



Diabetes Online Community #DOC

Impact and evidence of social media use amongst people with diabetes

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We are now living in a virtual world, a world where we carry a whole library of facts, information and resources in our pockets and in our handbags...in the form of a smartphone. We are as accessible and contactable as we want to be. We have the answer to most questions within a few seconds at our fingertips. For some this can be seen as a blessing, for others they see it as a curse. Some hail the advent of smartphone's and social media networks as groundbreaking 21st century technology which has changed the face of day-to-day life as we know it. Others see this social media revolution as marking the decline of face-to-face conversation, that we are losing our ability to socialise away from our phones and for many can present even greater challenges in the form of an addiction and withdrawal from society. Social media can be defined as the interaction among people in which they create, share, exchange information and ideas in virtual communities and networks.¹

#DOC – Diabetes Online Community

So what is the evidence and impact of the use of social media networks amongst individuals with chronic diseases such as diabetes? A Google search for diabetes returns 290 million results, a search of the term 'diabetes online support' shows 28 million results. The diabetes online community, otherwise known as #DOC is one of the largest and most prominent online communities amongst those living with chronic conditions. #DOC provides people with diabetes with valuable instant information, support and resources from their peers, without having to wait months for a visit with a healthcare professional to access equal information. Changing dynamics in healthcare, no longer see healthcare professionals as the sole providers of information.

The most common social networking sites for people with diabetes are Facebook, Twitter, YouTube and blogs, in addition to many dedicated online discussion forums, such as the Diabetes Hands Foundation (tudiabetes.org). These sites can be a lifeline

for many and a source of huge comfort for people living with the day-to-day burden and challenges that diabetes can bring. But for many healthcare professionals, the use of social media amongst their patients can be seen as frightening and somewhat ridiculous. A fear of the unknown as well as issues such as unregulated sites, misinformation, propensity for litigation or sharing of clinical data, can cause healthcare professionals to shy away and dismiss social media as a powerful resource for many of their patients living with diabetes.

People with diabetes seek online information about the condition, treatment options, practical strategies and tools for managing diabetes in their daily lives, scientific breakthroughs, and advocacy efforts.² Very few healthcare providers engage and assist with this information overload by filtering and narrowing down online resources and search results for their patients. This can be due to common online obstacles such as difficulty distinguishing between high-quality, credible information, content that is out of date, inaccurate, or overly promotional.³

Impact and evidence

Diabetes is chronic condition, where reliance on self-management of those individuals living with it makes it unique amongst chronic disease state management. Patients who are actively involved in their self-management and care are more likely to manage chronic conditions more effectively.⁴ A study by Stafford found that people with diabetes reported spending a varying amount of time on self-care, with an average of about 20 minutes per day.⁵ As people manage their condition they build up expertise year by year. Self-management is a vital component in diabetes care but it is important to distinguish between a 'knowledge of diabetes' and the 'skill of managing diabetes'. Diabetes is a complex long term condition which requires a person to have a set of skills, resources and support independent of healthcare providers to be able to manage it effectively. These practical components of management can be found through social media.

Several factors can influence a person's engagement of social media for helping to self-manage their diabetes such as limited visit time with healthcare providers, lack of out-of-hours support and seeking clarification of what can be seen as sometimes conflicting advice given. Also the gratification and support given by their peers when a person successfully manages their diabetes can be a powerful sway in favour of a person's use of social media.

Social media has the potential to reach large audiences; worldwide more than 845 million people use Facebook and 140 million are Twitter users.⁶ Each minute, 695,000 Facebook statuses are updated and 98,000 tweets are tweeted.⁷ Social media reaches all communities and populations and is usually associated with age but is independent of educational attainment, race/ethnicity, and healthcare access. This is known as 'Web 2.0' a term used to describe the evolution of information on the internet that has moved away from static "read-only information" – to more advanced, interactive sites that allow users to share, create and contribute content.⁸

Social media networking can serve as a tool to engage and involve patients in their healthcare but due to the growth and widespread nature of social networking, there is very little research available to date on the impact of its use on those with health conditions. Amongst patients with diabetes networking via Facebook, the most commonly discussed topics were; sharing personal clinical information, requesting disease-

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specific guidance, receiving emotional support.⁹ Searching for health information is the third most popular use of internet technology.¹⁰

The Internet allows users to perform in-depth information searches and can help individuals to make decisions in relation to their treatment and care. Research shows that online social support programmes targeting chronic illness have been shown to decrease symptoms, improve health behaviours and reduce use of healthcare resources.¹¹ Online programmes can serve as an interactive medium for providing health information and enhancing social support.

The healthcare profession's quest for an evidence base of the benefits of these social networking sites may be in stark contrast to what a patient perceives as *'their'* evidence of the benefits to them. This is nowhere more apparent than in the many diabetes dedicated blogs that are online. These blogs provide a person living with diabetes with an instant connection to shared common experiences and makes them feel like they are not alone. They can act as a source of inspiration, seen in an example of well-known US Type 1 diabetes blogger Kerri Sparling, who commented in one of her blogs that 'Social media... shows people that there isn't such a thing as a 'perfect diabetic,' but there can be an educated and determined one'.¹²

Conclusion

Social media networks provide a powerful resource and forum for people with diabetes. The behaviours of how people acquire information in relation to their health is changing rapidly and healthcare providers will have to react to these trends. As

our patients become more informed, it is time for healthcare providers to acknowledge that they are no longer the sole providers of healthcare information. As healthcare is becoming more patient-centred; there should be an onus on the healthcare providers to study, engage and understand the role social media has to play in their patient's self-management. Diabetes is growing to epidemic proportions worldwide, burdening already overwhelmed healthcare systems, therefore denying access to information and resources for people who may need it the most. This will push people with diabetes to turn to alternative sources of information, support and resources, with social media networks filling this obvious gap.

Social media can also provide healthcare providers with new ways to reach out to people to deliver diabetes education and promote social support. The use of social media amongst their patients can no longer be ignored by healthcare providers as a tool of empowerment. There is also a place for healthcare professionals within these communities to learn more about people with diabetes by engaging with these online resources. The role of social media in the medical and healthcare sectors is far reaching, and many questions in terms of governance, ethics, professionalism, privacy, confidentiality, and information quality remain unanswered. While guidelines on the use of social media

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for nurses in Ireland exist¹² further research, training and support will be needed as to their role in patient education and support.

Popular social networking websites for people with diabetes

- Diabetes support: www.diabetessupport.co.uk
- Our diabetes: www.our-diabetes.org.uk
- Patients like me: www.patientslikeme.com
- Diabetes mine: www.diabetesmine.com
- Diabetes Hands Foundation: www.tudiabetes.org

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