I was put on baclofen 1 pill a day.. Symp. got worse. Doc upped to 3 a day...worse yet..Doc upped to 5 a day.. I could not breath, walk, and weak as hell.. Wife cut back to 1 a day.. all symp. went away but the ache in my legs.. I thought it was the als.. It was the damn baclofen."
7. Drug interactions	Thread C: "I take effexor without it Iam a real fu**ing jerk.they just make thinks easyer. but when i was onn lithium the lithium made the effexor not work so i stopped lithium wish find something that worked together."
8. Drug efficacy	Thread T: "I have excess saliva but not as serve as you report. My doctor prescribed HYOSCYAMINE, 1 teaspoon four times a day in my PEG TUBE. It is working fairly well. If I miss a shot the saliva increases."
9. Physical therapy	Thread R: "It takes a lot out of me when I go to my Physical Therapist. They insist I do bike riding for 15 minutes. I'm exhausted when I come home & have to sleep. I was wondering if that was the cause. I'd like to hear what others have to say about PT."
10. Occupational therapy	Thread U: "I cling dearly, to each wasting function and do not relish giving up any capacity, willingly. My occupational therapist advises me to get used to doing less and stop pushing myself; useful advice, as maybe: I am unable to oblige! Mentally and emotionally I need to keep trying to be as physically active as I can, without going to extremes."
11. Diet and exercise	Thread A: "Zero Rx meds for me. I do take supplements, CoQ10, vitamin E and C, multi vitamin and Melatonin at night to help sleep. Exercise/workout everyday."

12. Treatment costs	Thread N: "My neurologist had me on IVIG for a year when he misdiagnosed me as having multifocal motor neuropathy with conduction block. Pretty expensive stuff. I was getting it every three weeks-$2500 a pop."
13. "Other" (under subcategory Non-drug treatments)	Thread P: "Yesterday I had four or five side teeth removed. ow! As I said in an earlier post, my lower teeth are horizontal, allowing the upper teeth to drill into the lower gum. I will return in two weeks to get the other side done. This shift in my teeth is definitely due to ALS. If you notice teeth shifting or a change in your bite, go to a dentist in a rehab hospital. Ordinary dentists won't know what to do. Perhaps teeth shifting should be listed under Symptoms."
RQ3: "Content" codes	**Example threads/quotes**
1. Neuro[logical] specialists	Thread G: "A lot of neuro's become irrelevant to a large degree once a dx is made if all they do is prescribe Rilozole and "manage the disease's progress". Given the internet and forums like this, most PALS know as much as their neuros, at least as far as knowing the CAUSE, the CURE, and the TREATMENTS."
2. General physicians	Thread M: " I didn't do the cleansing, Dave. I emailed my GP and he said the most the cleanse would do is give me diarrhea.Getting to the toilet is hard enough as it is, let alone having diarrhea too."
3. Family	Thread E: "I am with you all the way. About 15 years ago my wife and I were involved in a herbal MLM that was promoting Colon Cleansing and later Liver Cleansing.We did the Colon Cleansing and WOW we were blown away with the improvements to our health and well-being."
4. Friends	Thread Q: "When my daughter was playing softball in high school a couple girls on the team hung around our house enough that they learned how to suction. If Deb was in the concession stand working and they heard my vent beep they'd come do it if they weren't in the field. A couple of my son's friends know how to do it too but only do so in case of an emergency. LoL."
5. Professional for hire	Thread R: "Next week I am to start some starter sessions using a motorised exercize cycle, to get some more movement in my legs all done from my wheelchair. The Rehab Nurse is going to visit me at home with a Physiotherapist to do a complete medical check to ensure I can indeed use this device without harm."
6. Clinics	Thread G: "I have been sorely disappointed in the ALS Clinic I go to for treatment. I don't really expect a cure but I am tired of being

	written off!"
7. "Other" (under subcategory Providers)	Thread J: "I think my onset is 2 months after I was "hit" on the back of the head/neck using cupped hand repeatedly (about 30 times) by my massage therapist."

Table 4: PALS discussion threads referred to in findings about undiscovered public knowledge.

Thread	Subject line	Total # posts	# Posters	Notes
C	Anti-depressants	11	9	Eight posters are PALS, one is a PLM staff member
D	baclofen	5	5	All posters are PALS.
L	New issue of ALS journal out today	10	3	One poster is a PALS, one is a PLM researcher, and one is a friend of a PALS.
K	Information to share about fronto temporal dementia	15	11	Nine posters are PALS, one is a PLM staff member, and one is a PALS caregiver.
P	Front teeth erosion	7	6	Five posters are PALS, one is family of a PALS.
B	Itching 1, 2, 3.	6	5	Four posters are PALS, one is a PLM staff member.

Table 5: PALS discussion threads referred to in findings about authoritative knowledge.

Thread	Subject line	Total # posts	# Posters	Notes
N	IVIGlobulin Therapy	19	9	The first nine posts by six posters occur in two days; three people posted twice. The next six posts were made by one individual—a PLM staff member, not a PALS — eight days later. The final four posts were made in two days three months later, by two new posters and two individuals who posted in the original set
G	Proactive MDs	10	6	Whole thread occurs within 24 hours.
M	What have you done to your gut?	22	19	All posters are PALS.
H	ALS & Neurotoxins	10	10	Eight posters are PALS, one is a caregiver, one is coded as "Other."
J	What trigger your ALS?	14	9	All posters are PALS.
E	Glutathione	28	13	26 posts are from PALS, two are from a PLM staff member, and 4 posts are blank.