

Research article

Using the Internet as a source of information and support: a discussion paper on the risks and benefits for children and young people with long-term conditions

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ABSTRACT

Children and young people who have long-term conditions are likely to seek health-related information via the Internet. Because of their continuing contact with children with such conditions, primary care practitioners may be well placed to discuss with them and their families the risks and benefits of accessing information online. This includes not only the relative merits of particular sites but also more general online safety issues. To achieve this, it may be helpful for primary care practitioners to consider how they view risk in general, the risks associated with the Internet and the vulnerabilities of children and young people, particularly those with long-term conditions.

Keywords: children, Internet, long-term conditions, young people

What is already known about this subject

- Using the Internet to access health-related information carries some risks.
- Using the Internet to access health-related information has benefits.
- Children with long-term conditions may be perceived as particularly vulnerable to harm.
- Perspectives of risk and benefit vary between individuals.

What this paper adds

- Primary care practitioners may be well placed to discuss the risks and benefits of using online health resources with children, young people and their families.
- Being able to discuss general perceptions of risk and harm with primary care practitioners may enable children with long-term conditions to learn to manage the risks and maximise the benefits of using online resources.
- Exploring their own perceptions of risk and benefit, and their application to online resources, may enable primary care practitioners to feel equipped to have such discussions with children and their families.

INTRODUCTION

An increasing number of children and young people live with a long-term health condition. The term 'long-term conditions' covers a vast range of health issues, including asthma, diabetes, epilepsy, cerebral palsy, visual or hearing impairments, cystic fibrosis, mental health problems, mobility problems and palliative care needs. However, one common issue for these children and young people is that, regardless of the nature and severity of their condition, they will need, and are likely to seek, information about it.

Health care professionals' roles are increasingly expected to encompass not only providing health care and advice but also the ability to knowledgeably discuss health-related resources.^{1,2} The Internet is one such resource, and provides a means by which children and young people with long-term conditions can find and exchange information, advice and support. In many cases, those who provide day-to-day care and advice to children and young people with long-term conditions and their families are primary care practitioners. As a result, it may be especially useful for those working in primary care to be confident in discussing not only the benefits, but also risks (such as being exposed to cyber bullying) of children and young people using the Internet to gather health-related information.^{3,4} It likely seems to be helpful for such discussions to be informed by an understanding not only of the risks and benefits of using the Internet, but how individuals' more general perceptions of risk and benefit may influence their views on the risks of children and young people using the Internet.

This paper, therefore, discusses possible perspectives on the risks and benefits of accessing online health information that primary care professionals may wish to consider in their dialogues with children, young people and their families.

THE BENEFITS AND RISKS OF CHILDREN WITH LONG-TERM CONDITIONS SEEKING ONLINE INFORMATION AND SUPPORT

Using the Internet is an integral part of children and young people's lives, and, like many activities, carries a range of benefits, but also risks to their safety and well-being.^{5,6} Online activities are an important social medium for many young people,^{5,6} and may be particularly significant for those with mobility problems or communication difficulties that make face-to-face friendships hard to initiate and maintain. The counter to this is that the use of online social media may reduce children and young people's peer interactions offline, and their ability to develop associated social skills. Using electronic media, including the Internet, excessively has also been linked to children developing an unnecessarily sedentary lifestyle, with consequent risks to their health and well-being.⁷

As well as its potential value for social interactions, the Internet provides a plethora of information, ranging from professional and academic articles to people's opinions and experiences. It also provides a convenient milieu in which people with long-term conditions can exchange information, advice and real-time support.² These resources may be especially

useful for children with rare conditions, where the information available and opportunities to meet peers with the same condition face-to-face are limited. In addition, all children and young people may benefit from having the opportunity to give, as well as receive, information, advice and support.

A particular source of information that is set to become available to individuals via the Internet is online access to their own health records.⁸ Whilst parents will generally gain this access on their child's behalf, it is a resource which children and young people will be able to use for themselves, and have sole access to, when they are sufficiently mature.⁸ This is likely to be beneficial to individuals in terms of easy access to information, which can also be shared and discussed with others if the individual wishes to do so.⁸

Notwithstanding the benefits of the information that is available via the Internet, the quality of the information offered and the nature of the people encountered online are variable. Children and young people are likely to encounter useful, supportive, contacts and helpful information, but also risk being exposed to offensive comments, bullying^{3,5,6} and inaccurate or even dangerous advice.

The anonymity offered by the Internet likewise carries benefits and risks. It may be useful for children and young people who want to discuss sensitive issues without disclosing their identity, or those who want their otherwise invisible health needs to remain unknown. However, this anonymity can be a means for people to engage in bullying, or to make abusive contacts with children.^{3,5,6}

In relation to online access to personal health records, the benefits of this opportunity need to be considered alongside the risk of information being misunderstood, causing distress or anxiety, or of individuals feeling coerced to share information with people from whom they would prefer to keep it private.⁸

Given these risks and benefits, primary care practitioners may find it useful to consider their views on what constitutes an acceptable risk that is outweighed by the potential benefits, and what does not, so as to use these to inform discussions with children and their families. This includes not only their views about online health resources but also their more general perceptions of the risk and benefit.

Risk and benefit

Risk exists when something that is valued, including material resources, or one's physical or emotional health or well-being, is placed in a situation in which it could be lost. Such risks exist in almost every area of life, but in order for a person to consider taking a risk that action must also carry the potential for some benefit.⁹ Deciding whether or not to take a risk, therefore, depends on whether the individual perceives the potential gain to outweigh the loss that may be incurred. One challenge in determining risk is that each individual will have a different perspective on the importance of the potential loss or gain presented by a given situation. For example, perspectives on whether the gain of peer support that young people may experience in online communities outweighs the risk of being given bad advice or being targeted by abusive dialogue may differ between young people, primary care practitioners and parents.

Decisions about whether a particular risk is worth taking are, therefore, influenced not only by highly individual perceptions of the relative value of what is put at risk compared to what may be gained but also by people's perspectives on risk. A risk control perspective, for instance associates risk with threat, danger and harm, sees it as desirable to remove or avoid all risk and gives adults a responsibility to prevent children from being exposed to risks.¹⁰

A contrasting view, the risk-taking perspective, sees risk as a positive entity, linked to learning, empowerment and self-determination.⁹ This view places taking risks, and even experiencing some degree of adverse outcome, as a central part of children's learning. It considers it important for children and young people to learn to identify risky situations, consider and experiment with different ways of managing these and develop the ability to decide which risks they are prepared to take, and how they will manage the outcomes of those risks.¹¹ The risk-taking perspective views this process as an important part of children and young people learning to develop autonomy and take responsibility for their actions.¹² It gives adults a responsibility to enable and support children as they learn through taking risks; some of which will be successful and lead to gains and some of which will inevitably lead to losses. This perspective links with addressing concerns about children's online safety by developing their abilities to understand online risks and strategies for keeping themselves safe, so as to acquire the skills which they will need as adults.^{13,14} For example, using social media at any age includes the risk of encountering negative, derogatory or abusive comments, and bullying. A valuable part of children and young people's learning would, therefore, be seen as being to gain skills in handling such situations, rather than avoiding situations in which there is a risk of this occurring. This may include enabling children to decide whether the benefits they believe they will gain from a particular site outweigh the problems it may bring, to learn how to manage negative comments and to determine the best thing to do when information or requests for information seem unreasonable or worrying. In relation to personal health records, the risk-taking perspective would see the role of adults, including primary care practitioners, as being to work with children and young people on learning how to take responsibility for and control of this access. This could include how to manage any concerns that accessing their records might create, and developing the skills to negotiate with others what information they are prepared to share.

Making such decisions nonetheless requires primary care practitioners to consider at what point they would deem an action unacceptably risky or harmful, compared to what they would see as a reasonable risk, and a learning opportunity for a child or young person. It may also require them to explore these potentially highly individual perspectives with children and their families.

Acceptable risk

Determining which situations constitute good learning experiences and which constitute a failure to protect children from harm is far from easy. This is partly because individuals all have different priorities, beliefs and values that influence

what they see as worth risking for the potential gain offered. For example, for someone whose priority is to gain high-quality information, the risk of being given inaccurate information may greatly outweigh the potential benefit of making friends via social media. For others, the reverse will be true. Similarly, perceptions of whether particular situations are harmful or not can be perceived differently by different people: a comment that is seen as intimidating by one person might be viewed as irritating but trivial by another.¹⁵

As well as the variability of perceptions of situations, and the value that individuals attach to particular outcomes of risks, people have different general risk-taking propensities, with some more inclined to take risks than others. These very individual characteristics and perceptions will affect adults' inclination to encourage children or young people to engage in activities which entail risk, a child or young person's desire to engage in such activities and each party's perceptions of the riskiness of a given situation.¹⁶ It also means that there is no one acceptable risk, or level of risk taking in any element of life, including online activities. However, working with children, young people and their families to explore the potential risks and benefits of situations, what they see as reasonable risk, and why, may be beneficial in enabling them to access online information in a manner with which they feel comfortable and safe. As well as learning about accessing online information, this may enable them to learn about themselves, and how they can decide about and manage risky situations. It may also provide parents and their children with an opportunity to engage in discussions about how to proceed when their views on acceptable risk differ.

Practically, perceptions of online risk may also be influenced by the confidence that individuals have about using the internet.^{17,18} Health care professionals are likely to have varying degrees of confidence in using online resources.¹ Similarly, families may have differing levels of knowledge and confidence in this area. As well as debating more general issues of risk, primary care practitioners may, therefore, find it helpful to utilise available guidance on online safety as a reference point to discuss what can, and cannot, be done to reduce unnecessary risks online.⁴ This may also be a useful start point from which professionals can initiate discussions about how to tailor such advice to a particular child or young person's cognitive and emotional developmental level, and how, over time, they can be helped to learn to manage their own online safety. In general terms, a public health approach to child protection in which prevention and early intervention are key has been recommended.¹⁹ In relation to online activities, this approach might include primary care practitioners being aware of, and open to discussing, the risks and benefits of using the Internet to access health-related information with children, young people and their parents.

Whilst these considerations apply to all children and young people, there are some additional issues which those who work with children and young people who have long-term health needs may need to weigh up in discussing the use of online resources.

Children with long-term conditions and vulnerability

Vulnerability is usually associated with the notion of an individual being at risk of harm from a danger or threat, and in need of protection because of this.²⁰ Children are generally perceived as being more vulnerable than adults, and those who have long-term health conditions are often regarded as more vulnerable than their peers. For instance, disabled children are at greater risk than their peers of suffering abuse or maltreatment.^{21,22} Thus, children, and particularly those with additional health needs, are generally seen as being in need of some degree of protection from harm.

Affording children protection from harm is a part of a parent and professional's duty. However, rather than seeing vulnerability as a weakness or deficit, which adults must manage for children, vulnerability, be it because of age, health, experiences or personality can be regarded as a common human trait, as everyone is at some time vulnerable in some way.²³ Huta and Hawley²⁴ suggest that rather than being viewed negatively, vulnerability, if managed positively and supportively, can give people the opportunity to develop strategies which will improve their long-term strength, confidence and safety. In addition, as all people are at some time vulnerable, rather than being avoided, people should be encouraged to recognise their vulnerabilities, learn to manage them effectively, and thus increase their self-awareness and control over their lives.²⁰ This has links with the risk-taking perspective, in that rather than avoiding situations where they are vulnerable, people are encouraged to recognise their vulnerabilities and determine how they can best manage them. This perspective suggests that primary care practitioners who work with children and young people should not only acknowledge and understand but also enable children to recognise and take control of their vulnerabilities, including those related to online activities. It sees professionals as having a key role in enabling children, young people and their families to determine how they can manage their vulnerabilities so that, as adults, they are less likely to suffer harm than they would otherwise be.

The desire to attribute blame when something goes wrong can, nonetheless, mean that professionals are inclined to adopt a risk avoidance stance, wherein advice is geared at avoiding risk, rather than enabling children and young people to learn about it.^{11,25,26} In contrast, the risk-taking perspective would encourage professionals to engage in open dialogue with parents, children and young people about the risks and benefits of

seeking information and support online. This would include discussion of the many interpretations of risk, risk taking and how children and young people can be enabled to learn about managing online risks and making appropriate choices. This may include identifying: what each individual's child's vulnerabilities are, how these relate to online activities, whether online activities will increase or decrease their vulnerabilities in particular ways, whether the perceived risks are definite risks, potential risks, highly likely or marginally likely. It is also useful to consider whether the short-term apparent safety of risk avoidance creates longer term dangers or harms. Discussing worst case scenarios, how the risk of these compares to the benefit of a particular activity, and how each worst case scenario might be avoided or managed may also help children, young people and families to make decisions about their online activities.

CONCLUSION

Whilst the responsibility for a child's care and well-being rests with those who hold parental responsibility for them, primary care practitioners have a responsibility for helping families to maintain their children's safety. They should, nonetheless, also work with children and young people to enable them to develop resilience and to reach their maximum level of autonomy and independence in adulthood.²⁷ This may include enabling children and young people who have long-term conditions to use the Internet for health purposes in a way that they feel safe with. It is, therefore, useful for primary care practitioners to not only be aware of the value of the resources the internet can offer but also the risks involved, and what can be done to minimise these risks. Alongside this, practitioners should be prepared to discuss online risks and benefits with families, and how children and young people can be enabled to learn to manage these safely.

Perceptions of the benefits and risks of children using online resources to gain health information are highly individual. One of the challenges for professionals is, therefore, to work with children, young people and their families to consider what level of risk taking is acceptable, and whether the benefit of taking a particular risk, and the disadvantage of not taking it, outweigh the risk of harm being incurred from it. It may be pertinent for professionals to also explore their own views on risk, vulnerability, Internet use and how these influence their responses to children and young people with long-term conditions seeking online health-related information.

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