Doctor, Nurse or Apomediary?

What Role should Healthcare Professionals Play in Assisting Patients with Long Term Conditions to Access, and Make Sense of, Information from the Internet

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Abstract: This position paper explores healthcare professionals' roles in mediating the information that people with long term conditions obtain via the Internet. It explores how the way in which long term conditions are conceptualised may influence the roles and approaches which healthcare staff should adopt, and contrasts the intermediary and apomediary roles which this may include, and how such roles may be enacted in healthcare provision.

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1 INTRODUCTION

This position paper explores the role changes that healthcare professionals may need to consider in relation to the information that patients with long-term conditions can now gather via the Internet. It suggests that the roles which it is seen as appropriate for healthcare professionals take on should be guided by how long term conditions are conceptualised, as this will determine where responsibility for condition management lies. These roles should also be informed by consideration of whether apomediatory or intermediatory approaches are appropriate.

2 BACKGROUND

Historically, expertise in the causes of ill health, diagnosis of disease, it's treatment and management, has rested with healthcare professionals. However, over recent years there has been a move towards partnership in care, and recognition of the knowledge and expertise which patients have and can contribute to the management of, and decision making about, their health (Department of Health [DoH], 2001); (Schwartz et al., 2006). There are a number of reasons for this shift, but a significant factor is the increasing volume of information about health related issues that is available to the public via the Internet (Diaz et al., 2002); (Schwartz et al., 2006); (De Boer et al., 2007); (Iverson et al., 2008), (Kommalage, 2009). Patients are increasingly likely to use the Internet to access health related textbooks, journals, reports, conference proceedings, the websites of individuals and organisations, social networking sites, blogs, and support and special interest groups, before, after, or as an alternative to, consultations with healthcare staff. The likely result of this is that consultations between patients and healthcare professionals may increasingly be expected to include discussions of the information which patients have accessed, it's quality, and perceived value, as well as their direct health care needs (Diaz et al., 2002). This paper therefore discusses the positions which might be taken in relation to the question: What role should healthcare professionals play in assisting patients to access and make sense of information from the Internet?

3 CHANGING EXPERT PATIENTS

The move to patients being seen as partners in care has been accompanied by the development of the concept of expert patients, wherein healthcare providers and patients share and value one another's knowledge, expertise, and experience (DoH, 2001). However, this has tended to assume that healthcare

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staff contribute expertise in anatomy, physiology, disease processes, it's treatment and management, and patients contribute knowledge of how certain regimes or interventions work for them, given their priorities, values, and lifestyle choices (DoH, 2001); (Coulter, 2002); (Badcott, 2005). The expanding availability of information that patients can access via the Internet, including probable diagnoses, investigations, treatment options, disease processes and trajectories, as well as more social aspects of the effects of health issues, may create a new type of expert patient, who has expertise that has previously been located within the domain of healthcare staff. Whilst doubts have been expressed over whether patients could attain expertise in the theory behind disease processes and management (Badcott, 2005), it has also been suggested that people who live with long term conditions sometimes attain greater medical or technical knowledge of their condition than some healthcare staff (Kirk et al., 2005); (Hewitt-Taylor, 2007). This may be particularly true where patients can access, appraise, and debate evidence from a wide variety of Internet sources.

Whilst this ability to access a range of health related information and evidence can be beneficial, it also presents challenges for all concerned (Iverson et al., 2008). How the benefits of the range of information available on the Internet can be maximised, the challenges managed, and the roles and responsibilities of healthcare staff within this process merits some thought. This may be particularly pertinent to people who have a long-term condition, and who may be more likely than others to access and seek to discuss information about their condition that they have gleaned online.

4 THE PROS AND CONS OF THE AVAILABILITY OF INFORMATION

Patients having increased access to health related information means that they can confirm and augment information given to them by healthcare staff, gain a more in depth understanding of their condition, and use this to enhance their decision making and personal choices (Salo et al., 2004); (Iverson et al., 2008). In terms of peer advice and sharing experiences, Internet based support groups, discussion forums and social networking sites can provide a useful milieu in which the implications of individual's decisions can be tested with peers, and lifestyle issues considered with input from others who have to manage similar situations (Carter et al., 2007); (Iverson et al., 2008). Such sites can also be used to signpost peers to sources of information and advice, and give suggestions regarding their quality. Increased access to information also has the potential to enhance discussions between healthcare providers and their patients, so that ideas, hypotheses, and research findings can be explored and debated, fact can be distinguished from opinion or hope, and each party gain a greater understanding of the other's perspectives on diagnosis, treatment, and interventions. This can enhance decision making, and working relationships between staff and patients, as a full range of views and perspectives can be brought into play, and each party understand the perspectives and boundaries of the other.

These positives outcomes are nonetheless countered by some challenges. The quality of information on the Internet is variable, and may not be applicable or relevant to all cases within a broad diagnostic category. In addition, some treatments described online may not be widely available (Salo et al., 2004); (Dickerson et al., 2004); (de Boer et al., 2007); (Iverson et al., 2008). Thus, patients may access information of a dubious or harmful nature, or which creates false hope or frustration and anger for those who feel that a treatment they have read about, and consider potentially beneficial, is not available to them. Whilst many patients will be well versed in the skills of information searching and appraisal, some may need assistance to access, evaluate and synthesise the range of information with which they are presented. This leads to the key question of where, and from whom, such people can or should gain assistance in appraising the information available to them, and how this will affect healthcare consultations.

Internet use may effectively filter out some consultations, if patients seek information and advice online rather than from healthcare staff (Iverson et al., 2008). The availability of health focused social networking sites may mean that some patients feel very little need for discussions with healthcare staff, having achieved this elsewhere. Conversely, if patients aim to discuss their findings from a trawl of Internet based information with their care providers in a meaningful way, this is likely to increase the length of time which individual consultations take, and change the skills which healthcare staff are expected to have (Salo et al., 2004); (Schwartz et al., 2006); (Iverson et al., 2008). Checking and reinforcing information with patients and directing them to further online resources may nonetheless improve condition management, and

reduce treatment needs in the long term (Iverson et al., 2008), making a short term increase but long term reduction in resource usage.

Whilst there are clearly benefits and challenges to patients accessing a range of health related information and advice via the Internet, this is the situation in which practitioners now work, and is likely to continue to be so (Schwartz et al. 2006); (de Boer et al., 2007). Health care professionals therefore need to consider the implications which this has for their day to day work, professional roles, and preparation for practice. As well as being important for healthcare staff, it is an important debate for healthcare consumers, so that what is and is not seen as a reasonable expectation of healthcare staff is clear.

5 WHOSE RESPONSIBILITY IS INFORMATION RETRIEVAL AND SYNTHESIS?

There are two key issues to consider when debating how and by whom patients with long term conditions should be offered assistance in collating and synthesising the plethora of information available to them on the Internet. Before deciding on where responsibility lies in terms of accessing and using Internet based resources, who is responsible for a person's health needs related to a long term condition requires clarification. Whilst acute and long term health conditions exist on a continuum rather than being absolutes, a broad distinction for ease of discussion might be between acute health needs, which are new for the individual, and long term health needs, which the person has, or is expected to experience, for some time.

One view is that as the number of people who have long term health conditions is increasing, and what were once health needs become a part of an individual's day to day life, managing them, and accessing, interpreting, and making informed decisions about the information associated with them, becomes the responsibility of the person concerned. In this scenario, it would be seen as the individual's responsibility, if presenting in a healthcare encounter, to have accessed, read, and summarised the key points of their findings about their health, either themselves or with the help of family, peers, or other media. Equally, in this situation, healthcare professionals might have a very limited role. For example, social networking sites, such a patientslikeme.com create communities that enable patients to obtain, evaluate, and explore, treatment related information with peers, rather than professionals.

A second perspective is that whilst a person with a long term condition has a health need, which affects them and which they manage day to day, it is still a health need, because a disease process has caused it, and responsibility for it is shared between healthcare staff and the patient. In this model, healthcare staff and patients would be jointly responsible for gathering, evaluating and exploring the alternatives for treatment and condition management. Healthcare provision would then include, as a core function, the ability to work with patients on accessing, interpreting, and synthesising the available evidence.

A third view would be that the person's condition is primarily a health need, and the remit of healthcare professionals to mange. In this view, healthcare staff, as experts in health, would be seen to have superior information to patients, and responsible for imparting this to patients, directing them to approved information, but not necessarily for devoting time to discussing information which patients have gathered with them.

As well as determining who should take on the role of assisting patients to retrieve and manage information, the approach which is taken to achieve this also merits some thought. Eysenbach (2008) and O'Connor (2010) distinguish apomediation and intermediation. In apomediation, the apomediary, as a peer or equal, recommends or guides a person to existing information which is available and accessible to them without the permission or influence of the apomediary. Apomediation may occur by means of people and tools, but it's purpose is to guide peers to trustworthy information or add credibility to existing information. The information, and interpretation of it , however, remains available to and controlled by the individual (Eysenbach, 2007). Intermediation, in contrast, refers to situations in which an expert, such as a healthcare professional, effectively stands between the consumer, for instance a patient, and information. The patient can only access the information via the professional, and it is information which they have developed, or approved.

Intermediation would perhaps would sit most comfortably in the third approach, where healthcare staff are seen as the experts, able to give advice and direct others to appropriate, approved information which they should take note of. Apomediation more closely matches the first two options, although the

second option provides more possibility of grey areas regarding the role of healthcare professionals. In the first instance, it would be the responsibility of the patient to select the sources of apomediation that they require, including peer networking sites, and to use these to gather and synthesise information. Their need for access to healthcare staff would largely depend on needing clinical input, or utilising the gatekeeping functions of professional, such as obtaining prescriptions or referrals (Hewitt-Taylor and Bond, 2012). The second road is the more complex, and would require some thought as to how existing provision would be tailored or modified to include apomediary roles.

6 CHANGING ROLES

Where there is a belief that responsibility for the management of long term conditions is shared, how current healthcare provision will accommodate the role of healthcare staff in information retrieval and synthesis requires some thought.

If such roles are seen as falling within the remit of healthcare providers, who should take them on requires consideration. This might be best achieved by medical staff, as a part of their existing consultative role. Alternatively, it could be a role that clinical nurse specialists or practice nurses adopt. The latter might create a one stop shop in which patients who attend consultations with medical staff have already had the chance to discuss information retrieval, and explore their findings, so as to present a more focused synopsis of their own evidence for discussion during the consultation. A third option may be for healthcare providers to create a role and place for specialist apomediaries within their structure. Currently individuals offer such services, but outwith the healthcare setting, and an option may be to incorporate non clinical staff into such roles within the healthcare structure. Equally, other models or approaches may exist and be beneficial.

7 CONCLUSIONS

The volume of information available via the Internet brings with it benefits and challenges for healthcare staff and patients. A key issue which merits debate is the way in which health care providers should respond to the increase in information which patients who have long term conditions are likely to access. The way in which such conditions are conceptualised, in terms of their nature and where responsibility for their management lies are key issues in debating whether intermediary, or apomediary approaches to information management are most appropriate. Where apomediation seems the right approach, who should fulfil this role, and how it should be funded and managed merits discussion.

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