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SYMPOSIUM: ABJS CARL T. BRIGHTON WORKSHOP ON HEALTH INFORMATICS

The Potential Research Impact of Patient Reported Outcomes on Osteogenesis Imperfecta

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Abstract

Background Osteogenesis imperfecta (OI) is an inherited connective tissue disorder with many phenotypic presentations ranging from mild to severe. It is often called “brittle bone disease.” Treatment consists of physical therapy, surgical interventions, medications and, in some cases, experimental therapies. Because treatment is not standardized and is often experimental, information on the success of different methods is usually not available or well documented.

Questions/purposes We therefore asked if social networking can make OI patients’ lives better. How would a bone disorder community work? Is it possible for patients to know how well they are doing in comparison to others like them, and if they are getting the most successful treatment for their disease?

Methods An evaluation of how PatientsLikeMe®, a personal research and social networking website and database for patients with life changing illnesses, can aid in improving patient outcomes through the anonymous sharing of medical information.

Results PatientsLikeMe® could help patients answer the question, “Given my condition, what is the best outcome I could hope to achieve, and how do I get there?” Participants could record their real-time day-to-day progress in achieving their treatment goals, such as preventing fractures, and share that with the community to help patients, caregivers, researchers and industry learn more about OI.

Conclusions Social networking can change the lives of Osteogenesis Imperfecta patients for the better, and make them a part of the treatment discovery process. Here we present a possible OI online community and demonstrate its potential utility for patients and medical professionals alike.

Introduction

Social networking has changed the face of personal interaction. Nearly three quarters of online teens and young adults use social network sites [7]. Forty percent of adults 30 and older used social networking sites in the fall of 2009 [7]. PatientsLikeMe® (http://www.PatientsLikeMe.com) is a personal research and social networking website that captures and longitudinally displays data reported by patients with life changing illnesses. The aim of the site (which currently consists of 17 disease communities and over 61,000 patients) is to help patients maximize their outcomes to the fullest extent possible and answer the question: “Given my status, what is the best outcome I can hope to achieve, and how do I get there?” [1].

PatientsLikeMe® is freely accessible via the Internet and is free from traditional advertising methods such as banner advertisements and pop-ups. Revenue relies upon the sale of anonymous aggregated data, clinical trial awareness programs, and market research surveys for the pharmaceutical industry and other research partners. Companies typically buy custom reports that detail what patients are discussing in our forums, and deploy surveys

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Each author certifies that they have or may receive payments or benefits from a commercial entity related to this work, and both authors are employed by and have stock ownership in PatientsLikeMe®.

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across the site to get answers to key questions. Companies also engage PatientsLikeMe® to complete custom research projects including rating scale development and data mining for outcomes information. PatientsLikeMe®'s goal is to make strategic partnerships that incentivize industry to put the patient's voice at the centre of their efforts by making it a competitive advantage. The business model is transparent and explained to patients in a statement entitled "How Does PatientsLikeMe® Make Money?".

PatientsLikeMe® is not seeking to replicate the work of non-profits such as the OI Foundation. PatientsLikeMe® does not produce expert content, raise funds for support services, carry out lobbying, or sponsor research. Rather, the company partners with non-profits to increase the visibility of their services, and has a program called PatientsLikeMeInMotion that encourages patients to raise money for non-profits and sponsors the creation of PatientsLikeMe® member teams of walkers/runners for fundraisers.

The current 17 PatientsLikeMe® communities were not selected at random. The first criterion for a community is patient demand; patient requests for communities are collected on the site. The second criterion is fit for the PatientsLikeMe® platform. Communities are best suited for diseases where patients have valuable insights into their own disease and treatment, and can help other patients find answers to questions such as: what happens to a patient like me; what are the best treatments & products; and how do I live the best I can? The third criteria is commercial viability- is there a market for patient data for this disease? In other words, the suitability for a vibrant community is not solely a product of the prevalence of that disorder. PatientsLikeMe® has active communities in conditions as prevalent as mood disorders (prevalence 20,900,000 in the United States [5]) and as rare as progressive supranuclear palsy (PSP, also known as Steele–Richardson–Olszewski syndrome) (prevalence less than 15,000 in the United States [8]). The sponsorship of funded communities also allows for the development of orphan communities that are not current markets for the pharmaceutical industry.

For the clinical bone disorder community at large, the key questions for the creation of social networking communities are:

1. Can social networking make patients' lives better?
2. Where do we need to go? (i.e., How would a specific bone disorder community work? Is it possible for patients to know how well they are doing in comparison to others like them, and if they are getting the most successful treatment for their disease?)
3. How do we get there? (What do we need to do?)

Can Social Networking make Patients' Lives Better?

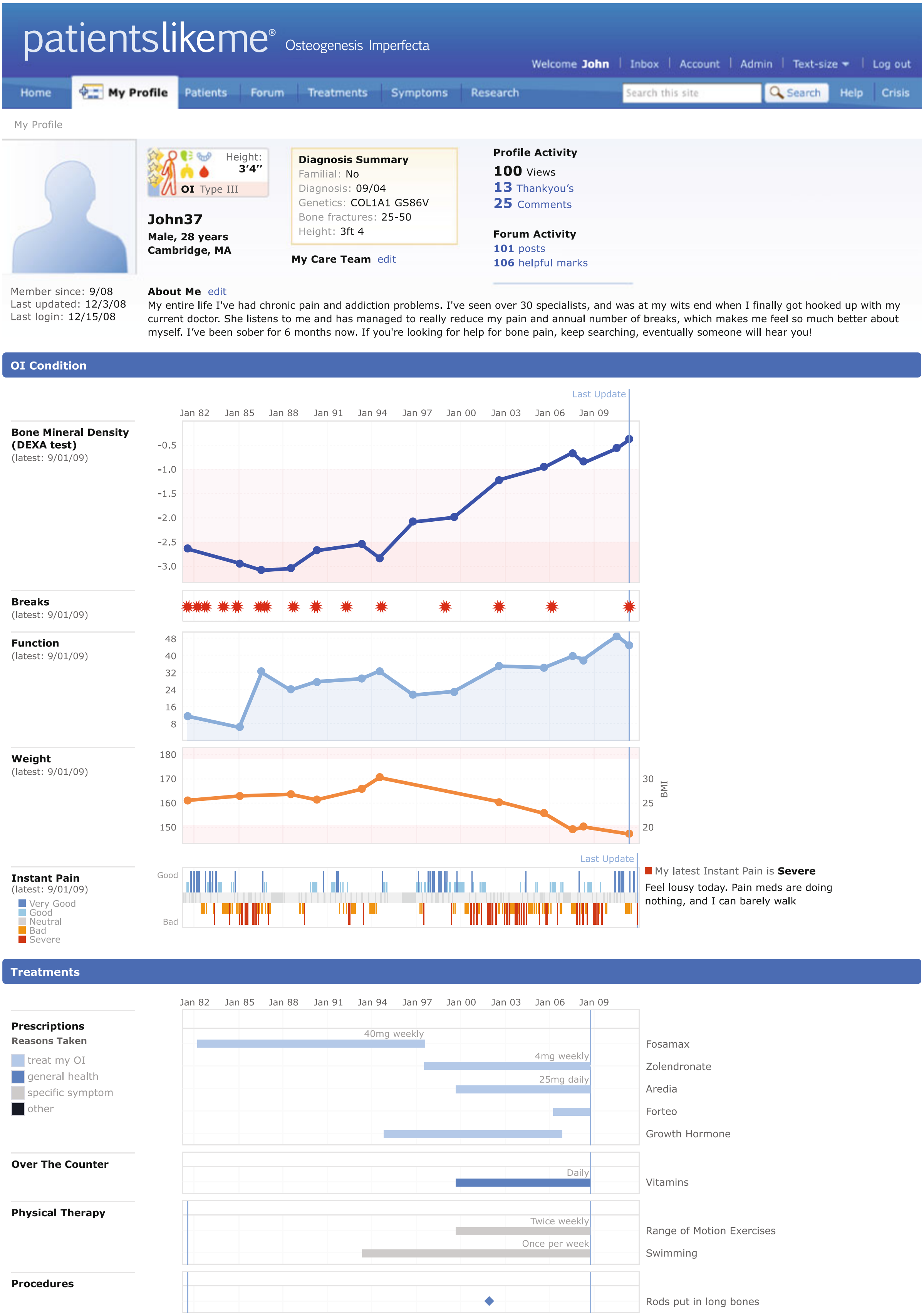
Several bone diseases and disorders would fit the suitability criteria for a PatientsLikeMe® community, one of which is osteogenesis imperfecta (OI). Often called "brittle bone disease," OI is an inherited connective tissue disorder with a range of phenotypic presentations referred to as "types". Severely affected patients suffer multiple fractures with minimal or no trauma, and may have hundreds of fractures and breaks in a lifetime. In contrast, mild forms of OI may manifest themselves solely through premature osteoporosis or severe postmenopausal bone mineral loss [2, 6]. Patients often suffer from chronic pain [3]. The number of cases is unknown, but there may be as many as 30,000 in the United States [3]. The goal for patients with OI is to reduce fracture rates, prevent long-bone deformities and scoliosis, minimize pain, and maximize mobility and other functional capabilities. OI research is a rapidly changing field and many different treatments are under investigation. Treatment is not standardized, often experimental, and frequently involves physical therapy, surgical interventions, and medications.

It is easy to imagine that patients with OI could have improved outcomes with increased knowledge; patients could effectively teach each other how to live better. The prognosis for a patient with OI varies greatly depending on the number and severity of symptoms, but also with lifestyle.

Where Do We Need to Go?

How would such a community work? Is it possible for patients to know how well they are doing in comparison to others like them, and if they are getting the most successful treatment for their disease?

Elements of a PatientsLikeMe® OI community would ideally address every area of treatment and therapy, in addition to relevant psychological and social issues (Fig. 1). Patients would be able to find other patients "like them" using the search and browsing tools, and connect with matches on items such as the genetic cause of their OI or disease characteristics; people with OI often have muscle weakness, hearing loss, fatigue, joint laxity, curved bones, scoliosis, brittle teeth, pulmonary disease, and short stature in addition to multiple fractures. Members could locate other patients with similar circumstances and medical experiences and discuss the profiles, treatment reports, and general health concerns on the forum, private messages, and comments they post on one another's profiles. Clear delineation of the type of OI the patient had would also prevent errors of inference regarding treatments and



Height: 3’4’’
OI Type III

John37
Male, 28 years
Cambridge, MA

Diagnosis Summary
Familial: No
Diagnosis: 09/04
Genetics: COL1A1 GS86V
Bone fractures: 25-50
Height: 3ft 4

My Care Team edit

Profile Activity
100 Views
13 Thankyou’s
25 Comments

Forum Activity
101 posts
106 helpful marks

Member since: 9/08
Last updated: 12/3/08
Last login: 12/15/08

About Me edit
My entire life I've had chronic pain and addiction problems. I've seen over 30 specialists, and was at my wits end when I finally got hooked up with my current doctor. She listens to me and has managed to really reduce my pain and annual number of breaks, which makes me feel so much better about myself. I’ve been sober for 6 months now. If you're looking for help for bone pain, keep searching, eventually someone will hear you!

OI Condition

Bone Mineral Density (DEXA test)
(latest: 9/01/09)

Breaks
(latest: 9/01/09)

Function
(latest: 9/01/09)

Weight
(latest: 9/01/09)

Instant Pain
(latest: 9/01/09)

My latest Instant Pain is **Severe**
Feel lousy today. Pain meds are doing nothing, and I can barely walk

Treatments

Prescriptions
Reasons Taken

Treatment	Dose
Fosamax	40mg weekly
Zolendronate	4mg weekly
Aredia	25mg daily
Forteo	
Growth Hormone	

Over The Counter

Treatment	Dose
Vitamins	Daily

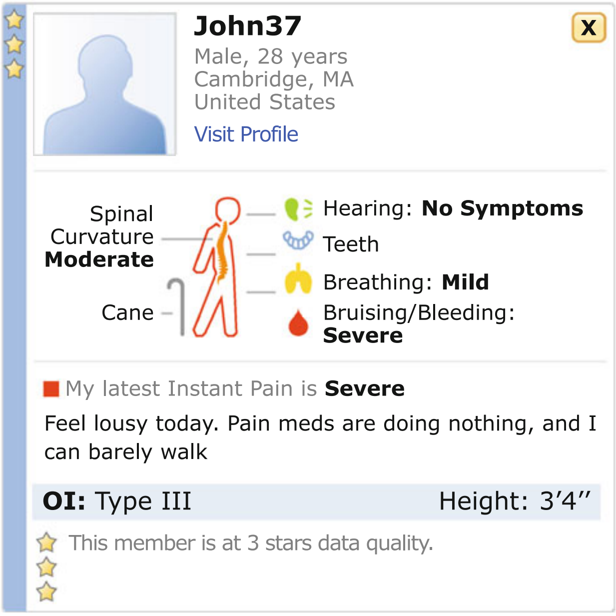
Physical Therapy

Treatment	Frequency
Range of Motion Exercises	Twice weekly
Swimming	Once per week

Procedures

Rods put in long bones

Fig. 1 This is an example of an osteogenesis imperfecta patient profile.



John37
Male, 28 years
Cambridge, MA
United States

Spinal Curvature **Moderate**
Cane
Hearing: **No Symptoms**
Teeth
Breathing: **Mild**
Bruising/Bleeding: **Severe**

My latest Instant Pain is **Severe**

Feel lousy today. Pain meds are doing nothing, and I can barely walk

OI: Type III Height: 3′4″

This member is at 3 stars data quality.

Fig. 2 This is an example of a possible osteogenesis imperfecta informational "nugget".

experience, though certain aspects of the experience of living with OI would be uniform across types.

Prominently displayed at the top of each member profile would be their measure of bone density, since a goal of treatment is to increase bone density as much as possible. Patients would be able to display the results of their dual energy absorptiometry (DEXA), spirometry, electrocardiogram, and/or an echocardiogram longitudinally. This outcome measure would clearly delineate how well the patient is doing.

The next chart on an OI site would be a line graph of the individual's functional level over time, superimposed onto a backdrop of population-level data. Function would be assessed through a clinically validated, self-administered functional rating scale. Other patients would compare the bone mineral density and functional level with the patients' treatments and behaviors, and learn from others' successes and failures.

Other elements of the profile would include a record of breaks and relevant details (such as how the break occurred, so patients could learn patterns, if any), and weight/BMI. Finally, a measure of mood or psychological health would aid in completing the picture of how a patient is doing. Every element of the profile would be available for personal use and could be browsed and critiqued by other members.

Another element of the PatientsLikeMe® profile is the "nugget", which lets others know who a person is and how they are doing at a glance (Fig. 2). The ability to communicate using visualizations and graphs instead of text is employed throughout the site, and allows for the site to be used by individuals of all reading comprehension abilities.

How Do We Get There?

Through the creation of PatientsLikeMe® bone disorder communities such as an OI community, patients will become empowered in their ability to obtain information in real-time [4]. In addition to disease severity, demographic data, such as age, sex, background, and relevant genetic information would be displayed and searchable to better find patients with similar conditions and lifestyles. By anonymously sharing their treatment, symptom, progression, and outcome data with the entire community, users would facilitate knowledge management and transfer.

Discussion

The PatientsLikeMe® platform allows patients to continually capture, quantify, display, and share the status of their pathology, their ability to function, and anything they are doing to change their status such as treatments or lifestyle modifications.

There are some limitations to the PatientsLikeMe® platform. PatientsLikeMe® communities are best suited for diseases where patients have valuable insights into their own disease and treatment. Some of the common problems in orthopaedics, like back pain, do not have much variation in treatment or treatment is standardized. Other diseases have populations that are curable, and those patients would not have reason to return to the site, preventing the formation of a viable community. In other cases, the physician/provider has better knowledge about the disease than a patient can self-report.

There are no plans to launch an OI or other bone community at PatientsLikeMe® in the near future, but the goal is to build communities for every life-changing illness. This tool would positively affect those afflicted with OI, and could aid patients, industry, and medical professionals alike with the discovery of new information.

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