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Storytellers as partners in developing a genetics education resource for health professionals

Maggie Kirk [a,*], Emma Tonkin [a], Heather Skirton [b], Kevin McDonald [c], Buddug Cope [d], Rhian Morgan [c]

[a] NHS National Genetics Education and Development Centre, University of Glamorgan, Pontypridd, Wales, United Kingdom
[b] Faculty of Health and Social Work, University of Plymouth, Wellington Road, Taunton, Somerset, England, United Kingdom
[c] Genomics Policy Unit, Faculty of Health, Science and Sport, University of Glamorgan, Pontypridd, Wales, United Kingdom
[d] Genetic Alliance UK, Wales Gene Park, Heath Park, Cardiff, United Kingdom

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SUMMARY

Advances in genetics are bringing unprecedented opportunities for understanding health and disease, developing new therapies and changes in healthcare practice. Many nurses and midwives lack competence and confidence in integrating genetics into professional practice.

One approach to enhance understanding of genetics is to simulate clinical exposure through storytelling. Stories are acknowledged as a powerful learning tool, being understandable and memorable, stimulating critical thinking, and linking theory to practice. Telling Stories, Understanding Real Life Genetics is a freely accessible website that sets people's stories within an education framework. The links between the stories and professional practice are made explicit and additional features support learning and teaching.

Care of the storytellers within an ethical framework is of paramount importance. Storytellers are viewed as partners in the project. The challenges encountered include preserving the authentic voice and dignity of the storyteller. Project team members have also experienced 'professional shame' when negative experiences have been recounted, and the stories have had an impact on the team.

The experience of working with storytellers has been positive. The storytellers want to be heard so that others will benefit from their stories. They serve as a reminder of why this work is important.

Introduction

Helen went swimming one morning with her daughter and son, an apparently healthy, fit 19 year-old. He swam to the end of the pool, collapsed and died. Helen's story tells of her determination to 'make sense' of her son's death and to identify the cause. It was eventually discovered that he died from an inherited cardiac condition (Long QT syndrome), and that her husband, daughter and grandchildren are also at risk from the condition, for which they are now receiving treatment. There was a very strong family history of sudden cardiac death, which had never been picked up by health professionals. Helen told her story because she wanted to raise awareness about Long QT.

> *I was so often dismissed as being a neurotic mother and I'm not a neurotic mother. … I love my children and I love my husband and I didn't want it happening again and that's the reason I am doing this now …*
>
> Helen (www.tellingstories.nhs.uk)

Helen's account is from a collection of stories gathered to provide a web-based education resource for health professional groups, to promote awareness and understanding about genetics and how it impacts on people's lives. Advances in genetics are bringing unprecedented opportunities for understanding health and disease, developing new therapies and changes in healthcare practice (Green and Guyer, 2011). Amongst the key achievements noted by the House of Lords Science and Technology inquiry into genomic medicine (2009) are:

- Predictive diagnosis and single gene conditions, with genetic tests for over 1000 diseases currently available for clinical testing.
- Diagnosis of genetic subtypes of common diseases such as diabetes, Alzheimer's disease, Parkinson's disease and several types of cancer.
- Use of genetic-genomic tests to inform disease management, e.g. through tumour profiling to identify breast cancer patients who are more likely to respond to trastuzumab (Herceptin).
- Predicting individual responsiveness and side effects to certain drugs, e.g. responsiveness to warfarin, or to identify potential hypersensitivity reaction to abacavir for HIV treatment.

This paper will outline the value of stories in education and how they have been used in the development of a genetics education

* Corresponding author at: NHS National Genetics Education and Development Centre, Faculty of Health, Sport and Science, Glyntaf Campus, University of Glamorgan, Pontypridd, Wales CF37 1DL, United Kingdom. Tel.: +44 1443 483074; fax: +44 1443 483118.
E-mail address: mkirk@glam.ac.uk (M. Kirk).

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resource for healthcare professionals. It will also discuss how the storytellers have been involved as partners in the process.

Background

Calls for health professionals working outside of specialist genetics services to be better educated in genetics-genomics are longstanding and even in countries with established strategies for development, there is an acknowledgement of the scale of the challenge (Department of Health, 2008; Green and Guyer, 2011). There is a substantial body of evidence to show that there are significant deficits in genetics education of nurses nationally and internationally, with no real foundation of knowledge on which to build (for a review see Burke and Kirk, 2006). Many UK nurses and midwives have difficulty in making a connection between genetics and their professional practice, and many lack confidence in integrating genetics knowledge and skills into practice (Kirk et al., 2007; Metcalfe et al., 2007), a finding also highlighted in a review of genetic competence of midwives (Skirton et al., 2010). This is compounded by educators who lack confidence in teaching genetics, and who may have limited clinical experience of genetics (Kirk and Tonkin, 2006). In a global survey of nurse leaders, participants identified a lack of professional engagement in genetics–genomics as a result of inadequate awareness and knowledge among educators and practitioners amongst the significant barriers to fully integrating genetics–genomics into nursing education (Kirk et al., 2011a).

In their review, Tonkin et al. (2011) note the growing abundance of genomic resources for nurse education but acknowledge that finding the most appropriate resource can be taxing. A survey of nurse educators (Kirk and Tonkin, 2006) reported the three highest ranked resources needed to support genetics teaching as:

- Access to users or providers of genetics services willing to talk to student groups;
- Annotated scenarios and case studies;
- Websites.

With access to genetics service users constrained by geography and by pressure to limit observers at genetics clinics to specialist trainees, opportunities for 'clinical exposure' are limited. One approach to enhancing nurses' understanding of genetics is to simulate clinical exposure through the stories of people affected by genetics.

Stories in Healthcare Education

The development of web sites dedicated to patient stories is a relatively recent phenomenon (e.g. Healthtalkonline, www.healthtalkonline.org; Patient Voices, www.patientvoices.org.uk/) but storytelling is recognised as a valuable resource within healthcare, with a 'growing realisation that patients and service users are a rich source of health-care related stories that can affect, change and benefit clinical practice' (Haigh and Hardy, 2010; p411). Wilcock et al. (2003) argue the potential of patient storytelling to inform improvement in healthcare by responding to the needs of patients and carers Ziebland and Herxheimer (2008) echo this, calling for health professionals to recognise the value of patient stories as a contribution to the evidence base, particularly in capturing and communicating the essence of patient experience. Gregory (2010; p630) states that 'patients are no longer regarded as passive recipients of healthcare; they have become active participants, with personal stories to tell about the journeys they have travelled from sickness to health.' She reflects on how narratives can provide insight into the patient's perception of their own therapeutic and rehabilitation needs and, in conveying patient experiences, how they can encourage healthcare professionals to reflect on their practice and respond to service-user needs. Kirk et al. found that a 'lack of attention paid to the patient voice' (Kirk et al., 2011a; p110) was cited by nurse leaders as a significant barrier to the integration of genetics-genomics into nursing education.

Stories are acknowledged as a powerful learning tool in health professional education (e.g. Christiansen, 2011; Schwartz and Abbott, 2007). The literature suggests that stories can promote learning because they:

- attract the attention of the student and draw them into the world of another (Christiansen, 2011)
- are understandable and memorable (Cox, 2001).
- stimulate critical thinking (Kirkpatrick et al., 1997)
- can help link theory and practice (Koenig and Zorn, 2002)

Davidson (2004), examining an education approach that used storytelling as a primary tool, found it provided opportunities for more active involvement of students and made the material seem more realistic. Lordly (2007) found a similar positive effect in the classroom, and concluded that stories can influence how students approach professional practice. Storytelling has also been reported to benefit midwifery students by increasing their cognitive skills, developing their emotional skills and by helping to define their role (Hunter and Hunter, 2006). Its merit in helping to develop empathy, explore ethical issues and promote tolerance and cultural sensitivity amongst healthcare providers is also recognized (Fairbairn 2002). Cangelosi and Whitt (2006) suggest that storytelling in an online learning environment is an effective and efficient education approach, helping students learn through sharing, reflection and interpretation of stories. The literature thus seemed to support our intention to develop an online genetics education resource using stories.

Telling Stories Understanding Real Life Genetics

Telling Stories, Understanding Real Life Genetics is a website of over 100 stories, hosted by the NHS National Genetics Education and Development Centre (Fig. 1; www.tellingstories.nhs.uk). The stories (available as text supported with video clips) are organised into 11 themes to aid searching and lesson planning: professional competences and learning outcomes illustrated; genetic condition; inheritance pattern; genetic intervention; professional role; issues raised; clinical specialism; life-stage. The resource is enhanced by additional features (Fig. 2) including suggested activities to accompany learning or teaching, and explanatory notes on how the story links to professional practice via the UK genetics-genomics education framework (Kirk et al., 2003, 2011b).

There were three key considerations in the development of the resource.

Educational Value and Accuracy of Content

While stories are compelling in their own right, the main function of the website is educational and its development is underpinned by adult learning principles (Knowles et al. 2005). Links between a story and professional practice are made explicit and users are encouraged to draw and reflect on their own experience. It is imperative that the content is accurate and that the stories are supported by information that enables users to develop their knowledge base. To support self-directed learning, we aim to make the site accessible to the novice, while facilitating further learning beyond the actual stories. Key terms within the story are identified and included in a glossary. Basic information about the condition is added to each page, including the inheritance pattern, signs and symptoms of the condition and medical management. Given the many thousands of genetic conditions, it is important that we take this approach, and we direct users to reliable and appropriate external resources, to seek further information about genetic conditions for themselves and their patients.

Ensuring accuracy of the content is fundamental. To ensure a high standard, the project team ensures that each story is assessed and annotated by a subject expert. A first annotation is undertaken by a