



Transfer to Adult Care—Experiences of Young Adults with Congenital Heart Disease

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More than 90% of children born with congenital heart disease survive into adulthood due to successes of cardiac surgery and medical management. Interviews with 16 young adults with congenital heart disease to explore their experiences of transfer from pediatric to adult care were performed. The analysis identified five themes; *Feeling secure during the transfer process*, *Experiencing trust in the care*, *Expecting to be involved*, *Assuming responsibility for one's health is a process* and *Lack of knowledge leads to uncertainty*. In conclusion; a structured and gradual transfer process was necessary to enable the informants to shoulder the responsibility for self-care.

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THE INCIDENCE OF children born with congenital heart disease (CHD) is one percent worldwide. Development of diagnostic methods, medical treatment, pediatric cardiac surgery and catheter interventions have resulted in improved long-term survival. Nine out of ten children with CHD now reach adulthood (Moons, Bovijn, Budts, Belmans, & Gewilling, 2010; Tennant, Pearce, Bythell, & Rankin, 2010). Even if the child is well during childhood and adolescence, the risk of complications increases during adulthood in some cardiac defects (Gurvitz et al., 2013; Marelli & Gurvitz, 2011). It is recommended that young adults with moderate or severe CHD should undergo regular medical check-ups (Sable et al., 2011).

Within adult care, there are special CHD units (adult congenital heart disease—ACHD clinic), to which young people are referred for follow-up. From an international perspective, the age at which such transfer is planned and the

way it is carried out differs but it most commonly occurs at the age of 18 years (Hilderson et al., 2009), which is also the case in Sweden.

The preparation for the transfer involves letting the patient gradually assume responsibility for his or her own health and self-care. Previous studies have revealed that young adults lack knowledge about which type of cardiac defect they have, its treatment, risk of complications and the importance of continued medical follow-up (Dore, De Guise, & Mercier, 2002; Moons et al., 2001; Van Deyk et al., 2010). Although it is of crucial importance that young adults undergo regular medical check-ups after transfer to an ACHD clinic, studies from, Canada and Belgium have shown that the compliance with such recommendations varies (Goossens et al., 2011; Reid et al., 2004; Wray, Frigiola, & Bull, 2013).

Aim

The aim of the study was to explore the experiences of young adults with congenital heart disease in Sweden after transfer from the pediatric cardiac clinic to the adult congenital heart disease clinic.

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Table 1 Demographic and clinical characteristics of the study population 16 young adults with congenital hearts disease (CHD).

Characteristics	n (%)
Gender	
Male	5 (31%)
Female	11 (69%)
Patient age, years	
20 (1994)	2 (12,5%)
21 (1993)	4 (25%)
22 (1992)	7 (44%)
23 (1991)	2 (12,5%)
24 (1990)	1 (6%)
Leisons	
Mild grade	0
Moderate grade	7 (44%)
Complexity grade	9 (56%)
Treatment	
Surgery	16 (100%)
Years with transfer	
18	14 (87%)
19	2 (12%)
20	1 (0,5%)
21	1 (0,5%)
Meeting for transfer	
Yes	8 (50%)
No	8 (50%)
Clinical visit frequency	
Every 6 months	5 (31%)
Every 1 years	5 (31%)
Every 2 years	4 (25%)
Every 3–5 years	2 (12%)

Informants and Methods

The research design was a descriptive qualitative study. Data were collected through individual interviews. The participants were invited by either a research nurse or a medical physician. They received a letter with information and a consent form. If they wanted to participate, they returned the consent form. The participants ($n = 16$) were 19–24 years old (median 22 years), had CHD and lived within the catchment area of two regional clinics in Sweden. The inclusion criteria were to understand and speak Swedish, having been followed-up by a pediatric cardiac clinic (PCC) and then transferred to an adult congenital heart disease clinic (ACHD) having made at least one visit there. Individuals with a cognitive impairment who were deemed incapable of understanding the meaning of participation in the study were excluded. All were provided with written information about the study, a consent form and a stamped response envelope (Table 1).

When those who chose to participate ($n = 16$, 5 men and 11 women) had returned their consent form, the first author (AA) contacted them by telephone providing them with further information and an opportunity to ask questions about the study. The informants chose the time and place for

the interview. The following locations were chosen; a private room in a hospital ($n = 13$), the informant's home ($n = 1$) or a café ($n = 2$). The interviews were carried out from December 2013 to October 2014.

The interview started with an open-ended question: *Can you describe how you experienced the transfer from the Pediatric Cardiac Clinic to the ACHD-clinic?* During the initial narrative, the interviewer did not pose any questions but allowed the informants to freely relate their recollections. An interview guide with questions like “How did the doctors and nurses prepare you for the transfer?” “How did your parents handle the transfer?” was used as support during the interviews and to ensure that all subject areas were covered. The informant was allowed to speak freely and the interviewer did not interrupt by asking questions until she/he had finished. Follow-up questions were: *Can you expand ...? Can you provide examples? How did you experience it? What did it mean to you?* Confirmatory questions were: *Have I understood you correctly? Does it mean...?* The interviews lasted between 15 and 53 minutes (median 27).

Data Analysis

The interviews were audio-recorded, transcribed verbatim and analyzed by means of qualitative content analysis (Graneheim & Lundman, 2004). The analysis process started by two of the authors (AA, A-CB), individually and repeatedly reading the transcribed text in order to gain an understanding of the content, after which they identified, condensed and coded meaning units. Codes at level one were not counted since the ambition was not to present the manifest analysis. No codes were eliminated. When the two authors had reached agreement about which codes had similar content, the codes formed sub-categories, which were sorted into five categories. Finally, the plausibility of the results was discussed with the third author (E-LB) in order to enhance trustworthiness.

Ethical Considerations

The informants provided written consent after having received information about the study. They were informed that the data would be coded to ensure that they would remain anonymous, that participation was voluntary and that they were free to withdraw at any time without any influence on their care (World Medical Association, 1964). An Advisory Statement for conducting the study was provided by the Regional Ethical Review Board in Gothenburg (no. 953-13). According to the routines of the university, all data are stored in a safety box for 10 years and only the research group will have access to it.

Results

The analysis of the interview data resulted in the following categories: *Feeling secure during the transfer process, Experiencing trust in the care, Expecting to be involved, Assuming responsibility for one's health is a process and Lack of knowledge leads to uncertainty.* The

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