

IMPROVING PATIENT HEALTHCARE

An examination in an Epidermolysis Bullosa Context



Abstract: Epidermolysis Bullosa (EB) is a rare, painful genetic disorder that fills every aspect of the carrier's life. Given the severity of the condition, many EB patients struggle to receive social support from their physical communities; however, online communities give these patients and opportunity to interact and communicate within a community of like-minded individuals who aim to improve EB patient healthcare. Examination of the Epidermolysis Bullosa Online Community highlighted that the platform could be leveraged to create a powerful virtual support community through knowledge and experience sharing, but not be a means for EB specialists to conduct virtual consultations due to the specialist knowledge and physical touch required to treat EB. Instead, EB specialists and experts should leverage the platform to disseminate information.



OCTOBER 22, 2017
NEHAL TAILOR - 300251632
INFO402 – Research Report

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Introduction

Epidermolysis Bullosa (EB) is a rare, often painful, genetic skin condition that fills every aspect of a carriers life (Gowran et al., 2015). Due to the highly fragile nature of EB patients, it is often hard to gain social support through physical communities, and receive adequate healthcare through support services. EB support services are often coordinated with healthcare practitioners through the international EB patient organisation, Dystrophic EB Research Association (DEBRA) International, of which DEBRA New Zealand is a branch. DEBRA New Zealand was established in 1980 to support families, ensure EB patients know they're not alone, ensure practical advice and guidance is shared, and ensure clinicians and families are provided with information and access to best practice care and EB treatments (NZ, 2008; Schober-Flores, 1999).

Although DEBRA New Zealand aims to ensure that EB patients remain up-to-date with key information regarding various forms of EB and treatments, interactions with physical communities and accessibility to healthcare is often difficult. Accessibility through the Internet has given rise to online communities, opening a range of possibilities that have the potential to improve EB patient healthcare. Online communities give EB patients a chance to engage with other users, which may not be possible due to the delicacy of their skin, and provide a means to disseminate information to a larger target audience, raising awareness nationally and globally about the skin condition. Healthcare practitioners and EB researchers can share a wider range of information regarding EB research, increasing information dissemination regarding medical advancements and treatment solutions.

Recently, the availability of e-healthcare has meant that the physical presence of patients may not be required, with digital technologies aiding healthcare practitioners to provide telehealth services. E-healthcare has the potential to expose EB patients to a wider range of EB skincare specialists; however, may be complicated to utilise effectively due to the highly complicated nature of more dystrophic cases.

The following report will examine the Epidermolysis Bullosa Online Community (EBOC), hosted by RareConnect, and its potential to improve patient healthcare through increased social support, and why physical examinations of EB patients will continue to be more viable than virtual consultations.

Literature Review

Phenomenographic understandings and subthemes

Green, Hartley, & Gillespie (2016)'s phenomenographic understandings and subthemes examine service providers' experiences of service separation. The four understandings include depersonalisation, clinical voyeurism, negotiating intangibility, and managing change, shown in Figure 1. Examination of these understandings and subthemes should provide insights into how phenomenographic conceptions affect EB specialists when considering e-healthcare services through the EBOC.

# Understanding	Subthemes	# Understanding	Subthemes
1 Depersonalization: 'Is this for real?' The derealization incited by service separation	Disengagement: Sense of high "virtuality" and being less concrete or "real" Disruption: Continuity loss from technological latencies	2 Clinical Voyeurism: 'Watching me, watching you' Peering down the camera lens at the patient's body live streamed on-screen	Looking glass: Zooming in on patients on-screen with magnification Picture-(not)-in-picture: Eye contact and camera mismatch; provider attentive to how they are perceived when looking offscreen
3 Negotiating intangibility: 'I see you but I don't feel you' Loss of touch erodes physicality toward patient; clinician can examine patients vicariously if needed	Dismemberment: Provider only sees half of patient; detail lost if whole body is on-screen Disempowerment: Provider lacks haptics, diagnostic tools-of-trade (e.g., stethoscope) or use of one's own hands	4 Managing change: 'From physician to technician' Clinician feels blurring of their identity versus role boundaries	Clinical identity: Specialist expert identity is routine and familiar Technical role: Technology is unfamiliar, erodes confidence

Figure 1. Phenomenographic understandings and subthemes, adapted from (Green et al., 2016)

Depersonalisation considers the sense of 'virtual reality' caused by the digitised nature of technology infusion in e-healthcare. Depersonalisation includes disengagement and disruption, considering the effects of distance and technical issues, and how this may affect virtual communication. In the case of EB, examination of depersonalisation considers the loss of physical touch from virtual arm's length consultations, affecting how EB specialists conduct services.

Clinical voyeurism considers practitioners' discomforts when watching a patient on-screen. Green et al. (2016) acknowledged this can often be common for virtual clinical consultations occurring under the specialist umbrella of dermatology, which is relevant to the examination of EB. Clinical voyeurism includes the looking glass effect and picture-(not)-in-picture, considering a, "practitioner's heightened experience of watching and observing patients on-

screen,” and the “eye contact mismatch that often occurs with teleconferencing and inset on-screen pictures” (Green et al., 2016).

Negotiating intangibility considers the provider’s inability to perform hands-on clinical examinations. This includes dismemberment and disempowerment, which consider body language cues, physical state in movements, tactile sensations and haptic feedback. Physical loss of feedback affects how EB specialists recommend treatments to EB patients using the EBOC.

Managing change encapsulates practitioners’ experiences regarding their formal/shifting role and maintaining a stable identity. Stable identity considers how practitioners define themselves in a professional context, and shifting roles consider the tasks and processes which the practitioner conducts to carry out work-related duties.

Green et al. (2016)’s new understanding-based theory of service separation practices can be applied to assess why e-healthcare, though an emerging trend, may not be viable for EB patient healthcare.

Types of Social Media usage by patients

Sridevi & Arunkumar (2017) present a framework to determine why patients resort to social media for support, depicted in Figure 2.

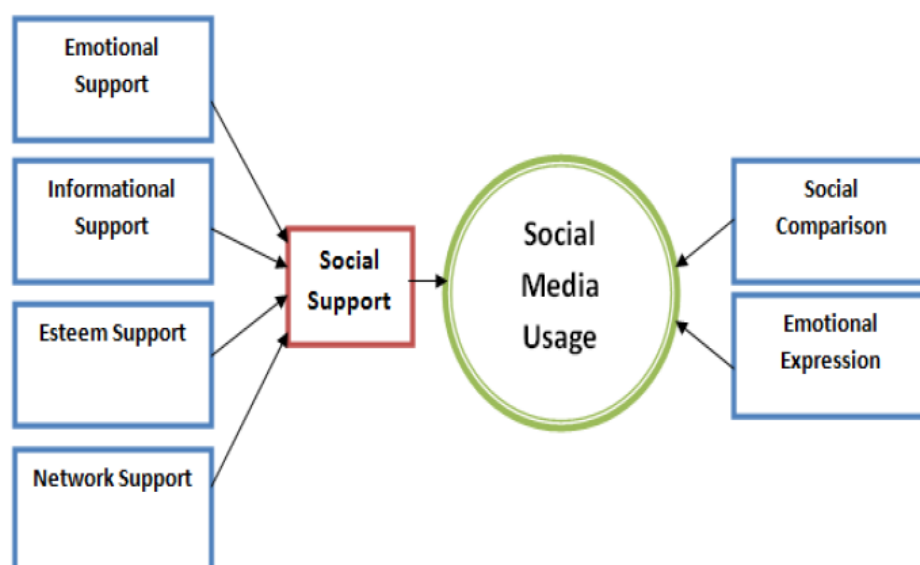


Figure 2. Types of Social Media usage by patients, adapted from (Sridevi & Arunkumar, 2017)

Social media usage is defined as the, “process of interaction among relationships which is intended to improve sense of belonging, coping, esteem, and competence through actual and perceived exchanges of psychological resources”. Patient use of the EBOC has the potential to therefore increase social support.

Emotional support occurs when patients meet their effective or emotional needs with online discussions.

Esteem support aims at encouraging individuals to take appropriate actions to live with their conditions successfully, and share their experiences regarding new treatments, finding encouragement prior to beginning their treatments.

Information support is a powerful tool for newly diagnosed patients that are in need for inputs about their condition and available treatment options. This can be provided by EB specialists, patients and researchers.

Network support considers how patients are connected to the wider community, highlighting the fact that they’re not alone. It gives EB patients the opportunity to develop relationships depending on what information has been shared on their condition that is relatable.

Emotional expression and social comparison also benefit patients using social media as the online expression of emotions provides patients with unique opportunities to communicate without having to worry about immediate reactions or feelings of those who co-exist with them in their online community.

The model presented will identify how the EBOC enables patients to interact with each other without inhibition, understand the integrity of their condition, and to learn how EB treatments work.

[The Honeycomb Framework](#)

Moorhead et al. (2013) explore diversity of social media platform forms and functions, utilising Keitzmann, Hermkens, McCarthy, & Silvestre (2011)’s honeycomb framework. The social media ecology presented through the honeycomb framework, is built upon 7 building blocks which Moorhead et al. (2013) used to examine different social media platforms and their implications on health care providers. Each block allows investigation of, “a specific facet of social media user experience, and its implications for firms” (Keitzmann et al., 2011).

As distinguished in Figure 3:

- Identity considers “the extent to which users reveal themselves”;
- Conversations considers “the extent to which users communicate with each other”;
- Sharing considers “the extent to which users’ exchange, distribute, and receive content”;
- Presence considers “the extent to which users know if others are available”;
- Relationships consider “the extent to which users relate to each other”;
- Reputation considers “the extent to which users know the social standing of others and content”;
- Groups considers “the extent to which users are ordered or form communities”.

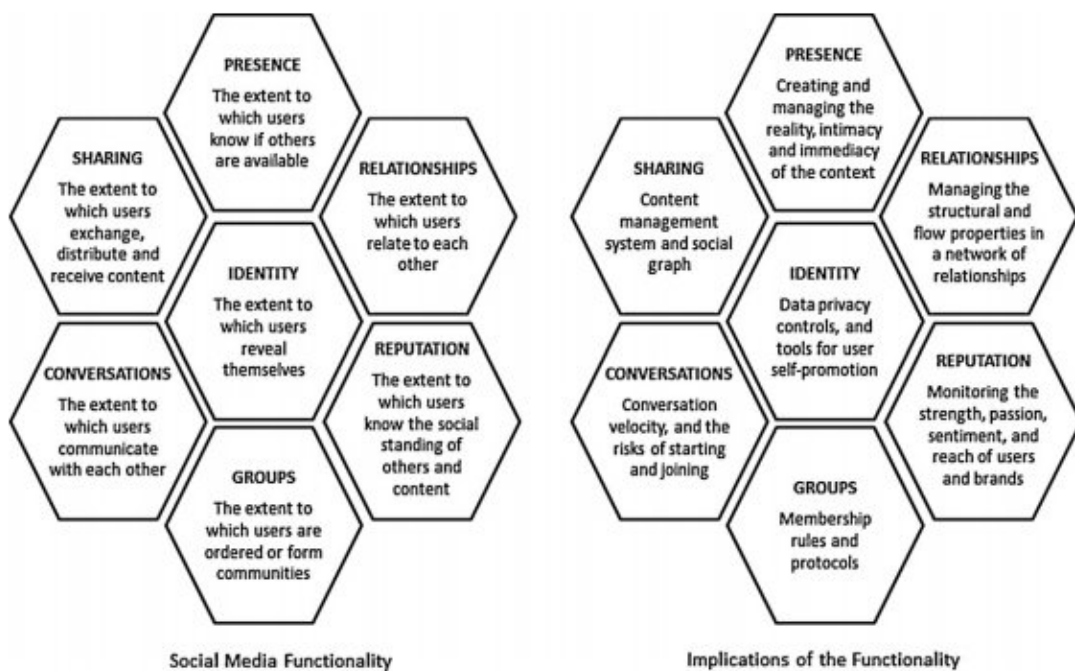


Figure 3. The Honeycomb Framework, adapted from (Keitzmann et al., 2011)

The honeycomb framework can be applied to the EBOC to identify its key functionality based on how EB patients and community members interact on the platform.

Method

The phenomenographic understandings and subthemes (Green et al., 2016), types of social media usage by patients (Sridevi & Arunkumar, 2017), and honeycomb model (Keitzmann et al., 2011) were applied to the EBOC, shown in Figure 4, to examine whether social support and patient healthcare could be improved through the integration of online communities in everyday EB patient lives. For the purposes of this report, EB nurses were included as being EB specialists.

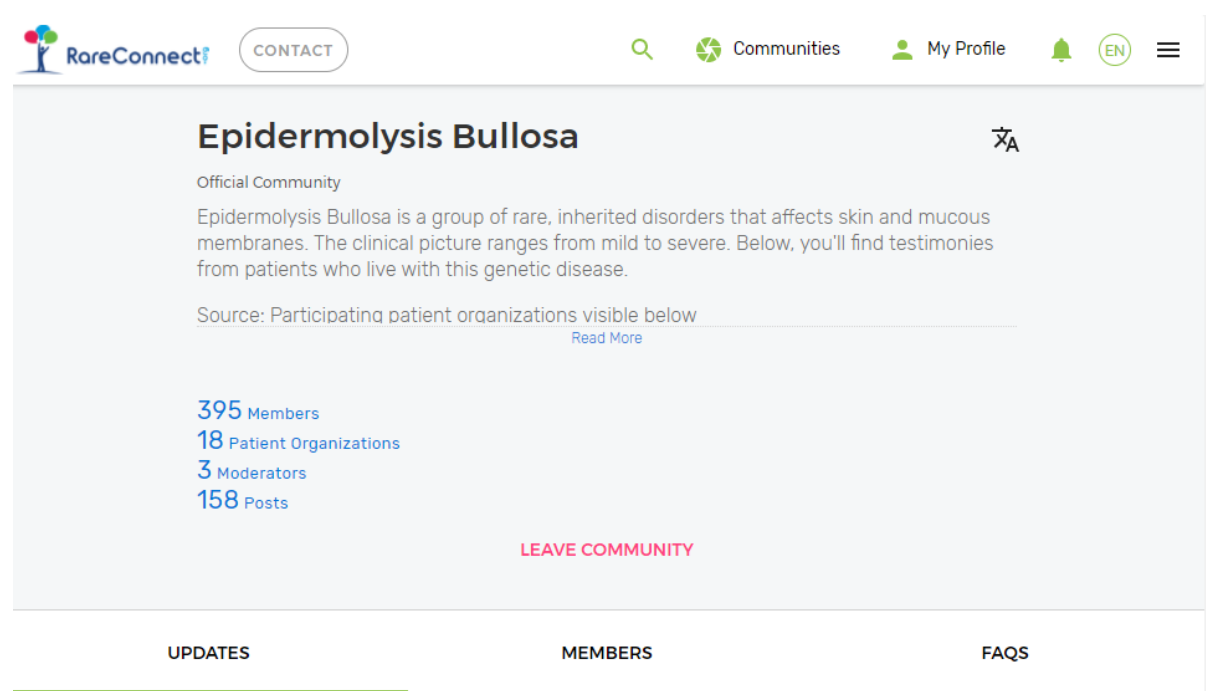


Figure 4. RareConnect Epidermolysis Bullosa Online Community (RareConnect, 2011)

Challenges faced regarded accessing relevant information related to EB in a digital context. Most academic literature was based on investigations into the condition itself, therefore assumptions were made regarding how virtual communications influenced the use of the EBOC. The findings and discussions were based on healthcare online community literature, with the assumption that these were applicable in an EB context, and how a regular user would interact with the platform.

Findings regarding the phenomenological understandings are based on how EB specialists currently interacted with EB patients, and how e-healthcare could change the effectiveness and reliability of EB healthcare practices.

Findings

Phenomenographic understandings and subthemes

Depersonalisation

Disengagement:

In the ‘real’ world, EB specialists communicate face-to-face with EB patients, acting on behalf of EB organisations. For example, Foster & Holmes (2007) identified that EB specialists visited young adult EB patients on an informal basis so that they became more comfortable. EB specialists and researchers also communicate with EB patients face-to-face during annual DEBRA conferences. In contrast, the EBOC creates a ‘virtual’ world where EB specialists can communicate with EB patients globally, providing advice and treatment options; however, EB specialists would be expected to feel a sense of emotional or psychological disconnect from EB patients as they wouldn’t be interacting physically. Mitigation of disengagement could include local EB specialists communicating within the EBOC, monitoring EB patient posts, and providing advice relevant to patient communications.

Disruption:

Time diseconomies of scale can occur on the EBOC when EB patients communicate online and must wait for a response. For EB specialists, it may be harder to reap the rewards of time invested into specialist training should patients no longer need them for support (Green et al., 2016). Disruption can also occur if the EBOC became unavailable due to technological failures, in which case members of the community would have to re-establish a connection for continual communication. This would mean EB specialists must still maintain personal contact with EB patients regardless of any virtual communications.

Clinical Voyeurism

Looking Glass

Given the nature of EB, it would be unlikely that EB specialists would be less likely to address sensitive EB-related issues. Patients may feel unnerved by virtual consultations; however, not being touched may cause less pain.

Picture-(not)-in-Picture

Often, EB patients also need support from other family members, therefore it is likely that virtual communications will take place with others in the room. EB specialists should therefore be aware of any others in the room; however, given that specialist care is required for EB patients, virtual consultations may reduce the effectiveness of services.

Negotiating Intangibility

Dismemberment:

EB specialists communicating on the EBOC must rely on the information provided by EB patients, missing subtle nuances as they cannot view or interact physically with the patient (Green et al., 2016). This could lead to subtle discomforts of patients being missed, impacting the quality of healthcare received. Some patients may not be able to describe all their symptoms, often picked up during physical consultations.

Disempowerment:

Some of the posts on the EBOC, upon examination, showed that EB community members communicated with each other through shared experiences rather than published findings for queries regarding tattoos, piercings and skincare products, showing some disregard for specialist knowledge (RareConnect, 2011). EB specialists may also feel they are unable to treat EB patients due to spatial and temporal distances, leading to service inefficiencies. This may mean face-to-face examinations may still be the best means to treat EB patients, since EB specialists would lose the power and authoritative voice to treat EB patients.

Managing Change

Clinical Identity:

EB specialists on the EBOC identified themselves as community managers on EB member posts, as shown in appendix A (RareConnect, 2011). Community managers communicated with members readily; however, their roles may have been switched from being technicians working for EURORDIS to physicians who help EB patients online (Green et al., 2016). These community members may not have the specialist training received by EB specialists, therefore not being 100% credible sources for EB treatments.

Technical Role:

The EBOC managers would likely have been tasked with monitoring the implementation of the virtual support platform. As these community managers may not be EB specialists, often

they redirect EBOC members to relevant content related to their queries (RareConnect, 2011). Should the EBOC become widespread, EB specialists may become more engrossed in ensuring the EBOC runs smoothly rather than providing high-quality healthcare services.

Social Media Usage Framework

Social Media Usage

Social Support:

Al-Kadi & Chatterjee (2012) state that other health social networks (HSNs), “targeting specific conditions aim to change the behaviour of the user, or communities that aim to prevent certain conditions such as minimising condition-related complications”. Such communities provide patients with tools to manage their condition. The EBOC provides a platform for EB patients, specialists, and researchers to communicate through, gaining updates on medical advancements and conference proceedings related to the EB. Given the nature of EB, Gowran et al. (2015) state that, “appropriate support services are required when dealing with the physical, psychological, and social challenges of living with rare disease”.

Emotional Support:

Jun Zhou, Zhenfu Cao, Xiaolei Dong, Xiaodong Lin, & Vasilakos (2013) identified that patients utilising e-healthcare have opportunities to share their health conditions and medical experiences, gaining mutual support and comfort from older patients. This emotional support provided through the EBOC evidently helps younger EB patients and their families understand how to cope with EB in their daily lives.

Informational Support:

Al-Kadi & Chatterjee (2012) stated patients sharing personal health information on HSNs are more likely to manage conditions better since they are personally involved in the collection and use of personal health information. Furthermore, the EBOC can empower EB patients, specialists and researchers by providing tools which can allow them to strip down the boundaries of knowledge exchange and share information that can make living with EB more bearable (Al-Kadi & Chatterjee, 2012).

Esteem Support:

HSNs have the ability to bring people together who share the same symptoms, allowing for mutual support to be built through shared experiences, eliminating physical boundaries (Al-Kadi & Chatterjee, 2012).

Gowran et al. (2015) acknowledged that EB patients often have low self-esteem, living with disfigurement and pain, coping with physical impairments, and loneliness. The EBOC provides EB patients a platform to communicate with other users and understand how to live successfully with their condition, building EB patient self-esteem.

Network Support:

EBOC members know that they can post online and discuss EB without being judged or ridiculed by malicious respondents. Network support occurs when EBOC members communicate freely and know they aren't alone, developing relationships from shared experiences and interactions with each other.

Social Comparison:

HSNs also target EB patient symptoms to change user behaviour or reduce condition-related complications. Social comparison between EB patients occurs when patients with the same form of EB can communicate with each other, comparing symptoms to support each other. The EBOC can therefore enable patients to better manage their form of EB through a support network, as they know how other EB patients are living daily.

Emotional Expression:

The EBOC also allows EB patients to express their emotions and provide valuable advice to their peers online (Al-Kadi & Chatterjee, 2012). Being able to emotionally express feelings means EB patients can better cope with their condition rather than feeling closed off from the rest of society.

The Honeycomb Framework

Identity:

Identity on the EBOC relates to members of the community, removing a psychological barrier apparent outside the virtual world, giving EB patients opportunities to interact with each other without reservation. It is evident that EB members don't mind disclosing their name, age, gender and location online (Keitzmann et al., 2011; RareConnect, 2011). RareConnect requires members to sign up or login to contribute content; however, there is a

lack of accountability for who can and cannot join as anyone can become a member, highlighting an inability to authenticate members upon subscription (Al-Kadi & Chatterjee, 2012).

Identity also raises the issue of EB patient privacy being compromised since the nature of their condition would be known to any online user part of the EBOC, therefore care must be taken to ensure that no malicious or harmful behaviour is apparent. Page moderators monitor the EBOC to ensure such content is not published, although there is no process to stop members joining.

Conversations

The EBOC is designed to facilitate conversations among EB patients, and with groups of EB organisations, specialists, and researchers. It allows community participants to post their thoughts regarding EB topics or queries relating to the skin condition, and gain updates on annual international EB conferences (RareConnect, 2011). Such organisations can contribute to patient conversations, showing international support for EB patients. Use of the EBOC means EB patients can converse about topics of interest without having to be physically present in the same location (Gowran et al., 2015).

Sharing

Content can be freely disseminated on the EBOC provided users have a 'handle' or identity. Betts, Donoghue, Aikin, Kelly, & Boudewyns (2016) identified that healthcare providers were historically limited to relying on their own knowledge, literature, and consultation notes from colleagues available at an arm's length; however, online communities give access to a global collection of medical knowledge. The implications for the EBOC are that specialists and patients can be linked to a wider scope of EB-related knowledge through one platform. Such knowledge can include personal experiences, treatments, trials, EB-related projects and studies, and public interest in understanding the condition. Litchman, Rothwell, & Edelman (2017) acknowledged that online health communities are also formats of peer-health, allowing individuals to interact and seek information and support online. This interaction clearly occurs on the EBOC, where members share their experiences to advise EB patients on queries related to everyday life, therefore highlighting the core functionality of the EBOC.

A weakness Betts et al. (2016) identified was that access to more information doesn't necessarily translate to better quality information. Similarly, after assessing the EBOC, more

information is available to EB patients about personal experiences; however, this information is not always relevant to all forms of the skin condition or relatable to by the wider community. If EB researchers and specialists also posted on the EBOC, regular members may find it hard to understand medical terminology, so content becomes more irrelevant; however, current sharing highlights the EBOC has more social, not research-based, content.

Presence

The EBOC provides a visual map of members and patient organisations that are members of the community, as shown in Figure 5 (RareConnect, 2011). Although the EBOC doesn't indicate when users are available online, it does show that there are other members globally situated nearby who users can interact share experiences with. This can build a bridge between the 'real world', where EB patients may find it hard to interact, and the 'virtual world', where EB patients can freely interact with like-minded individuals (Keitzmann et al.,

LEAVE COMMUNITY

396
Members

18
Patient Organizations

3
Moderators

159
Posts

UPDATES

MEMBERS

FAQS



2011).

Figure 5. EB Online Community – User Location Map (RareConnect, 2011)

Relationships:

EB patient-to-patient relationships can arise when the form of EB is relatable. Relationships on the EBOC tend to be more open as information is shared freely. The EBOC may have some depersonalised relationships between community members initially due to the global reach of the platform; however, over time and with increased interaction within the community, members would become more comfortable with sharing experiences, and forming relationships. Litchman et al. (2017) also identified that older community members could become role models following successful management of their condition, weighting as having greater credibility than regular or newer users. Implications for the EBOC include those members who post more often being more reliable and credible with advice. Members can then continue communicating, becoming involved with the community and receiving support.

Reputation:

Users of the EBOC can determine the trustworthiness of user-generated content based on who posted (Keitzmann et al., 2011). EB patient organisations associated with DEBRA International would hold the highest reputation amongst the organisations involved with the EBOC, therefore user-generated content contributed by these organisations would be more trustworthy to EB patients. User-generated content related to conferences and updates on the latest EB treatments need to be accurate and reliable for members to be able to reap benefits. Incorrect, unreliable information has potential to have severe negative implications to EB health, both mentally and physically due to the nature of the skin condition. However, EB patient contributions also are reputable sources as they understand what other EB patients go through; consistent with findings by Johnson & Ambrose (2006), who acknowledged information sharing and exchange between individuals with similar conditions as credible sources.

Groups:

Al-Kadi & Chatterjee (2012) identified that HSNs have targeted users. For the EBOC, the target users are EB patients, specialists and researcher. Within the EBOC, members could be split into groups such as general members who can post and interact with content contributed, community managers who regularly reply to user posts, and administrators/moderators who monitor and remove content when deemed inappropriate.

Discussion

Findings from examining the EBOC are consistent with Johnson & Ambrose (2006) who suggested that online communities can, “invite the pooling of isolated fragments of knowledge, forming a rich web of collective intelligence”. Integration of the EBOC into EB healthcare practices has the potential to improve EB patient healthcare by connecting patients to a supportive, global EB community. DEBRA International should encourage global DEBRA subsets to integrate the use of the EBOC into their services to encourage EB patients to share their experiences. Although some EB patients may still require local support groups and interactions with DEBRA, some physical communities may still not fully understand and accept EB patients. Encouraging EB patients to utilise and interact within the EBOC can allow them to gain immense social support, so they don't have to feel lonely, can converse, and share experiences with each other without the fear of being judged dismissed or embarrassed about their condition (Nambisan, Gustafson, Hawkins, & Pingree, 2016).

Investigation of the honeycomb model and types of social media usage also highlight that sharing is a key functionality for the EBOC, so patients can receive social support. Such an assumption can be made as the EBOC is primarily used to share experiences and provide advice to community members. Opportunities arise as EB patients can interact over spatial and temporal distances, gaining support from a global community of like-minded individuals who understand, live with, and can relate to new community members. Examination of the EBOC also highlights that emotional and esteem support are evident in conjunction with shared experiences and conversations. Users clearly utilise the EBOC to communicate with each other and provide advice based on personal experiences which can often hold more credibility than academic sources. The ability for the EBOC to build a bridge between ‘real’ and ‘virtual’ worlds further emphasises that EB patients can benefit from platforms that are centred around geographical spaces rather than specific locations. If users require synchronous interactions, then alternative means of communication, such as Facebook, could be used.

Given the benefits of the EBOC, there are also negative implications for EB patients. Disconnect may occur if EB patients relied wholly on the EBOC for medical advice and treatments. It is still essential for EB patients to communicate and interact physically with EB specialists to get medical treatment. Therefore, e-healthcare through the EBOC may not be a viable means to improve patient healthcare from a practitioner perspective. EB specialists

may not be able to utilise the EBOC to conduct medical consultations because of the nature of the skin condition; however, these specialists can utilise the EBOC to disseminate medical facts and provide vital information regarding EB to a global network of EB-related members, provided the EBOC becomes widely adopted.

Conclusion

By understanding how EB patients interact on the EBOC, healthcare providers and EB researchers can recognise the benefits of implementing knowledge transfer and support services through a social platform. Should DEBRA encourage the widespread use of the EBOC, EB patients can contribute their experiences to help younger EB families understand and cope with EB in their daily lives. Exposure of the EBOC and its global reach as an online social platform produces opportunities to build a community who accepts EB and can lessen the hardships present in EB patients' daily lives, improving their social support system, therefore their overall healthcare.

Although it would not be appropriate to use the EBOC to conduct consultations, experts can utilise the platform to gain support and disseminate findings impacting EB patients' daily lives. As specialist training is required to handle EB patients, online consultations should be limited, but the EBOC should be leveraged to encourage knowledge sharing throughout the EB network.

Appendix A



sandrarc

1 day ago

originally written in English



Hi @lisalee,

Just a quick personal note to say hi and welcome to the EB community. My name is Sandra and I work with EURORDIS as a community manager on RareConnect. Although my son suffers from severe Dystrophic EB form and he is exactly at the same age as your son, but given the fact that we live so far from you unfortunately we can't arrange meeting, but I do agree with you that these personal contacts between them are beneficial and precious even with an older EB sufferer. There are lot of things our kids can do despite all those disease limitations.

In the Members section visit the community map and if you wish to get in direct contact with any member of this community that has marked location on the map, send me an email at sandra.pavlovic@eurordis.org and I'll make sure this happens.

Some of the other ways to reach others near you or globally is to contact DEBRA of America organisation <http://www.debra.org/> (you may want to attend on some meetings or other events they are organising) and you could join these Facebook groups:
<https://www.facebook.com/groups/176025602452624/>
<https://www.facebook.com/groups/16884589256/>

Best wishes to you and your butterfly child, Sandra

Example of clinical identity where technicians become physicians to aid EB patients.

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COMMENT: This is a first class report, following all the assignment instructions and managing to achieve a well thought out appraisal of the role online communities (in terms of both health professionals and those afflicted by EB) and interaction between them can play in improving medical, social and informational support – both individually and collectively.

While I understand there were personal motives in pursuing the topic area, you have nevertheless produced an excellent (and highly interesting) report. Well done!

Grade: A+