Supporting patients and families with inherited cardiac conditions

It is estimated that about 340,000 individuals in the UK are affected by inherited cardiac conditions (ICCs), which are a major cause of sudden death in the young (Department of Health, 2013). This risk of sudden death and the wider availability of preventative therapies has increased the number of relatives seeking cardiac screening and/or predictive genetic testing. These patients undergo a series of tests and may need follow-up. A number of centres have established registries for ICCs to ensure patients have complete screening and are not lost to follow-up; these registries have become an important tool for research.

Many patients affected by, or at risk of, ICCs may remain asymptomatic. However, while we know of the negative psychosocial impact of undergoing these tests, little is known about the impact of clinician/patient interaction on patient decision making, coping and psychosocial wellbeing.

Aims of the scholarship
The aim of my Florence Nightingale Foundation Scholarship was to explore best practice in specialist ICC clinics and learn how maintaining a registry can benefit patient care. I visited centres in Canada (Ottawa and Vancouver) and Australia (Brisbane and Sydney), which have active, established ICC patient registries.

I also wanted to use the scholarship to inform my PhD research proposal to develop a psychoeducational intervention to support patients with, or at risk of, ICCs. To achieve this, I visited an expert on self-determination theory (SDT), Professor Luc Pelletier, director of the Human Motivation Research Laboratory at the University of Ottawa in Canada. SDT looks at motivation and our natural tendencies to behave in healthy, effective ways (for more information on SDT, visit http://selfdeterminationtheory.org).

I wanted to explore whether SDT could be used as a theoretical framework to develop the intervention. Applying SDT to the field of ICCs is novel, but it has been successful in smoking cessation, weight loss and substance abuse programmes.

Implications for practice
- Patients with inherited cardiac conditions (ICCs) should be referred to a multidisciplinary specialist clinic
- A registry can help track ICC patients and their families to ensure timely and comprehensive clinical care
- Research can be facilitated by maintaining a registry
- Psychoeducational needs of patients and their families must be considered

Dissemination
This work has been shared with the ICC clinical teams at Guy's and St Thomas' Hospital Foundation Trust and King's College Hospital, London, and will be used to help improve the care for ICC patients and their families. It is hoped the findings will be published and presented in conferences and forums to maximise dissemination and the impact on patient care.

Author
Teofila Bueser is Health Education England/National Institute for Health Research clinical doctoral research fellow, King's College London, and honorary cardiac genetic nurse, Guy's and St Thomas' Hospital Foundation Trust and King's College Hospital, London.

Citation