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Consumer Empowerment in Dermatology

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Summary

Health care consumers increasingly confront and collaborate with their medical providers. We describe consumer success in other medical fields and in dermatology, especially dermatologic disease advocacy and improving dermatologist-patient interactions.

Keywords

health care consumer; Internet; patient advocacy; medical information

What is a Medical Consumer?

Increasing political pressure and improved access to medical information provided by the Internet have strengthened consumer (i.e. patient and patient advocate) participation in the medical enterprise [1]. Advocates argue that consumer involvement helps research better reflect patient needs and improves medical outcomes [2], and major policy decisions increasingly focus on patient centered ideals [3]. Skeptics reply that unreliable sources can too easily influence and misinform patients.

Currently consumer resources focus more on life altering or potentially fatal diseases, such as heart disease, cancer, diabetes, and adult immunodeficiency syndrome (AIDS). The relative scarcity of dermatology advocacy may reflect the perception that many skin disorders seldom cause death [4]. Dramatic examples of life-threatening skin disease such as metastatic melanoma [5], however, do exist. Furthermore, many common skin conditions have significant morbidity due to the psychological burden produced by visible disease manifestations. Psoriasis patients feel socially stigmatized [6], and acne patients often suffer a “greater psychological burden than a variety of other disparate chronic disorders” [7]. The mental health

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of dermatology disease sufferers can deteriorate [8] even to the point of suicide [9]. More dermatology advocacy will help patients obtain better disease information and management.

Consumer Success In Other Fields

AIDS provides the epitomal example of how consumer activism can change healthcare, especially for those with a highly stigmatized diagnosis. Using methods ranging from red ribbons to civil disobedience, AIDS consumers demonstrated how to creatively advocate for their cause [10].

Cancer consumer groups have also increased in number [11] and influence in more recent years [12]. Over the past decade, breast cancer has become the premier force in consumer driven research, leading to the United States National Breast Cancer Coalition (NBCC) being named as “the world’s most influential medical consumer lobby group” [13]. Breast cancer consumers now play a major role in research funding decisions and policy-making campaigns. The NBCC has led a grassroots advocacy campaign to encourage the United States Congress to pass the Breast Cancer and Environmental Research Act (BCERA) which would make peer-reviewed NIH grants available to study the relationship between environmental factors and breast cancer [14]. The NBCC has also initiated Project LEAD (Leadership, Education and Advocacy Development) that provides scientific training to breast cancer advocates and addresses the criticism that consumers lack the knowledge needed to influence research decisions [15]. The NBCC has brought “acceptance of the idea that breast cancer survivors must have a say when policies are formed and decisions about research funding are made” [15].

The Susan G. Komen Breast Cancer Foundation has “pioneered cause-related marketing” with pink ribbon campaigns that have raised awareness and funding [16]. Breast cancer advocates involved politicians and celebrities to widen their audience. The availability of “pink” products that promise to donate funds to breast cancer research gives *all* consumers, not only breast cancer advocates, the opportunity to promote breast cancer research funding. Pink ribbons serve as “a public education vehicle that lends instant recognition and a positive tone to an otherwise anxiety provoking issue” [17].

Prostate cancer advocacy has also increased and provided prostate cancer patients with decision-making tools to better weigh treatment risks and benefits [1,18,19]. These interventions have helped men take a more active role in treatment decisions [1,18], decrease anxiety [18], and increase knowledge of treatment side effects [1].

Recent Trends: Direct Advertising, Alternative Medicine, Childhood Vaccine Refusal

Consumers clearly play an important role in driving the market for the medical services they receive. Annually, billions of dollars fund direct-to-consumer (DTC) pharmaceutical advertising [20]. Consumer influence and patient empowerment has become a marketable tool that seeks to influence the quality of medical care. Currently, about 5% of the United States population has received a prescription due to DTC advertising [20]. While some feel that DTC advertising unduly preys on patient fears [12] and undermines the physician-patient relationship [20], others feel that it fosters physician-patient communication [21,22,23].

On another front, the increased use of complementary and alternative medicine (CAM) illustrates consumer influence on health care delivery [24]. In studies in the United States and other developed nations, CAM utilization rates by cancer patients run from 7–73% [24,25] at a cost of over \$36 billion dollars annually [26]. Due to patient demand, many hospitals now offer CAM [27]. Governmental agencies (e.g. NCCAM and the White House Commission on

Complementary and Alternative Medicine Policy) also increasingly explore CAM efficacy [28].

While clinical research may be industry driven, researcher focused, and unresponsive to patient needs [2,15,29], consumers serve as the ultimate recipients of research benefits, [2,15,29,30, 31,32] and their contributions highlight their growing importance [29,33]. Mass media may further complicate consumer disease management decisions by publicizing breaking research with potentially misleading headlines [34–36].

The importance of consumer influence is further demonstrated in the debate over childhood vaccines. Some parents remain reluctant to vaccinate their children because of a presumed link between vaccination and autism [37]. Despite the lack of a “causal association between measles mumps rubella (MMR) vaccine or thimerisol containing vaccines (TCVs) and autism” [38], autism advocacy groups continue to campaign against vaccinating children. Due to the vast consumer response, SAFE MINDS has sponsored more than \$750,000 in research in this area [39]. The strength of the autism advocacy movement has raised concern that large amounts of money for autism research have diverted funds away from other childhood diseases with less powerful advocacy groups [40].

Researchers increasingly consult with consumers on scientific study design [41]. The Cochrane Skin Group (CSG) serves as an example of the growing inclusion of consumers at all levels of healthcare research. The CSG produces and disseminates systematic reviews of dermatologic practices. It routinely involves consumers in the production of systematic reviews of the medical literature [42]. Consumers serve as authors, translators, and reviewers [43]. Medical professionals have been encouraged by the CSG to make research more productive and relevant through alliances with consumers [15]. At the same time, medical journals have been challenged to involve patients through comment on their publications [29].

Though critics air concerns [44], many authors cite examples of consumers improving all stages of trial design from establishing priorities and drafting experimental protocols to helping with recruitment and data analysis [45]. Consumers add enthusiasm, inject humanity into research teams, and offer clarity to medical writing by reducing jargon [45]. Further research should “identify whether their [consumer] involvement leads to actual, rather than merely perceived, benefits for research processes and output,” [31] and examine associations between consumer involvement and changes in patient care.

The Internet: New Challenges and Opportunities

Consumers increasingly turn to the Internet for health information. In 2006, 113 million Americans searched for health-related information online [46], but 75% of those who seek health information online do not consistently assess its validity or online posting date [46]. Governmental and non-governmental agencies have responded with programs designed to fairly label reliable health information on the Internet. Alternative “stamps of approval” for websites that contain information deemed safe and useful for consumers have emerged after the failure of The World Health Organization’s initiative to create a top level Uniform Resource Locator (URL) Internet domain “.health” that would only include verified information [47]. Sites such as Healthfinder, Medlineplus, and Health on the Net (HON), specify criteria that identify valid health information [48].

Google has established an advisory group on healthcare, composed of representatives from consumer, physician, and provider organizations to help solve the problem of consumer misinformation [49]. When using the search engine Google, clicking on the “For patients” link narrows the search toward sites that have been “labeled” by health information quality agencies. For example, using the search term “acne” and clicking on the “For patients” link returns results

frequently labeled by Health on the Net, the National Library of Medicine (NLM), and the Centers for Disease Control (CDC). HON “promotes and guides the deployment of useful and reliable online health information, and its appropriate and efficient use” and is accredited by the United Nations in Geneva [50]. Websites like HON emphasize the importance of users patrolling the sites that display the HONcode and alerting them of dubious content [48].

Google has attempted to “enlist the help of the health community [organizations such as the NLM and HON] to help us know which links contain medially reliable information, sift these reliable links so that they tend to show up relatively earlier in the search results, and then let you [the consumer] decide which groups in the health community you trust” [51]. Consumers however may fail to discern the “stamps of approval” on relevant medial information. Even when patients become critical of health information sites, the difficulty of sifting through the abundance of material generated by an Internet search engine remains.

While consumers may enter symptoms into search engines to obtain diagnoses [52], physicians may benefit even more from this exercise [53]. Two physicians recently demonstrated that Google yielded correct diagnosis in 15 of 26 (58%) medical scenarios. Google was “exceedingly good at finding documents with co-occurrence of the signs and symptoms used as search terms and human experts are efficient in selecting relevant documents” [53].

In 1998, the 10 most prevalent dermatology diagnoses were: acne vulgaris, dermatitis, actinic keratosis, skin cancer, viral warts, benign tumors, psoriasis, epidermoid cyst, seborrheic keratosis, and all subsets of tinea [54]. An Internet search for consumer resources regarding these disorders yields notable patterns. For example take the most common dermatologic ailment, acne vulgaris, that affects more than 80% of persons by age 21 [55]. A Google search for “acne” led to numerous websites initiated by acne sufferers, health professionals, governmental agencies and the public (e.g. Wikipedia) (Figure 1). Numerous advertising websites claimed to offer patients the increased ability to manage and understand their skin condition. The results page offered a refined search for information on acne treatment, symptoms, tests and diagnosis, causes and risk factors, as well as advice for patients and health professionals. Nine of thirteen immediate “hits” obtained from a search for “acne” were sponsored advertisements (Figure 1). It may be difficult for the average dermatological consumer to differentiate such advertisements from unsponsored information.

Google has embraced the consumer-directed medical information search strategy and created multiple avenues for patients to access quality medical information on the Internet. For instance, of the top 10 dermatology diagnoses mentioned previously, 7 had the “For Patients” option on the initial Google search. In addition, there is a new and exciting option called “Dermsearch” (www.dermsearch.com) for dermatology patients searching for peer-reviewed information online. Dermsearch powered by Google, offers information from peer-reviewed medical sites to increase consumer education and awareness.

In addition to providing peer-reviewed information to consumers, tools like Dermsearch may shield patients from advertising. Using the search term “psoriasis” on Google (using the “For patients” link), compared to Dermsearch yields noticeably different results. While the initial search results are arguably similar on both domains, the regular Google search yields an additional 10 sponsored links ranging from psoriasis.org to multiple websites hawking herbal remedies. Google search for “melanoma more:for_patients” also raised concern. Among the sponsored sites was a website claiming “the truth is that the proven cancer prevention strategies and the real cures for cancer do not need a prescription, nor do they require surgery or barbaric procedures like radiation or chemotherapy” [56].

Dermatology consumers

Dermatology consumers may seek more Internet advice than other medical consumers because dermatologists spend less time with their patients on average than other physicians [57]. Frustration with the explanation received from the treating physician, feelings of helplessness, desire for anonymity, coping with feeling ill-informed, and seeking information for another may all motivate the search for online information [58]. Dermatologists should therefore attempt to guide their patients towards the most reputable sites of outside information possible while taking into consideration the new motives of Internet agencies, which strive for validated medical advice.

In the near future, the Internet may become influential in patient care in other ways besides providing information. In many practices, patients can now utilize email communication to solicit information from their physicians or other members of the healthcare team in order to learn more about their specific conditions. The availability of email as a new medium for information exchange allows for increased levels of consumer involvement in their own healthcare, but also presents new challenges to physicians in terms of the efficiency, liability, and ethical responsibility of treating patients over the web.

Physicians need assurance that patients will use email privileges in an appropriate and resourceful manner. A recent study collected over 3,000 patient-physician email messages to assess the effectiveness of such a tool. Results verified that the majority of emails focused on a *single* issue with the most common topics relating to information updates for the physician, prescription renewals, questions about general health, obtaining test results, referrals, notes of gratitude or apology, and billing questions [59]. Perhaps more importantly, very few email conversations sought sensitive information, less than half required a physician response, and almost none transferred an urgent message [59]. Information such as this suggests that the majority of patients would respect the goals of an email-based conference and may benefit from a more time-efficient method of communicating with their doctors.

Additionally, it has also been observed that 98% of patients were “very satisfied” with email conversations while 65% of patients would more likely choose a physician who accepted email [60]. Telephone volume of offices that implemented physician-patient email services was 18.2% lower than offices that did not, [61] and answering patient questions by email was 57% faster than by telephone. [62] Such consumer driven preferences will increase health care efficiency, and optimize the physician-patient relationship. While email increases physician and patient communication, dermatologists must also consider patient health literacy [19]. Plain language information and decision aids should be available for all medical consumers [1] and must be implemented into areas of medical research. In response to this demand, some hospitals provide librarians who will conduct Internet searches and consolidate information packets for patients with complex or rare medical issues [63].

To facilitate the open exchange of medically relevant information, dermatology advocacy groups should moderate websites that help filter patient information. The National Psoriasis Foundation (www.psoriasis.org), serves as a prime example and contains resources for patients regarding new developments in psoriasis research, provides information on treatment, and assists patients with their search for a local physician. As a result, patients who are members of the society are more satisfied with the treatment that they receive [64].

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Figure 1.
August 2008 www.Google.com Internet search – “acne”