



In this article...

- The role of disease registries in clinical care and research
- Supporting patients with inherited cardiac conditions to make decisions

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 autonomous decision making for 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>).

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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

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.

Shared learning

I found that clinical services provided in specialist ICC clinics in Canada and Australia are similar to those in the UK but tend to be smaller and family members have easier access to screening.

In Australia a comprehensive national registry is maintained, while in Canada this is done nationally for specific ICCs. In Australia, aside from helping to facilitate the day-to-day needs of the clinic, the registry has been used to produce meaningful research, which has given insight on service delivery and patient and

family experiences. In Canada, the registry has helped develop better diagnostic criteria for patients with ICCs. It was clear that ICC registries provide robust information for clinical care and research, and can aid patient recall when follow-up is required.

After my consultation with Professor Pelletier, I concluded that SDT can be used as a theoretical framework to develop a psychoeducational intervention that can help patients with, or at risk of, ICCs to make autonomous decisions about their care.

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. **NT**

- This article reports on a Florence Nightingale Foundation travel scholarship. The scholarships give nurses and midwives an opportunity to study practice elsewhere in the UK and/or overseas. For more information visit: Bit.ly/FNFTTravelScholarship

References

Department of Health (2013) *Cardiovascular Disease Outcomes Strategy: Improving Outcomes for People with or at Risk of Cardiovascular Disease*. Bit.ly/DHCardioStrategy