
Power of crowdsourcing: Novel methods of data collection in psoriasis and psoriatic arthritis

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Background: Crowdsourcing is a novel method of collecting research data from diverse patient populations. The quality of research data obtained through crowdsourcing is unknown.

Objective: The primary aim of this pilot study was to examine how data collected from an online crowdsourcing World Wide Web site compare with those from published literature in psoriasis and psoriatic arthritis (PsA).

Methods: Crowdsourced data were collected from a health crowdsourcing site from August 23, 2008, to June 27, 2011. The crowdsourced data were compared with findings from systematic reviews, meta-analyses, and clinical trials.

Results: A total of 160 online patients with psoriasis or PsA were included in the analysis. Among them, 127 patients with psoriasis provided 313 complete responses on psoriasis symptoms and 276 complete responses to psoriasis treatments; 33 patients with PsA provided 91 complete responses on PsA symptoms and 79 responses to PsA treatments. We compared topical treatments, phototherapy, and systemic treatments for psoriasis and PsA from crowdsourced data with the published literature. For the treatment with the largest response rates, equivalency testing was performed comparing crowdsourced data and the published literature. Overall, crowdsourced data were not equivalent to those published in the medical literature.

Limitations: Crowdsourcing sites used different outcomes measures from those reported in clinical trials.

Conclusion: Differences existed in assessment of treatment effectiveness between crowdsourced data and those published in the literature. With improvements in the collection of crowdsourced data, crowdsourcing can be a valuable tool for collecting patient data in real-world settings for psoriasis and PsA. (*J Am Acad Dermatol* 2012;67:1273-81.)

Key words: crowdsourcing; crowdsourcing; data collection; psoriasis; psoriatic arthritis; treatment.

Traditional clinical trials use defined patient inclusion and exclusion criteria that tend to select for relatively homogenous study populations that may not necessarily reflect real-world patient populations. Patients without access to research facilities, those with scheduling conflicts, and certain racial groups may be underrepresented in traditional clinical trials.

Novel methods of data collection are emerging through patient-initiated reporting of symptoms and treatment responses. One notable method of data collection is referred to as “crowdsourcing.” “Crowdsourcing” is broadly defined as the act of outsourcing assignments to a large group of people or community.¹⁻⁸ Crowdsourcing World Wide Web sites specializing in health care serve as a forum for

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patients to report disease symptoms and treatment outcomes. Advantages of crowdsourcing include recruitment of more diverse study populations and collection of data that better reflect real-world experience.² Patients find crowdsourcing sites appealing as a way to share their clinical experience and to obtain immediate feedback on how their responses compare with responses of other online patients.^{7,9} Patients are also attracted to the time- and distant-independent nature of the interaction without having to travel long distances to research facilities.^{10,11}

Few studies in the literature address the quality of medical crowdsourced data and how they compare with clinical trial results. Psoriasis is ideal for obtaining crowdsourced data because it is a relatively common disease that affects both adults and children. Psoriasis is a common, chronic, inflammatory skin disease with associated arthritic, cardiovascular, and psychosocial comorbidities. Psoriasis affects approximately 3% of the US population with an average age of onset of 33 years.¹² Psoriatic arthritis (PsA), a spondyloarthropathy characterized by synovitis, enthesitis, dactylitis, and spondylitis, develops in approximately 5% to 40% of patients with psoriasis.^{13,14}

Crowdsourced data from online patients with psoriasis and PsA may provide insight into the patient-reported effectiveness of various treatments. The primary aim of this study was to examine how data collected from patients with psoriasis and PsA through an online crowdsourcing World Wide Web site compare with those from the published literature.

METHODS

Crowdsourced data

Although several health crowdsourcing sites exist, we obtained data from CureTogether (www.curetogether.com). CureTogether is one of the top widely used health sites with crowdsourced information on dermatologic diseases.¹⁵ On the CureTogether crowdsourcing site, patients with psoriasis and PsA can report their symptoms and effectiveness of various treatments (Figs 1 and 2). If a symptom or treatment is not available, the patients can add new symptoms or treatments to existing lists, but no mechanisms currently exist to resolve similar

entries. The symptoms are usually grouped into physical and psychologic symptoms. Treatments are categorized as prescription, surgical, over-the-counter, or lifestyle changes.

Data from the crowdsourcing site were collected from August 23, 2008, to June 27, 2011, from 127 online patients with psoriasis and 33 online patients

with PsA. The 127 patients with psoriasis provided 313 complete responses on psoriasis symptoms and 276 complete responses to psoriasis treatments. The 33 patients with PsA provided 91 complete responses on PsA symptoms and 79 responses to PsA treatments. Although users can chronicle their disease progression on the World Wide Web site, we limited our analysis to initial symptom and treatment-response reporting. Patient self-reported psoriasis and PsA symptoms were categorized into skin (12 symptoms), pain (2 symptoms), and physical functioning (1 symptom). Online responders reported their symptoms as minimal, mild, moderate, severe, or extreme. For each symptom, cross-tabulated frequencies were calculated by severity rating.

The categories of psoriasis treatments included lifestyle/dietary changes and home remedies (11 treatments), over-the-counter medication and supplements (10 treatments), prescription (10 treatments), alternative/other (6 treatments), and surgical (1 treatment). Online patients reported their response to the various treatments as: made it worse, made it slightly worse, no effect/uncertain, moderate improvement, and major improvement. The categories of PsA treatments included prescription (14 treatments), lifestyle/dietary changes and home remedies (6 treatments), and surgical (1 treatment) treatments. For each treatment, cross-tabulated frequencies were calculated by effectiveness rating.

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Search strategy for peer-reviewed literature on psoriasis and PsA therapy

In this study, we compared crowdsourced data with peer-reviewed literature. The search strategy to identify peer-reviewed data on psoriasis and PsA treatment efficacy consisted of a 4-tiered approach. First, we performed a literature search for systematic reviews and meta-analyses of psoriasis and PsA

CAPSULE SUMMARY

- Crowdsourcing in medical research is the act of sourcing data collection to patients or community through an open call.
- Treatment efficacy for psoriatic diseases reported by patients participating in crowdsourced research was not equivalent to that gathered from participants in traditional clinical trials.
- Quality of crowdsourced data can be improved through use of validated outcomes measurements.

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