Using social networks to help patients self-care

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Social media may create opportunities for people with long-term conditions to manage their own care but health professionals must be aware of those opportunities.

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Social networks are creating new ways for people with long-term conditions to seek support and offering new ways for health professionals to communicate with patients who have long-term conditions. There is evidence this may be helpful but nurses need to be skilled at operating in these new digital spaces to support patients effectively. This article discusses the growing use of social networks in long-term conditions, focusing on their use in diabetes care.

The need to support people with long-term conditions (LTCs) such as diabetes is a significant challenge to the NHS. Rising incidence coupled with the cost of care means we need to find new ways to enable patients to self-manage their conditions. The aim is to empower them to become “expert patients”, who are able to take more responsibility for themselves in order to reduce costs and increase their independence (Greenhalgh, 2009).

Self-management and peer support

There is evidence that improving people’s ability to self-care improves outcomes and quality of life. What is less clear is how this can be achieved (Health Foundation, 2011).

Self-management is crucial in complex LTCs such as diabetes. Although they have periodic contact with health professionals, patients need to master a range of skills and make lifestyle changes to manage their condition independently (Diabetes UK, 2009). For example some must follow strict dietary rules while others must manage complex data and equipment such as insulin pumps. These patients need ongoing support to maintain their skills and sustain the necessary lifestyle changes (Funnell, 2010).

Peer support is one of a range of activities defined as self-management. Dennis (2003) defined it as “support from a person who has experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population”. She also noted that there is a difference between support from lay individuals, who may or may not be “peers”, and peers who are trained to provide more expert support. This provides a continuum between untrained lay helpers through to highly trained paraprofessionals.

The role of networks and peer support

Networks are defined as “nodes or points linked by pathways” (Malby and Mervyn, 2012), and function through cooperation, reciprocity and mutually supportive relationships (Powell, 1990). Social networks exist with people as the nodes, linked by relationships.

Arguably the same key factors can be applied to groups of patients with LTCs, such as diabetes. For example, in hierarchical organisations, diabetes education programmes are structured and tend towards tightly governed behaviours. In contrast, self-organising online networks are held together often by cooperative and

Social networking sites give patients the chance to share and discover information.

In this article...

5 key points

1 Social media provide opportunities for some patients to forge supportive relationships with their peers

2 Health professionals need a range of skills to work with patients in the digital environment

3 Health professionals must respect the existence of remote peer relationships among people with long-term conditions

4 Some patients may benefit from appropriate signposting to social networks

5 More evidence is needed on the value of networks for patients
Evidence on peer support in diabetes favours peers as paraprofessionals who have the “know what”, or knowledge of diabetes, and its management. There may be good reasons for this. While patients must be educated about their condition, this is an ongoing challenge for professionals and services – peers in a paraprofessional role may be a partial solution.

Greenhalgh et al (2011) also identified that “educators should be trained to value and promote exchange of tacit knowledge between experienced, self-managing patients and newly diagnosed or under-confident ones”. This may require staff to change their attitudes and beliefs. Dennis (2003) described emotional, informational and appraisal support as motivational interventions that promote the persistence and endurance needed by people with LTCs. However, they may also need skills to make sense of this information from peers, which goes beyond that offered in basic diabetes education sessions.

Health literacy is described as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services to make health decisions” (Stiles, 2011). As such, “know-how” information obtained from peers could be included in patient education to improve health literacy. Supporting skills development is, however, a different challenge for educational services.

Who can be a peer for a patient with diabetes? Could, for example, people with type 1 diabetes be peers for those with type 2 diabetes and vice versa? Could there be a cultural dimension to choice of peer? The answer is probably “it depends” and, if peers are genuinely self-selecting and mutual, it would be for individuals to make these choices.

Day-to-day management of diabetes, therefore, goes beyond understanding the disease and its complications. Greenhalgh (2011) suggests it is concerned with smaller everyday decisions and how to resolve smaller day-to-day problems. Mutual, non-hierarchical peer relationships with people who have experience of diabetes and its day-to-day management is valuable to patients and warrants further research. Box 1 outlines characteristics of this concept.

The emergence of social networks
Social networks are transforming the way people communicate with each other and can be a powerful way to disseminate information about health and wellbeing, providing they are used appropriately. Choice of relationship in this environment is usually controlled by users; they choose whether to participate and, if they do, with whom they form relationships. New technologies are enabling patients to “self-organise” and create relationships with peers online in new ways (Box 2).

People with LTCs can find social

**BOX 1. CHARACTERISTICS OF A PEER RELATIONSHIP**

- Likeness: individuals identify with people like themselves
- Mutuality: both peers choose to have a “peer relationship” and it operates in both directions for mutual benefit
- Non-hierarchical: no evident power base
- Self-selecting: peers choose who they form relationships with
- Likely to be focused on “know how” rather than “know what”

**BOX 2. CASE STUDY: ONLINE PEER SUPPORT**

@NinjaBetic1 has had type 1 diabetes since her teens and is in now her 20s.

I came together with my diabetes consultant in March 2012 to create an online diabetes group, ninjaBetic. We aimed to provide peer support for people in our area but, within a few weeks, we had a global following with people of all ages interacting. We have come together as a community to share our thoughts and feelings about diabetes as well as our stories and experiences.

I use Twitter, Facebook and my blog site as these provide different options for communication depending on how much a person wants to interact. People contribute as much or as little as they like and do so at times that suit them.

Communities and relationships have been built around these social networking sites and I feel that my diabetes management has improved greatly since I started using them.

Every day I learn something new about my diabetes from listening to others. I have picked up invaluable information that enables me to build on the knowledge I receive during diabetes appointments.

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**“Act holistically and think about the effect of your actions”**

Sara Nelson
Discussion

networks particularly useful sources of support. Some have the advantage of offering responsiveness and speed to help people address day-to-day problems as they occur. Organic social networks usually do not operate in organisation framework or at specific times and are available all the time, although organisational constraints may mean others, such as chat rooms, are only available at restricted times.

Diabetes online communities are emerging on Twitter using the hashtag #DOC. In August 2012 the first organised chat on Twitter for anyone interested in type 1 diabetes was held in the UK; Twitter is already an established medium for activities like these in other countries.

“Social capital” is an interesting concept in this area; it can be seen as the breadth of social connections that individuals have available to them as a resource (Social Capital Research, 2004). If social networks extend people’s connections to those who are also knowledgeable about diabetes, this widens the pool of resources available to people in the network. This enables them to resolve the day-to-day “know how” of diabetes and may give them access to support at any time of the night or day.

Points to be aware of on social media

Social networks are usually inclusive and flexible. Some, such as Twitter, have only “loose” security controls and are essentially open environments, where anyone can see users’ activity. Others give users more control over how much information is available about them and who can see it.

While social networks make it easier to find peers and maintain peer relationships, they also offer more malign opportunities – for example, enabling individuals to influence others maliciously or engage in inappropriate commercial activity, such as selling goods and services to vulnerable people. Users may need to become “streetwise” to enable them to discriminate between beneficial peer relationships and those that are less useful. Could health professionals play any part in this through facilitation and signposting?

Social exclusion is another potential risk if healthcare systems embrace social networks to support patients. Not everyone will have the technology, skills or connections to use social media so health professionals need to balance the needs of these patients with those of patients who are able to do so.

Health professionals’ views on social networks

Health professionals have mixed views about social networks and patients. Social networks and their members can challenge existing systems and thinking in ways that health professionals may find threatening. For example, as a result of connecting with other patients and sharing information on Patients Like Me (www.patientslikeme.com), people with neurodegenerative disease (amyotrophic lateral sclerosis), are experimenting with unlicensed drugs and treatments – as their life expectancy is so short, they are not prepared to wait for trials to be completed (Dockser-Marcus, 2012). They are not part of any trial and are making their own decisions about doses and recording outcomes on Patients Like Me. Health professionals have expressed concern about this but can do little to prevent patients from making connections and working together in this way.

Competency is another factor that may influence health professionals’ attitudes to social networks. As with many new forms of social activity, “norms” and cultures are emerging that people must learn to navigate in addition to mastering the technological skills to use the systems. There are few ways of learning in this domain other than experience through participation.

Summary

People with LTCs, such as diabetes, need ongoing support if they are to self-manage their conditions. Social media create both opportunities and threats for patients and health professionals. They provide an opportunity for patients to forge peer relationships that were not possible a decade ago, but health professionals need to think carefully about the skills they must have to be able to work with patients in this environment. They also need to accept and respect the existence of remote peer relationships that people form.

In some cases, appropriate signposting to networks may add value for certain patients. There is scant evidence on the value of networks for patients; researchers looking into this complex area could usefully focus on patients’ ability to self-manage, improving the quality of patients’ lives, and the role of peers and networks in this context.

References


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