NOTE

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Electronic Health Information and Long Term Conditions

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ABSTRACT

This article discusses the increasing availability of health-related information, and the impact that this can have for people with long-term conditions' expectations of healthcare providers. The article suggests a framework for decision making about the role that healthcare staff should play in the information searching, retrieval, and synthesis activities which people with long-term conditions engage in. The framework is based on a series of decisions related to: perceptions of ownership of long-term conditions; whether intermediatory or apomediatory approaches to information management are deemed to be most appropriate; and, as a result of these considerations, what, if any, place healthcare staff should take in the process of patients searching or and interpreting information about long-term health needs. These decisions will enable healthcare providers to plan services based on clear decision pathways, and to clarify to all concerned what are deemed to be reasonable expectations of health service provision.

The amount of health related information that is available to the public has increased greatly over recent years (Diaz et al, 2002; Schwartz et al, 2006; De Boer, 2007; Iverson et al, 2008; Kommolage, 2009). This creates the question of whether, and how, healthcare professionals and the services they work in should adapt existing provision to accommodate this.

Historically, the role of healthcare staff was focused on the causes of ill-health, diagnosis of disease, its treatment and management, with their key functions including developing diagnoses, prescribing treatment and interventions, and explaining health issues, disease processes, treatment and management choices to patients. Over recent years the way in which these roles are executed has altered, with a greater recognition given to the knowledge and expertise which patients, particularly those with long-term conditions, can contribute to the understanding and management of their conditions, and their role in decision making about their treatment and care (Department of Health, 2001, Schwartz et al 2006). At the same time, the information sources available to individuals, particularly electronic sources, have increased dramatically. The Internet in particular is rapidly perfusing everyday life. PEW Internet (2012) found that 85% of all Americans use the Internet, including 58% of the over 65s, a group traditionally seen as 'not being online,' suggesting that many people with long-term conditions can easily access a plethora of health- related information. This has implications for healthcare staff in professional and managerial terms, related to the responsibilities which staff have, or should take on, and how service provision may need to be adjusted to accommodate these.

This article therefore explores the place that healthcare professionals and services may occupy in relation to the information which patients with long-term conditions gather, and some options for enacting these roles.

Increased information: changes and changes

People who have long-term conditions are increasingly likely to access—via electronic and other sources—a wide range of information about their health needs. This may enable them to gain a more in depth understanding of their condition, enhance their discussions with healthcare professionals, and improve their decision making (Salo et al, 2004; Carter et al, 2007; Iveson et al, 2008). These positive elements of the increased availability of information are nonetheless countered by some challenges.The quality of the information that is available is variable, and even good quality information may not be applicable or relevant to all cases within a broad diagnostic category. In addition, some treatments described in online resources may not be widely available (Dickerson et al,2004; Salo et al, 2004; De Boer, 2007; Iveson et al, 2008). People may therefore seek to act on information of a dubious nature, or experience false hope, frustration and anger if they cannot access treatment that they have read about. While many patients are well-versed in the skills of information searching and appraisal, this will not always be the case and some

may need assistance to access, evaluate and synthesise the range of information with which they are presented during searching activities. From a health service provision perspective, discussions related to information retrieval and evaluation will take time, and increase the pressure on already stretched appointment schedules. These issues lead to question of what a reasonable expectation of healthcare professionals' input into assisting patients to obtain and appraise the information available to them is, and how any such input can or should be incorporated into health service provision.

Who is responsible for long- term condition management?

A key issue when debating how and by whom patients with long-term conditions should be offered assistance in collating and synthesizing the plethora of information available to them is: who is responsible for a person's health needs related to a long-term condition? One perspective is that as the number of people who have long-term health conditions is increasing, and health needs become a part of many individual's day to day lives, managing these conditions, including accessing, interpreting, and making informed decisions about the information associated with them, is the responsibility of the person concerned. This would logically mean that accessing information about their health, and summarising the key points of their findings with the help of family, peers, or other media—is the responsibility of the individual. Provided there is an opportunity for patients to discuss their findings during healthcare consultation this fits with the idea of patients being experts in their own conditions, and working in partnership with healthcare staff (Department of Health, 2001; Schwartz et al, 2006).

A second viewpoint is that while a long-term condition is a part of an individual's day-to-day life, it is still a health need, and responsibility for it is therefore shared between healthcare staff and patients. This again fits the model of partnership working (Department of Health,2001; Schwartz et al, 2006). However, it would perhaps mean that, as healthcare professionals and patients are jointly responsible for gathering, evaluating and exploring the alternatives for treatment and condition management, healthcare provision should include working with patients on accessing, interpreting, and synthesising the available evidence. A third option would be to see the person's condition primarily as a health need, with issues associated with its management, including direction on where to access information and the value of such information falling within the remit of the healthcare professional. This fits less well with a partnership and joint expertise approach, and may therefore be seen as incompatible with current thinking in healthcare.

Approaches to information mediation

As well as determining who might be responsible for assisting people with long-term conditions to retrieve and manage information, and what level of input this might include, the approach which is taken to achieve this, and, in terms of service provision who should fulfill this role requires consideration.

Eysenbach (2008) and O'Connor (2010) distinguish apomediation and intermediation of information.

In apomediation, a peer or equal recommends or guides a person to existing information that is already both available and accessible to them without the permission or influence of the apomediary. Apomediation may be carried out by people and electronic tools (for example, by a peer in an online forum, or by a computer programme which recommends other resources when one is accessed). However, its purpose is to guide peers to trustworthy information or to add credibility to existing information. An apomediary might, for example, guide a person to a particular website, suggest a particular social networking subgroup, or give their views on the quality of particular information. The information, interpretation of it, and decision making arising therefrom, however, remains available to and controlled by the individual (Eysenbach, 2007). Intermediation, in contrast, refers to situations in which a person deemed to be an expert (for example, a healthcare professional) effectively acts as the conduit between the consumer (for instance a patient), and information. At the same time as directing a person to, or providing them with, information the intermediary stands between an individual and resources of information, either because they have control over access to it, or because they play the role of expert in deciding it's value.

The way in which ownership of long-term conditions is viewed affects whether an apomediary or intermediary role will be most appropriate. An intermediary role sits less well with the perspective of patients as full or co- owners of their condition, and joint participants in healthcare decision making. In the era of patients being seen as partners in care, an apomediation, rather than intermediation, approach is perhaps the more appropriate, and healthcare staff could perhaps adopt this role, working with patients to explore their findings, alternative ideas for information retrieval, and synthesis of the information that they have gathered. Equally, though, such roles may fall outside the remit of healthcare. The notion of healthcare staff acting as gatekeepers and guides may be becoming outdated. Online there are a variety of ways of community apomediation, including tools such as discussion boards, Facebook and Twitter through which people recommend information sources to others. Fox (2011) describes such peer-to-peer healthcare as a 'way for people to do what they have always done— lend a hand, lend an ear, lend advice—but at internet speed and at internet scale.'

If, however, healthcare staff take on this role, whether apomediation forms a part of a clinical consultation, or forms a pre-appointment event, following which individuals present a focused synopsis of their evidence for discussion during the consultation requires some thought.

If a decision is taken that such discussions should occur outwith the clinical consultation, the identity of the apomediary, and where apomediation services should be housed, merit consideration. The role might

be fulfilled by healthcare professionals or other parties, either within departments where patients are already seen, to create a one-stop shop, or in a separate situation designed for this purpose. It could be incorporated into roles such as practice nurses or clinical nurse specialists, but there is also an option for it to be hosted by individuals who have no medical training, albeit within the healthcare structure.

As well as discussing the information which people have obtained, Salo et al (2004) and Schrwartz et al (2006) suggest that patients may expect healthcare staff to be able to direct them to web-based information, which will require familiarity with a range of intent resources. This function may be better provided by a person with expertise in information retrieval and synthesis, than expertise in a given condition. In terms of an apomediary being seen as a trusted peer, such a role might equally be most appropriately fulfilled by obtaining the services of expert patients who are also familiar with information retrieval and evaluation.

These decisions will affect the way in which services are organised, and the cost involved. Cost considerations should, however, include not only the cost of any service provided, but also the long and short term benefits or cost savings (Dickerson et al, 2004). For example, while devoting additional resources to enabling patients to discuss information retrieval and analysis may increase the direct cost of consultation time and others services such as apomediation, they might enable patients to develop information retrieval and analysis skills. This may ultimately filter out some consultations, and facilitate patients making better, more informed, decisions that reduce treatment needs in the long term (Dickerson et al, 2004; Iveson et al, 2008).

Conclusion

The volume of health-related information which is now available brings both benefits and challenges to healthcare users and providers alike. A key issue for health service managers is the way in which healthcare provision should respond to the information which people who have long- term conditions are likely to access. This requires a decision as to whether the existing style of consultation will need to be of sufficient length to allow exploration of patients' information gathering activities as well as their synopsis of evidence, and their direct health needs (Iveson et al, 2008). If such issues are to be included, the degree of discussion that is deemed reasonable in consultations—for example, whether this will be focused on findings or process or both, must be decided upon. This will allow appropriate allocation of time for appointments, and, if necessary, the development of associated services which will enable patients to discuss their information retrieval and synthesis needs and activities.

The way in which long-term conditions are conceptualised, in terms of their nature and where responsibility for their management lies are key issues in deciding whether and how health services

should provide such opportunities, including whether intermediary, or apomediary approaches are most appropriate, and by whom these should be carried out. This should enable choices which are reasoned in terms of ideals and resource usage to be made, and assist in creating clear expectations for all concerned over the roles, and availability of time for, discussion of information retrieval and analysis, in healthcare settings.

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