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Contact:

Dr Juping Yu, Faculty of Life Sciences and Education, University of South Wales,
Glyntaf, Pontypridd, UK
juping.yu@southwales.ac.uk

Young people's views on sharing health-related stories on the Internet

Abstract

There is an increasing interest in the use of stories in healthcare practice and education. However, there are few stories from young people concerning health and little is known about their views on sharing such stories on the Internet. The aim of this study was to explore young people's perspectives in this area. A qualitative method was used and a project website was purposely built to facilitate data collection. An online focus group with 13 young people was carried out in an asynchronous format. Participants valued highly the therapeutic effect of storytelling and the use of digital stories to share feelings and experiences with a wide range of audiences, suggesting that well-produced stories could be a useful learning resource. A number of concerns were also raised, including embarrassment, reaction of other people and online safety. Having stories available on the Internet can be beneficial; however, concerns especially about safety associated with Internet use and support for storytellers should be taken into consideration. A better understanding of young people's perceptions can provide valuable insights for future work with this age group on storytelling.

Key words: attitudes, health, online research, qualitative research, storytelling, young people

INTRODUCTION

There is an increasing interest in the use of patient stories in healthcare practice and education. The positive impact of storytelling on patients (Holm *et al.* 2005), bereaved parents (Maple *et al.* 2010), healthcare students (Davidhizar & Lonser 2003, Schwartz & Abbott 2007), and healthcare professionals (Holm *et al.* 2005, Crogan *et al.* 2008) has been reported in the literature. For example, in a pilot study, Holm *et al.* (2005) explored the potential therapeutic role of storytelling in patients with dementia, indicating that storytelling appeared to stimulate patients to communicate and interact with other people. An evaluation of a nurse-led storytelling intervention for patients with cancer showed that stress and anxiety levels of respondents in the storytelling group were significantly lower than those in the control group (Crogan *et al.* 2008). This intervention also helped patients find meaning in their daily lives, ease their suffering and accept impending death (Evans *et al.* 2008).

In terms of teaching and learning, storytelling has been found to be an effective way of helping students better understand patients' experience, learn related concepts of health and illness, and develop their skills in clinical settings (Davidhizar & Lonser 2003, Schwartz & Abbott 2007). Patient stories have also been used to enhance healthcare professionals' appreciation of how people live with a health condition. An example of the use of stories for genetics teaching and learning is seen on 'Telling stories, understanding real life genetics' website, hosted by the NHS National Genetics Education and Development Centre (<http://www.tellingstories.nhs.uk/>). This free, web-based resource uses stories from patients, carers and healthcare professionals to promote the understanding of genetics, its impact on everyday lives and its relevance to healthcare practice. Storytellers were motivated to share their stories to help others understand the impact of genetics on ordinary people (Morgan *et al.* 2009).

However, health-related stories from young people are lacking, especially those concerning genetics, and intriguing ethical issues have been raised from previous work undertaken within the authors' institute. For example, many participants in the project 'Genetic literacy and family history: A study of young people in the south Wales valleys' expressed no ethical concerns when sharing their personal profiles with research staff online via a social networking page (www.gamyproject.org).

Internet use is growing dramatically in many countries. In 2008, an estimated about three-quarters of the United States and the United Kingdom (UK) populations were Internet users (Internet World Stats, 2008). This figure raised to 93% among 16-24 year olds in the UK (National Statistics 2009). Young people are comfortable communicating and engaging in the virtual world and online applications become embedded into youth culture (Gross *et al.* 2002, Craig 2003, Boneva *et al.* 2006). Internet facilities are available in many places in the UK, such as private homes, work places, schools and most public libraries, and common online activities included emailing (91%), finding information (77%), downloading software (55%), and reading or downloading news or magazines (54%) (National Statistics 2009).

Despite the popularity of online applications among young people, little is known about their views on accessing and sharing health-related stories on the Internet. Such an understanding may help to indicate the most appropriate way to include stories from this age group.

THE STUDY

Aim

The aim of this study was to examine young people's perspectives on sharing health stories. The following questions are addressed:

1. Do young people think that sharing health stories online is beneficial and why?
2. Which factors may influence young people sharing health stories on the Internet?

Design

A qualitative, online research method was used to capture young people's views.

Participants and sampling

Eligibility criteria for participation included young people who were aged 16-19 years, either healthy or suffering from a disease. They also needed to be familiar with computer-based communication and have Internet access. Thirteen young people (four males and nine females) living in England and Wales, UK, participated. Seven were at school, four were at college and two were at university. One participant had suffered from asthma and inherited kidney problems, with one kidney working at only 21% of its full function. Four reported that there were some diseases, such as cancer and diabetes, running through their families. Nine indicated that they were White Welsh, three were White English and one came from other ethnic groups.

Table 1 illustrates the sampling process. Several groups were approached within the local community. Working through trusted stakeholders as a way of gaining access to young people allowed us to communicate with potential participants directly and to respond to their questions.

Research setting

The study was conducted in a virtual environment. A project website hosted by Ning, a free social networking site (www.ning.com), was developed for the purpose of data collection (<http://ypstorytelling.ning.com/>). This approach was deemed appropriate as we were exploring an online resource and it provided us with an opportunity to test an online method of data collection with this age group. The site was piloted with 11 colleagues and friends, and three young people, two of whom did not take part in the study. Access was restricted to registered members with a user name and a password. The site also provided information about researchers' contact details, a digital recruitment advertisement, netiquette, links to support services, a downloadable version of the information sheet and consent form, and some short videos related to genetics.

Data collection

An online focus group was carried out in an asynchronous format and facilitated by two moderators (JY & KM). Participants were able to read comments posted by others and to respond at their own convenience, not necessarily at the same time as others were participating.

To stimulate discussion, web links to two digital stories of young people were added:

1. Three foot seven: living with dwarfism - from the 'BBC Digital Storytelling' website (http://www.bbc.co.uk/wales/audiovideo/sites/yourvideo/pages/james_lusted_01.shtml)
2. Football and diabetes - from the 'YouTube' website (<http://www.youtube.com/watch?v=8BxW6RhO4Fs>)

Links to two other websites were also added:

1. 'NHS Choices: Your health, your choices'
(<http://www.nhs.uk/video/Pages/medialibrary.aspx?Tag=Teens>)
2. 'Telling stories, understanding real life genetics' (<http://www.tellingstories.nhs.uk/>)

The former site is developed for patients and healthcare professionals, while the later is primarily for health educators, students and practitioners, but also a useful resource for patients, carers and families.

All these sites are in the public domain and contain various health stories, including some genetic stories. The researchers were interested in using genetic conditions as an example, because advances in genetics are moving into everyday healthcare practice (Guttmacher & Collins 2003) and stories with a genetic element are often complex, with medical and psychosocial consequences for patients and other family members (James *et al.* 2006). Also, there are few stories from young people in this area.

The data collection lasted for three weeks between June and July 2009, including one pre-discussion week, one discussion week and one post-discussion week. During the pre-discussion week, participants registered with the project site and got to know moderators and other participants by joining the 'Getting to know each other' forum. During the discussion week, one forum with a few questions was introduced each weekday. Examples of the questions discussed included 'Are there any benefits of sharing health-related stories with others on the Internet? If yes, what are they and why?', 'What are the potential issues of sharing such stories?' and 'Do you think young people may want to share their health stories and why?' An open forum was introduced on Saturday, inviting participants to discuss anything they thought important to online storytelling, especially if it had not come up in previous discussions. All forums remained open for the post-discussion week for participants to contribute if they missed a discussion or wanted to give additional comments. In total, 130 postings were received.

Data analysis

Data from online discussions were copied, pasted and stored in the NVivo computer software package. A thematic analysis was carried out (Dey 1993, Strauss & Corbin 2008). Attention was paid to group interaction, a central aspect of focus group methods (Kitzinger 1995, Webb & Kevern 2001). Due to the absence of body language in a virtual environment, words, emoticons and abbreviations that participants provided were carefully checked to identify the interaction between members in terms of agreement and disagreement. Categories and subcategories were created to organise the data, suggested by both the discussion guide and themes that emerged from the data, such as 'empathy' and 'online safety'. Data were analysed by JY and NT independently, and cross checked by KM. No major differences were found.

Ethical considerations

The research was approved by the ethics committee of the researchers' institute. The purpose of the study and the nature of participation were fully explained to prospective participants. They were told that digital stories discussing health issues were available on the Internet but few were provided by young people. The researchers were interested in their thoughts about such stories being online and whether they were likely to be beneficial. Initially, 20 young people agreed to participate and gave written consent by post, in person or via email. Of these, 13 registered with the project website and contributed to the discussions (Table 1). Participants were informed of their right to withdraw without giving reasons. Capability to

'log out' at any stage provided greater protection for those who wished to withdraw, as this avoided coercion or pressure to remain, which may be felt by participants in conventional focus groups.

Participation could cause anxiety or distress for some participants and identifying emotions in an online environment is difficult. Using two moderators ensured greater monitoring of asynchronous activity by reading participants' responses carefully to look for any signs of distress, so participants could be directed to appropriate services via a private email or phone call. Two links were added to the project website: 'All Wales Medical Genetics Service' (<http://www.wales.nhs.uk/sites3/home.cfm?orgid=525>) and 'ChildLine' (<http://www.childline.org.uk/Pages/Home.aspx>). If participants wished to talk to someone or find out more information, they could contact these services for support.

Anonymity and confidentiality were preserved in data analysis and reports. Participation was voluntary, with a 20 pound voucher provided to thank participants for their time.

FINDINGS

Three key themes were identified: positive aspects of sharing health stories online, concerns about sharing health stories online and useful support for potential storytellers.

Positive aspects of sharing health stories online

Most participants were familiar with the format of 'digital stories' although some had never heard the term before. Such stories were thought to be 'modern, simple and effective', 'short and sweet', 'interesting', 'easy to understand' and 'get through to people more than streams of information'. It was also argued that stories available online could be shared with a much wider audience, because 'most people now have computers' and online stories 'can be accessed by anyone at any time'.

Sharing stories with others was believed to be beneficial to a wide range of people. To the general public, participants suggested that listening to others telling their stories was 'more appealing and more touching', which could change the way people think about health issues and 'adjust people's views on people with their type of condition and the prejudices which go along with it'.

The use of stories to share information and raise awareness of a health condition was valued, as the following quotes indicated:

I think that they can be very helpful for people who do not understand certain types of diseases, as they give them relevant and useful information. I believe that this is a good way of spreading awareness of diseases. (Participant 17, female)

I think that sharing stories related to a disease that can run in families is very important because it makes people aware of such illnesses, the patterns of which could quite easily have not been noticed beforehand. (Participant 18, female)

To healthcare professionals, stories were seen as a helpful educational resource. It was suggested that a site, even if it targeted professionals, needed to include some 'general information about symptoms, causes, prevention and treatment'. For example,

I can see how both stories could be a helpful teaching resource in the basic understanding of the two health issues. However, I agree that in order for the stories

to be effective teaching mechanisms they should include more detail about the health issues. (Participant 16, female)

Another participant disagreed, saying:

I see little point in including detail on the illness, as these stories [stories] are targeted at health professional[s] with hopefully a vast knowledge on the subjects (Participant 15, female).

The use of supplementary materials was recommended to enhance the effectiveness of learning especially for students.

Personally I think this method of information transfer is very useful, but as with all methods cannot be relied upon solely for guaranteed understanding by the learner. Combined with text/spoken word etc stories can be much more effective. (Participant 11, male)

Stories were thought useful in helping healthcare professionals to understand social impacts of a health condition on people's daily lives, as indicated thus:

I suppose they offer an insight into the social effects of such health problems as opposed to focusing solely on the medical aspects. (Participant 18, female)

I think, for health professionals to get a better understanding of what it's like the [to] be affected by a disease. Really I think there's no better way to learn what it's like to have a disease than to hear it straight from the mouth of someone. (Participant 13, female)

However, a balance between positive and negative sides of a story was thought to be important, as 'it would definitely create more empathy and give a more well rounded insight into the illness to see the positives and negatives (Participant 16, female).'

Participants believed that people affected by a health condition might be eager to share their stories, particularly the social impact of their illnesses. By sharing, it was thought that people could have an opportunity to be heard about how diseases affected them personally. This could act as a type of counselling and therefore might have potential therapeutic effects to storytellers:

. . . as it would give them the confidence to be more outright about themselves [themselves] and let them feel that they are helping others who struggle with diseases know that they can still enjoy life. (Participant 1, male)

Participant 11 argued that future generations of patients could benefit more from stories being shared than patients who actually gave their stories, saying:

I felt that sharing stories will prove [prove] fruitless for many of the people that share theirs. I think it more likely that it will prove [prove] beneficial firstly for trainee HCPs in understanding daily life effects of illnesses, then for future generations of sufferers benefiting from the gathered knowledge of the HCPs who will by then be the leaders in care. (Participant 11, male)

Some participants believed that stories could provide others affected by a similar condition with reassurance and help them cope with their lives more easily, because they could be reassured that 'there are others who feel the same way and have to deal with the same

issues.' They might also be encouraged to share their stories in the future, like a snowballing effect.

I do think that other people talking about situations in their family may lead more people to talk, as even though when something happens to a family member, they feel like the only person in the world, and just don't want to talk about it to anyone. (Participant 17, female)

Concerns about sharing health stories online

The main concerns participants reported included embarrassment, reaction of other people and safety on the Internet.

Embarrassment was considered to be a key concern. Participants thought that young people often tended to be very self-conscious during their teenage years, and the sensitive and personal nature of health problems added extra obstacles in addition to teenage embarrassment. This meant that young people in general might feel too embarrassed to share stories related to their health, as explained thus:

I wouldn't like to put a story up on the internet in which i featured...and i'd like to consider myself perfectly healthy (Participant 11, male).

Another participant also reflected this view, saying:

I agree with the others, I think there are some stories or illnesses some people may be too embarrassed to share. For example I sometimes watch embarrassing illnesses [on a television programme] and I think that if I had some of the illnesses that come up on that programme I wouldn't like to tell the world. (Participant 13, female)

Participant 16 felt that a mental health problem was one of these 'embarrassing illnesses' that young people would be reluctant to talk about. Some participants used the word 'wrong' while talking about illnesses, such as 'be embarrassed of what they have wrong' and 'everyone knows what's wrong with them', indicating a negative view of these conditions.

Reaction of others was another frequently mentioned concern. Participants with this view believed that opening up one's personal aspects of life could make storytellers vulnerable to the criticism of others who did not appreciate their stories, and this might result in others treating them differently. Worries about being bullied could have a big effect on young people's willingness to share, especially if they had been made fun of before due to their illnesses.

. . . as bullying is in some places very common now, young children may find telling their stories a weakness in the eyes of bullies and therefore decide not to spread awareness. (Participant 16, female)

Safety on the Internet was believed to be another issue of concern. Participants sharing this concern felt that personal information was often revealed while telling a story and such information could be misused by criminals. For example, an 18-year-old participant reported:

I just think it's unsafe these days for people to share personal information due to a variety of things from paedophilia to identity theft, although those are the extremes. (Participant 2, female)

This concern was shared by another participant, who reported:

We all know the dangers of online sharing as they have recently been raised in the public media. I would argue that it makes no difference to the 'realness' of the story

whether the real name or a false identity is used, as the audience need not know the difference: it happens on tv all the time: do we ever care? no. It is therefore important for the protection of the individual - be them [they] a youth or an adult - that they at least feel free to use a false identity and that they be carefully advised whether they do or not; as they should be as to who the content is released to. (Participant 11, male)

This participant supported the use of false identities to tell real life stories and highlighted the need to protect storytellers from becoming victims of the Internet. Respecting the autonomy of individuals was stressed by some other participants in terms of whether real identities should be used. It was believed that how or what was presented should be a personal preference.

I think it's completely up to the individual, if their [they are] comfortable, maybe even proud to present their story directly connected to themselves, then great, as it provides an authenticity and depth which is taken away with a pseudo identity. However if they are not, I don't think keeping it anonymous, lessens the story at all, it maybe lessens an emotional connection created with an authentic identity. (Participant 15, female)

Participants who supported the use of true identities believed that this could allow people to relate to the story more easily and to connect with the storyteller better.

. . . having the real name and the photo's of the person makes it more real to whoever is watching which to me is the purpose of these videos, to help health professionals understand how illnesses affect people in reality. (Participant 13, female)

However, some participants thought that people should not reveal their true identity if access to their stories was not restricted, suggesting:

Another way of sharing a story digitally could be to share it using just narrative without any pictures or names, literally just the story. (Participant 12, male)

Useful support for potential storytellers

Various recommendations were made on how young people could be better supported in order to share their stories. Although most participants thought that payment was not necessarily expected, offering some incentives to storytellers for their time was considered useful to keep them interested. The value of emotional support was highlighted, as Participant 18 reported:

As effective as material rewards may appear I think that the provision of emotional support for young people who suffer from such health problems would be far greater value to them. (Participant 18, female)

When asked about the role of healthcare professionals, families and friends in providing psychological support for young storytellers, support from families was valued, especially that from parents.

Yes, because if their older/younger siblings/parents give them encouragement and support them, they wouldn't develop a fear over they [their] illness. On the other hand if there [they] do not have that support/encouragement then they will develop a complex about the way they are and there [their] self confidence would become very poor and they would be more reluctant to share they [their] story. (Participant 12, male)

People close to storytellers were thought to be able to influence their decisions and thoughts, as well as to assist in making stories.

Depending on the severity of the illness, [this] will affect whether the storyteller will require assistance in producing the content. As a young person it would seem obvious to look straight to family members for that help. (Participant 11, male)

Technical support was also valued highly. The quality of stories was considered essential to enable a better connection with viewers. For example,

I however do think that a video like this could be better produced/edited to create a more emotional connection with the audience, as the purpose of it is to create a sort of empathy. (Participant 15, female)

When asked to explain how this could be achieved, she replied:

Maybe a video instead of photos. Just to create something more aesthetically pleasing . . . but perhaps a melody or song in the background, I think that can be very important in gaining a connection. (Participant 15, female)

To produce a good quality story was thought to be challenging and time-consuming. Therefore, professional support might be needed, as Participant 11 reported that ‘it would be highly advantageous to support them with professional equipment/personnel to produce the story.’ He went on to comment on the quality, reporting that ‘although this isn’t necessarily going to be BBC quality, as time goes on the quality of media productions will need to increase to maintain the effect it has on the audience.’

DISCUSSION

The findings reported here indicate that the participants valued the use of digital stories to share feelings and experiences with a wide range of audiences, and to express personal and social impacts of illness on everyday life. Stories available online can be accessed easily by a large number of people no matter where they live. However, factors other than technology and access can also influence whether and how people use web-based health information, such as perceptions and experience patients had with services and patients’ own care management strategies (Rogers & Mead 2004).

A well-produced story was thought to elicit an emotional connection and empathy with the audience. A true reflection of storytellers’ feelings and experiences with a balance of positive and negative sides might help viewers empathising with them better. Empathy is considered to be a central aspect of any form of caring relationship and is important for quality care (Reynolds *et al.* 1999, Department of Health 2008). It has been argued that empathy can be taught and developed, although it is difficult to evaluate training programmes aiming at developing empathy due to a lack of reliable measures to assess levels of empathy (Alligood 2005, Yu & Kirk 2008, 2009). Findings of the current study appear to indicate the potential to use digital stories to help healthcare students and professionals in empathising with patients and confirm the findings of a US study, where films were used to teach nurse students about empathy (Wilt *et al.* 1995).

Potential therapeutic effects of storytelling were suggested repeatedly. This view is consistent with the reported therapeutic use of storytelling with a variety of patient groups, such as children and young people with mental health needs (DeSocio 2005, Van Heeswyk 2005), older people with dementia (Holm *et al.* 2005), and cancer patients (Chelf *et al.* 2000, Crogan *et al.* 2008, Evans *et al.* 2008). Similarly, in a qualitative study of parents’

experiences following the suicide death of their young adult child, Maple *et al.* (2010) found that telling stories about their child offered these bereaved parents an avenue to get their voice heard, who often found themselves silenced and isolated in their grief.

Young people in the current study also valued the use of stories as a teaching resource. In line with previous research, storytelling has been increasingly used in a variety of ways in nursing and medical education to stimulate thinking and enhance learning outcomes (e.g. Davidhizar & Lonser 2003, D'Alessandro *et al.* 2004, Hunter 2008, Kieser *et al.* 2008, Cole 2009).

However, some concerns were also raised, especially about online safety. Advances in the Internet and web-based communication have greatly changed people's everyday lives. Young people often use instant messaging and chat rooms to engage with known and unknown peers on a regular basis (Subrahmanyam & Lin 2007). Risks of Internet use are increasingly discussed in the literature (e.g. Norris 2007, Hinduja & Patchin 2008). Irresponsible or naive practice, such as the disclosure of personal and identifying information on publicly accessible web pages, makes young people vulnerable, and they may become victims of various crimes (Tynes 2007, Hinduja & Patchin 2008). Online bullying, online harassment and Internet-initiated sexual assaults have been frequently reported (e.g. Wolak *et al.* 2004, Malesky 2007, Ybarra & Mitchell 2007). Findings of the current study mirror the contemporary concern about safe Internet use for children and young people. For health researchers and professionals, more stories from young people would be useful to facilitate teaching and learning; however, while stories are used in an online environment, relevant strategies must be in place to protect storytellers and prevent their information being misused. Promoting online safety can encourage engagement in Internet-based activity although 'tech-savvy' adolescents may be aware of the risks in online socialising (Tynes 2007).

Limitations

This paper has sought to address an under-researched area. The findings should be viewed in conjunction with some limitations. Firstly, the self-report nature of data collection may result in response bias, as is the case for much qualitative research. This is difficult to assess, but using the 'Getting to know each other' forum in this study before the formal discussions helped to promote the establishment of rapport, which in turn may have encouraged honest responses. Secondly, although participation was voluntary, some young people may have taken part because they wanted to help the researchers or their friends, limiting variation in the sample and responses. Lastly, we only conducted one discussion group. Only one out of 13 participants reported having a health condition and a few indicated that there were some inherited diseases running in their families. Most participants, therefore, expressed their views from a very vicarious standpoint and it is impossible to assess whether responses are likely to be different between those who are and those who are not affected by chronic conditions. It would have been helpful to have the views of young people who have already shared their stories and those with different health statuses from diverse social and cultural backgrounds. It is also worth considering how the online environment may have facilitated or inhibited participants to express their views. Despite these limitations, based on the findings, a number of recommendations can be proposed.

Recommendations

It is crucial to get young people engaged in the first place, in order to encourage them to share their stories about health issues, which are often sensitive and personal. Good communication skills of researchers and the use of techniques, such as the 'Getting to know each other' forum, can broke the ice and create an initial, friendly online environment for group interaction. Researchers should be transparent about what will be involved and the 'safety' of their stories being available online.

Relevant support, such as emotional and technical support, should be in place. Researchers need to be aware of various sources of support available to storytellers, for example, social and emotional support from families and close friends, and technical support from professionals through training and workshops. A caution regarding financial incentives to participate is needed due to potential ethical issues. For example, incentives may be an undue influence on the decision to participate and may lead to exploitation of vulnerable people.

Lastly, researchers should promote awareness of online safety. When researchers engage young people to share their real life stories, disclosure of identifying information needs to be avoided to minimise potential risks. Storytellers should be made aware of the limitations/restrictions on the availability of their story and this should guide their level of disclosure. Alternatives for safeguarding the identity of storytellers should be highlighted to encourage young people to give their story.

CONCLUSION

Exploration of young people's views provides some insight for the development of effective strategies to collect health-related stories from this age group. Having stories available on the Internet can be beneficial; however, concerns especially about online safety associated with the Internet use should be taken into consideration. A better understanding of their perceptions can inform future work with young people on storytelling. The insight provided by this study will benefit not only researchers working with young people in the UK, but also those working with other age groups here and in other countries.

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Table 1: The sampling process

Strategies		Male		Female	
		Registered online	Didn't register	Registered online	Didn't register
Contacts	Local schools	1	1	1	-
	Local churches	2	-	2	-
	Youth clubs	-	-	-	2
	Youth workers	-	-	-	-
	Local educational authority	-	-	-	-
	Colleagues	-	-	3	-
	Local colleges	-	1	1	3
Snowballing		1		2	
Project website (http://ypstorytelling.ning.com/)		-	-	-	-
Total		4	2	9	5