

Abstract

Online health communities provide important emotional and social support to those people living with epilepsy and their family. People can connect and discuss the barriers they are facing with likeminded people from all over the world. This is particularly beneficial as online interactions include both synchronous and nonsynchronous and are able to take place from pretty much anywhere, which allows users to maintain constant contact with their online health community. As a result, the group members develop a positive sense of social and emotional well-being.

Key Terms: Community/Communities, Online Health/Epilepsy Communities, Epilepsy, Web 2.0, Social & Emotional Support, Social Media Communities & Networks.

There are a variety of community's right across the globe, made up of people with similar interests, health, hobbies and religions. Prior to web 2.0, people were restricted as to who they could share a community with. But the ever-advancing technology allows for internationally transferable communication to take place anywhere and at any time. Hence, the meaning "community" has broadened to a new level where online community groups have become equally important as face-to-face community groups (Hampton & Wellman, 2018). Online health communities are a means of support for those struggling to deal with the daily challenges and barriers faced, and provide comfort to both the disabled and their loved ones knowing they are not alone in the battle against disability (Atanasova et al., 2017). For instance, epilepsy is a serious neurological disorder, affecting around 50 million people worldwide. The brain and central nervous system of a person living with epilepsy is permanently impaired. As a result, people living with epilepsy often face multiple physical, mental, and emotional barriers each day. As such, epileptic people can often become quite isolated from the rest of the world (Beghi, 2020). People living with epilepsy and their families require emotional support to build their coping strategies and resilience to challenges faced daily due to their ongoing disability. However, the family and friends of people living with a permanent disability do not always understand the struggles and additional support needs of their loved ones. Indeed, caring for a loved one with a permanent disability can be overwhelming and at times family and friends may also require additional support (Dako-Gyeke & Donald Donker, 2018). This paper aims to argue that online epilepsy community groups improve the social and emotional wellbeing of those living with epilepsy and their family. This will be examined by looking at the medical information and resources available online, increased self-perception and online community support.

Traditionally a community was known as a group of people connected through a common interest such as religion, race, health, values and hobbies. Furthermore, they were

those people that one would spend quality time with in person on a regular basis (Hampton & Wellman, 2018). In some ways, advanced technology has changed the way society views a community, as there is a wider variety of options to communicate and connect with people than there was prior to the release of Web based communication (Hampton & Wellman, 2018). Indeed, communication methods have changed, in that the new and improved virtual communities travel faster and further than before. But, never-the-less, the criteria for a community remain the same and the ever-growing online health communities are a prime example of this (Hampton & Wellman, 2018). Online health communities are online social networks related to the health sector. Their primary role is to provide patients and their families with information about illnesses, to obtain and offer social & emotional support, and to connect with others experiencing similar circumstances (Atanasova et al., 2017). These online community groups most commonly consist of a combination of likeminded people, who share a connection through knowing, caring, or treating an individual with a specific disability such as epilepsy (Atanasova et al., 2017).

Epilepsy is a serious neurological disorder, affecting around 50 million people worldwide. The brain and central nervous system of a person living with epilepsy is permanently impaired. Consequently, all areas of one's life including academic, personal, and professional are affected, creating many barriers and decreasing their quality of life (Beghi, 2020). Like a majority of disabilities, stigma is often associated with having epilepsy. This can have long-term negative effects on the social identity of people living with the disorder. Stigmatization is a type of discrimination developed through several avenues, such as a lack of contact, negative experiences and a lack of education. As a result, stereotyping of particular groups develop and the stigmatization continues into the future (Dako-Gyeke & Donald Donker, 2018). Despite society's lack of understanding about epilepsy and consideration for those living with the disability, the people living with epilepsy are not too

dissimilar to other people in society. They shop, work, study, travel and seek information, all of which contribute to the economy. The main difference is that often people with epilepsy face a considerable number of barriers while trying to complete everyday tasks, that would otherwise seem simple to someone who does not have epilepsy (Koponen et. al., 2007). Discrimination is inevitable for people diagnosed with epilepsy and for many individuals, epilepsy remains a defining feature of their identity. Such issues are a cause of significant concern for a number of people living with epilepsy and their families (Dako-Gyeke & Donald Donker, 2018).

Epilepsy affects not only the individual living with epilepsy, but it can also have an enormous impact on all members of the family and their surrounding network. Many of the negative events experienced by someone living with epilepsy are likely to extend to all family members. As stress in the family increases, it has the potential to place unnecessary stress on the family unit and increase the likelihood of seizures re-occurring (Chew et al., 2018). Online epilepsy support communities provide invaluable support to both those living with epilepsy, their family members, carers and the wider community. The extensive amount of medical information accessible online helps educate people on the neurological disorder. A few of the valuable medical tools available online are treatment and management plans, lists of health professionals and seizure diaries (<http://www.epilepsy.org.au>). But more importantly though, are the online forums which build a sense of community, connecting people with other likeminded individuals who are experiencing the same barriers and discussing coping mechanisms. By exchanging stories, a perception of belongingness, mutuality and loyalty is created that then links the individuals in a collective unity. As a consequence, the importance of online health communities continue to increase nationwide (He et al., 2019; Yuchao et al., 2021).

Web 2.0 has seen electronic communication progress with the development of social community platforms. Equally, global communication has increased and it continues to have a significant impact on the way people communicate in modern society. In fact, the elimination of distance as a barrier to communication continues to increase electronic communication and make society more global (Fuchs, 2020; Hampton & Wellman, 2018). The benefits of global society have proven significant to the health industry, increasing education and communication among those suffering from health related conditions, such as epilepsy. People with epilepsy and their family members now have immediate access to a range of medical advice within the online health community platforms. In addition, they can communicate with likeminded people from all over the world through electronic communication (White & Dorman, 2001). Furthermore, this communication can take place at any time night or day, and in the comfort of their own home, eliminating common physical and emotional barriers faced when trying to attend face-to-face social support groups (Fuchs, 2020; Hampton & Wellman, 2018).

People living with epilepsy experience an increase in self-perception when being involved with an online epilepsy support group. A person's mental model of him/herself in real life is presented to others through their actions and interactions. People also infer the identity of others based upon visual attributes such as one's appearance. Appearance allows people to recognize others and associate an identity with a person (Obst & Stafurik, 2010). When in full effect epilepsy is a visible disorder, therefore those affected by the disorder are commonly worried about "when the next seizure will occur and what people will think of them". Consequently the individual may withdraw from society and become isolated (Dako-Gyeke & Donald Donker, 2018). One of the first tasks that people must do when entering a virtual world is create a virtual representation for themselves – otherwise known as an avatar. This lets the user choose to identify their real-self straight away or potentially present with a

picture of their favourite movie star or cartoon character (Li et al., 2013). Furthermore, due to the anonymity of online communication it is up to the individual when he/she would like to first start discussing their condition and how much he/she would like to share.

Understandably, it's quite common for someone to hold back on disclosing all information initially (Li et al., 2013). However, the more often one accesses the site they begin to develop a sense of community within the group. This in-turn provides them comfort and they begin to open up to the group. As a result the entire online epilepsy support community benefits from the exchange of information and growing community network (He et al., 2019; Yuchao et al., 2021).

Another benefit to online health communities is the social and emotional support that develops between the members of the group. Emotional support is a critical form of social support, assisting in the development of coping techniques and providing encouragement and hope (He et al., 2019; Yuchao et al., 2021). In general, emotional support can be described as words or actions reassuring someone that they are appreciated, loved and respected.

Understandably, comfort and security are imperative during times of duress. This nurturing provides reassurance to the person, that they are cared for by others (Reblin & Uchino, 2008).

The initial diagnosis of epilepsy can come as a significant shock to both the individual and their immediate family. As a result of their diagnosis and additional needs, people with epilepsy and their families often face major psychosocial and emotional challenges (Beghi, 2020). Often the family members of those living with epilepsy don't fully understand the challenges that the individual is going through, and likewise the individual doesn't fully understand the pressure involved with caring for a loved one with epilepsy (Dako-Gyeke & Donald Donker, 2018). In order, to deal with the additional daily pressure endured by this disorder, epilepsy sufferers and their families seek social and emotional support. By becoming members of an online epilepsy community, individuals and their family are able to

exchange social and emotional support with likeminded people online (He et al., 2019). Accordingly, the exchange of emotional support online can have psychological benefits which transcend to the patient and their family networks. Evidence suggests that online health communities have proven to assist with a variety of different illnesses and diseases, being beneficial to both the group members and their family's social and emotional well-being (White & Dorman, 2001). As a result, online health communities have the potential to improve the social and emotional wellbeing of both those living with epilepsy and their family.

In conclusion, traditionally the word "community" has been associated with a group of likeminded people spending quality time in person, connected by an interest, religion, illness or nation. However, web 2.0 has changed people's perception of what a community is, in that, nowadays a community is not only those people you spend time with face to face but also those that you communicate with online (globally). The benefits of global communication are evident in the distance and speed at which information can travel and the flexibility of when and where this transaction can take place. This paper has identified some different motives for the growing success of online health community groups, more specifically those living with epilepsy or caring for someone diagnosed with the disorder. Epilepsy is a neurological disorder affecting millions of people globally. People living with epilepsy and those caring for them face several barriers throughout everyday life, such as stigmatization and isolation. Humans have a natural desire to belong and be affiliated with others, online health community groups have the potential to fulfil this desire. They connect people with other likeminded people, provide individuals with a source of information and assist in giving and receiving social and emotional support. An individual's self-identity typically results from the membership in a pre-established self-inclusive social group, including fostering and nurturing relationships. Consequently, the social and emotional well-

being of those living with and caring for a loved one with epilepsy benefits from being a member of an Online Epilepsy Community.

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