

A new dawn: The role of social media in diabetes education

Citation: Cooper A, Kar P (2014) A new dawn: The role of social media in diabetes education. *Journal of Diabetes Nursing* 18: 68–71

Article points

1. Self-care is an integral part of diabetes management.
2. People with diabetes can learn a great deal from their peers who have built up expertise in self-management through day-to-day living with the condition.
3. The development of interactive social networks online has enabled people with diabetes to create supportive online communities and share information about their experiences of living with diabetes.
4. Healthcare professionals should embrace the empowerment of people with diabetes and be aware of the online resources available to them.

Key words

- Diabetes
- Facebook
- Self-management
- Social media
- Twitter

Authors

Anne Cooper is Clinical Informatics Advisor (Nursing), NHS England; Partha Kar is Consultant Endocrinologist and Clinical Director of Diabetes, Queen Alexandra Hospital, Portsmouth

Anne Cooper, Partha Kar

Self-care is an integral part of the management of diabetes and people with diabetes build up expertise in self-management through day-to-day living with the condition. The internet has become a valuable resource for people with diabetes as social networks, blogs and patient self-help sites allow them to contribute to content, share experiences and make contact with other people in a similar situation. Although caution should be advised as some content may not be reliable, healthcare professionals should embrace this empowerment of people with diabetes and be able to help their patients find the most useful internet resources available. There is also a place for healthcare professionals within these communities and they can learn a lot about their people with diabetes by engaging with these online resources.

People with diabetes manage their condition as part of their everyday lives and good self-care is integral for the management of the condition. A study by Stafford et al (2005) found that people with diabetes reported spending a varying amount of time on self-care, with an average of about 20 minutes per day. As people manage their condition they build up expertise year by year, defined by Hartzler and Pratt (2011) as:

“experimental knowledge gained from personally managing the day-to-day experience of illness.”

In the technology guidance from NICE (2003), the outcome measures used to assess education for people with diabetes are traditional physiological measures and there is no assessment of skills development for long-term management, nor well-being measures; although, it is acknowledged that this is because there is a lack of evidence for these measures.

Self-management skills

There can be no doubting the importance of good self-management skills but it is useful to differentiate between “knowledge of diabetes” and the “skill of managing diabetes”. Self-management is the cornerstone of care for people with diabetes and ongoing support is needed to sustain the changes made during the educational process (Funnell, 2010).

Diabetes requires daily attention and management. People with diabetes will have periodic contact with healthcare professionals (HCPs) but they need to have the skills, attitude and support to manage their condition independently (Diabetes UK, 2009). Complex long-term conditions require the individual to be able to master and sustain a range of lifestyle and clinical interventions on their own. These skills range in complexity – some people with diabetes may simply be required to eat a particular range of foods, while others have to manage complex data and equipment, such as insulin pumps.

The role of social media

One way for people to gather practical information about managing their condition is from peers using social networks. The term “Web 2.0” is used to describe the evolution of information on the internet that has moved away from static information – what some people call “read-only web” – to more advanced, interactive sites, such as social networks, that allow users to create and contribute content. Examples of these sites include YouTube, Twitter, Facebook, Pinterest and Foursquare. These sites allow users to contribute content such as blogs, wikis, forums, pictures and videos. They are seen as providing social means of communication and are closely linked to the term “social media”, where people use these technologies to communicate and form social networks. They have created new platforms for information sharing and the generation of materials for participants that previously would have taken years to share.

Social media has had a profound effect on society, accelerating the way relationships are formed and information is now being shared in an unprecedented way. An example is the so-called “Arab Spring” of 2011, where social media is believed to have influenced how protestors in the Middle East organised themselves and communicated (Harris, 2012). Social networks are growing. The Office of National Statistics reported in 2011 that 60% of women and 54% of men engage with online social networks (Office of National Statistics, 2012).

Social media and health

There is an emergence of the use of social media in many areas of life and in the health arena platforms, such as “Patientslikeme”, have created opportunities for conversations to be had between people who have similar health conditions.

Social networks can relate to all aspects of our lives, including our health and well-being. For people with diabetes who have learnt skills through the application of knowledge of their condition throughout their lives, social media may make it easier to connect with people

who have a similar condition and similar experiences. It can also provide the environment and the tools for knowledge sharing and peer support. Social networks are formed when individuals use this technology to enable them to form relationships with others.

A simple search using the word “diabetes” on Facebook brings up page after page of groups within the site. Similarly, a simple search on Twitter using “diabetes” returns thousands of tweets. Farmer et al (2009) reviewed activity surrounding common medical conditions, including diabetes, on Facebook and found a large number of user groups that created interactions that would not have been possible without the Facebook platform. There were 39 606 members of groups that related to type 1 diabetes and, since the review was undertaken five years ago and social networks have continued to grow in popularity, it would be safe to conclude that these membership numbers would now be even higher.

There is a recognition in the clinical community that these sites, often created by people with diabetes, are on the rise (*Box 1*). Greene et al (2011) undertook a review to establish and review the most commonly used social networking sites for people with diabetes, for example, on Facebook. They found that some sites had more than 300 000 members, with minimal participation requirements or validation. All the sites offered the ability for members to communicate through posting and responding to questions. Some, but not all, were moderated by HCPs.

Evidence base

The evidence around the use of social networks for people with diabetes is limited, but it does indicate that there is an emerging field for

Page points

1. Social media have had a fundamental impact on the way people communicate with each other. New platforms, such as forums, allow quick and easy information sharing and discussion.
2. There is an emergence of the use of social media in many areas of life and in the health arena platforms have created opportunities for conversations to be had between people who have similar health conditions.

Box 1. 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

Page points

1. The evidence around the use of social networks for people with diabetes is limited, but it does indicate that there is an emerging field for potential research.
2. Healthcare professionals should not ignore these emerging trends and should seek ways to understand how they can participate and support people with diabetes to use this rich resource.
3. NHS spending on diabetes care now accounts for 10% of the NHS budget, therefore, it is important that we explore all ways of providing care to people with diabetes, and social media is a cost-effective option.

potential research. Most studies that exist focus on specific interventions, such as the provision of a website or health intervention, and few consider the concept or characteristics of networks where participants can share knowledge and experiences. Although there is no strong evidence of the impact – positive or negative – of the use of social networks by people with diabetes, what is becoming clear is that the behaviours of people are changing, with evidence that more people are engaging with others online. It is evident that, as social networking increases, people with diabetes, as members of the population in general, will be networking in this way (Greene et al, 2011).

HCPs should not ignore these emerging trends and should seek ways to understand how they can participate and support people with diabetes to use this rich resource. It may require a change of attitudes and behaviour and a shift from the position where the professionals are the sole source of information to a recognition of the potential for a more self-sustaining community of empowered people with diabetes – exactly what is needed in the current

economic climate. NHS spending on diabetes care now accounts for 10% of the NHS budget (Diabetes UK, 2013), therefore, it is important that we explore all ways of providing care to people with diabetes, and social media is a cost-effective option.

Social media: The view of a nurse with type 1 diabetes

My personal experience of social media has been two-fold, both as a nurse but also as a person with type 1 diabetes. I joined Twitter believing that I could make connections as a nurse, but what I discovered was a whole family of people who also have type 1 diabetes. Before this, I had little contact with my peers. I have learnt so much from this Twitter family, even though I have had diabetes for 34 years. For example, through discussions online, I have increased my confidence with using some of the more complex insulin pump settings and I also now use a continuous glucose monitor, which is something I had previously ruled out. I have watched this Twitter diabetes community grow significantly since I started using it.



Figure 1. Social media has had a fundamental impact on the way people communicate with each other.

Well-informed nurses and doctors also join in and it has strengthened to become an excellent source of knowledge and support.

Blogs have been the most exciting thing for me as a nurse and they have given me greater insight into diabetes, beyond my own experience. As professionals, the educational challenge is to encourage people with diabetes, regardless of their age, to make good connections and be able to select good sites and resources, enabling them to navigate the resources on offer.

A doctor's view

Healthcare professionals should see the explosion of social media as an opportunity, rather than a threat. Most diabetes organisations now have a presence on social media and online discussions regarding plans and models of care can inform HCPs' care. Educational areas range from simple professional development to simply appreciating the frustrations of people with diabetes, and understanding the need to move beyond targets and provide good individualised care.

The issue of confidentiality will need to be tackled and the security of online forums still needs to be sorted out before any direct, personal advice can be given from a HCP to the person with diabetes. The key message is to ensure that use of these forums is done in a professional manner and is not seen by any individual or organisation to compromise confidentiality or question the integrity of others.

Groups for people with diabetes, such as "Our Diabetes" (www.our-diabetes.org.uk) can give professionals an insight into what life is like for people with diabetes. If the feedback from people is that this is the forum they would like to use then it is the responsibility of HCPs to help it work. One also needs to bear in mind that social media are adjunctive and offer portals or avenues for a specific set of people – but not all people will want to participate.

As with any initiative in healthcare, its strength needs to be harnessed and, if done so, could prove to be a strong ally, not only in improving diabetes care but also bringing the people with diabetes and healthcare community closer. ■

Diabetes UK (2009) *Improving supported self-management for people with diabetes*. Diabetes UK, London. Available at: <http://bit.ly/LKu9jO> (accessed 23.01.14)

Diabetes UK (2013) *State of the Nation, England*. Diabetes UK, London. Available at: <http://bit.ly/Kxuohp> (accessed 23.01.14)

Farmer A, Bruckner C, Cook M, Hearing S (2009) Social networking sites: a novel portal for communication. *PostGrad Med J* **85**: 455–9

Funnell M (2010) Peer-based behavioural strategies to improve chronic disease self-management and clinical outcomes: evidence, logistics, evaluation considerations and needs for future research. *Fam Pract* **27**: i17–i22

Greene J, Choudhry N, Kilabuk E, Shrank W (2011) Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *J Gen Intern Med* **26**: 287–92

Harris J (2012) The year of the networked revolution. *The Guardian*. 13 December. Available at: <http://bit.ly/1eEn4vd> (accessed 23.01.14)

Hartzler A, Pratt W (2011) Managing the personal side of health: how patient experience differs from the expertise of clinicians. *J Med Internet Res* **13**: e62

NICE (2003) *Diabetes (types 1 and 2) – Patient education models*. TA60. NICE, London. Available at: www.nice.org.uk/TA60 (accessed 23.01.14)

Office of National Statistics (2012) *Internet Access – Households and Individuals, 2011*. Available at: <http://bit.ly/LKw2wXs> (accessed 23.01.14)

Stafford M, Russell L, Suh D-C et al (2005) How much time do patients with diabetes spend on self-care? *J Am Board Fam Med* **18**: 262–70

“As professionals the educational challenge is to encourage patients to make good connections and be able to select good sites and resources, enabling them to navigate the resources on offer.”

Anne Cooper

Twitter: @anniecoops

Blog: <http://anniecoops.com/>

Partha Kar

Twitter: @parthaskar

Blog: nhssugardoc.blogspot.co.uk