

WHAT IS THE IMPACT OF TRAVELLING FROM NI TO DUBLIN FOR SURGERY ON FAMILIES OF INFANTS WITH CONGENITAL HEART DISEASE?

CAILEAN COFFEY AND CHRIS MCCUSKER



INTRODUCTION

It is well established that psychological distress is elevated in parents of infants undergoing heart surgery. Understanding this is important because research tells us the **extent** of parental distress is associated with **later child adjustment**. Since cardiac surgery ceased in Belfast in 2015, a significant proportion of Northern Irish surgeries now take place at Our Lady's Children's Hospital Crumlin (OLCHC). We sought to understand the experience of parents who travel from Belfast to Dublin for surgery and especially any impact on psychological distress and coping.

METHODOLOGY

Fifteen parents of infants who had undergone CHD surgery within the past two years completed an online survey on Children's Heartbeat Trust website. Narrative transcripts were subjected to thematic analysis. Parents also completed the "Maternal Worry Scale" in order to compare contemporary levels of distress with those of an earlier cohort of parents whose infants underwent surgery at the Royal Belfast Hospital for Sick Children.

FINDINGS

As shown in Table 1 (below), there were no statistically significant differences between the current sample and the historic sample of parents whose child had undergone surgery in Belfast. Levels of worry were comparable in both samples.

Table 1

	Mean Worry Score	Standard Deviation
Current Study (2020)	22.06	8.16
Belfast Study (2009)	20.80	8.50

KEY THEMES

THEMATIC ANALYSIS ELUCIDATED THREE MAJOR THEMES:

- **A Spectrum of Stresses** was the most common theme. Almost all responses communicated additional worry from the travel itself, financial implications, and burdens such as leaving other children behind.
- **Accommodation** Whilst all were appreciative of having hospital accommodation to stay in close to their child, opinions on this varied on quality. Others noted the need to get hotel accommodation as an additional stressor.
- **The Pros outweigh the Cons** Despite the spectrum of stresses and additional worry of travel, there was a perception, across almost all parents, that the excellence of expertise and care outweighed those difficulties.

INTERESTINGLY, NO PARTICIPANTS SUGGESTED SURGERY BE RETURNED TO BELFAST AND NO KEY THEMES EMERGED REGARDING ANY DIFFICULTIES IN SHARED CARE ARRANGEMENTS.

CONCLUSION

Whilst travelling to Dublin undoubtedly caused additional stress for our sample, overall levels of worry / distress were no higher in these parents than they were in a historical group whose children had their surgery in Belfast. Moreover, parents in the current study echoed the ethos of the all Ireland network, that the benefits of travelling for surgery to OLCHC outweighed the disadvantages.