Where is the Patient in Genomics Teaching?

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**Abstract**

The molecular basis of genetics is often taught apart from the social and ethical implications and students struggle to contextualise clinical practice in genetics with wider implications for patients and families.

An integrated approach to genomics teaching with case studies and role-plays that incorporates the biological, social and ethical learning allows students to explore these aspects holistically and can help students understand and communicate the implications for patients and their families of routine genetic tests.

It is crucial for students to engage with the social and ethical implications of genomics from early on in the medical curriculum, as genomics and personalised medicine are now part of routine medical care.

**Keywords:** Genetics teaching; genetic diseases; genomics; genetic testing ethics

**Background**

Our question stems from designing and delivering an integrated, interactive 5 week unit that includes adaptations of six genetic cases each focused on a different ethical issue (Lucassen et al., 2010; Rebelo Hopkins, Crawford, & Turner, 2016). The molecular basis of genetics is often taught apart from the social and ethical implications and students struggle to contextualise clinical practice in genetics with wider implications for patients and families.

Current undergraduate genomics teaching in the early years also concentrates on the molecular basis of genetics and gene therapy leaving students unprepared to understand these key ethical issues and the implications of routine tests for patients and their families (Dhar, Alford, Nelson, & Potocki, 2011; Plunkett-Rondeau, Hyland, & Dasgupta, 2015). With the launch of the 100,000 genome project (NHS, 2012) there is an unprecedented need for genomics education in the medical curriculum to shift its focus from technological advances to social and ethical exploration (Dhar et al., 2011; McCarthey, 2014; McIlvried, Prucka, Herbst, Barger, & Robin, 2008; Nelson & Mcguire, 2010; Plunkett-Rondeau et al., 2015; Wiener, Thomas, & Goodspeed, 2010).
Approach

Our aims were to develop a unit that would allow students to explore and engage with the social and ethical aspects of genetic cases contextualised by current guidelines and clinical practice. Additionally, we wanted to address student feedback that indicated a lack of understanding of molecular mechanisms and ethical implications for families of genetic diseases. Our innovation was to integrate the biological, social and ethical learning so that students could explore these aspects holistically. An interdisciplinary team with specialities in biomedical sciences, genetic counselling and humanities was fundamental in maximising student learning. For each genetic case we developed role-plays with links to biological questions related to genetic mechanisms and genetic testing, with roles for patients, family members and healthcare professionals (Rebelo Hopkins et al., 2016). Students presented each case study in groups, in a symposium at the end of the unit.

Evaluation

Evaluations for this integrated interdisciplinary approach to genomics teaching were extremely positive from both students and staff perspectives. Students’ comments included: ‘The role plays were a good way of understanding the impact of genetic diseases on patients’; ‘The presentations along with the clinical cases and role play made it come alive and really understand the cases’; ‘Watching the role plays of other groups enabled me to consider different viewpoints and opinions on the ethical issues raised by each case study’. ‘The role play was good as I saw how others interpreted and presented the issues in the case study’.

Students reported that the unit helped them to explore implications for patients and families of genetic diseases, identify and discuss the ethical implications, as well as better understand the molecular mechanisms associated with current genetics and therapeutics. Students also found it easier to engage with clinical genetics and found the topic more interesting than when topics were taught separately. However, the limitations of this approach are that students need considerable preparation time and the logistics of running the symposium is time consuming and resource intensive for staff.

Discussion

Learning molecular and ethical aspects of genomics can be a challenge as students can find these topics hard to engage with and understand. This is further compounded by the complexity of trying to apply ethical guidelines as undergraduates without clinical experience. In our own unit some students requested right and wrong answers that could be applied to similar or all cases, especially for assessment purposes. However, the integrated approach facilitated students’ learning and engagement with these topics. Through using role play and drama the students create a lived experience to represent the patient and their family’s perspective of genetic disease, as well as exploring the roles of healthcare professionals (McIlvried et al., 2008). Furthermore, they are able to explore and discuss the application of complex guidelines with immediate discussion and feedback from the genetic counsellor. This use of roleplay, discussion and feedback enables students to learn through observation and imagination to create and develop their own meaning (Dewey, 1922; Fryling, Johnston, & Hayes, 2011).

There is a need for reform in medical schools programmes that do not have an integrated approach to science teaching. It could be argued that the logistics of the large cohorts in the undergraduate medical curriculum makes such initiatives impractical but the benefits of updating the training of future doctors and improving the quality of
patient care outweigh the impracticalities and should inform curriculum design.

**Take Home Messages**

It is crucial for students to engage with the social and ethical implications of genomics from early on in the medical curriculum, as genomics and personalised medicine are now part of routine medical care.

An integrated approach to genomics teaching can help students understand and communicate the implications for patients and their families of routine genetic tests.

**Notes On Contributors**

**Dr Susie Rebelo Hopkins** is a Senior Teaching Fellow in Medical Education and deputy for the BM6 widening access programme at the University of Southampton. She has a strong interest in widening participation, the role of open educational resources and mobile technology to enhance learning in biomedical sciences, as well as research in immunology and autoinflammatory diseases.

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Appendices

Declarations

The author has declared that there are no conflicts of interest.

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