Bachelor in Science (Nursing) (BSc (Cur))

Research Proposal

Nurses Perceptions and Experiences of Transition for Adolescents with Congenital Heart Disease: Qualitative study

Research Proposal submitted to University of Dublin Trinity College,

In partial fulfilment of the requirements for the

Bachelor in Science (Nursing) (B. Sc. (Cur.))
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CHAPTER 1

1.1 ABSTRACT

Research Question

What are nurses’ perceptions and experiences of transition for adolescents with congenital heart disease (CHD)?

Background - Due to advances in cardiology and cardio-thoracic surgery, life expectancy of patients with CHD has increased significantly (Deanfield et al. 2003). However as children and adolescents with CHD are at high risk of developing significant complications in adulthood, successful transfer to adult services for follow up care is imperative.

Guidelines issued by Cardiology associations, e.g. the European Society of Cardiology (ESC) (Deanfield et al. 2003), Department of Health UK (2006) and the American College of Cardiology/American Heart Association (ACC/AHA) (Warnes et al. 2008) state that structured and individualise transition programs, during the adolescent years of 12 – 21, are fundamental to ensure seamless transfer from paediatric to adult services ensues for patients with CHD. Education of CHD, possible complications which may occur, health and lifestyle behaviours that affect the disease and the importance of follow up care is highlighted, throughout these guidelines, as a fundamental attribute of transition programs. Furthermore, nurses’ are identified as being in a prime position to offer this education (Moons et al. 2006).

Aim of this study – The aim of this research is to gain insight into Nurses’ perceptions and experiences of transition for patients with CHD, with particular emphasis on their role in educating patients.

Method – The methodology chosen to explore this topic is a qualitative phenomenology approach. Data collection will take the form of semi structured, face to face interviews. An audio recording of each interview will take place and the researcher will also keep a field journal with written notes. All data and notes will be held in accordance with the Data Protection Act (Government of Ireland 2003) and destroyed once results are written up.

Sample – It is proposed that a purposive sample of 10 registered Childrens’ nurses (RCN), working full time on a paediatric cardiology ward in a large teaching hospital in Leinster, will be recruited. Ethics approval will be sought prior to starting this research and informed consent obtained from each participant.

Data Analysis - It is proposed that data collection and analysis will occur simultaneously. The researcher will endeavour to continuously reflect on their own participation in interview processes along with randomly selecting participants to read transcripts of interviews in order to ensure rigour and trustworthiness is maintained. Data will be analysed using Colaizzi (1978) method of analysing interview transcripts in qualitative research.

Findings - It is proposed that findings from this study will identify nurses’ experiences and perceptions of transition and that these findings will assist with national and international future research in transition and CHD, nurse education and practise development for nurses working with adolescents with CHD.
1.2 IDENTIFYING THE RESEARCH ISSUE OF INTEREST

At present it is estimated that there are over 1.2 million adults with congenital heart disease (ACHD) in Europe (Moons et al. 2006). As a result of their disease, over 50% of these adults will experience co-morbidities and residual effects such as endocarditis, arrhythmias, congestive heart failure and sudden death (Verheugt et al. 2010). Owing to this high risk of complications, CHD is quickly becoming one of the most common chronic illnesses in Europe (Billet et al. 2008). Early, ongoing and individualised education of adolescents, on their disease and the importance of regular follow up care as adults, is vital (Hildeson et al. 2008).

Cardiology associations world-wide have issued guidelines to highlight the significance of, early and ongoing transition programs, in the education of patients with CHD (Deanfield et al. 2003, Warnes et al. 2008). However, research on CHD has identified a lack of knowledge amongst this population (Veldtman et al. 2000, Moons et al. 2001).

Whilst the last decade has seen an increase in international literature on transition for patients with chronic illness, research on CHD, and in particular transition programmes for adolescents with CHD, is still quite scarce. When searching literature for this topic it became evident that no Irish research studies were available on CHD. Moreover, while education is highlighted as a fundamental attribute of transition programs and nurses’ are identified as being in a prime position to offer this education (Moons et al. 2006), a dearth of research exists on nurses’ opinions of their perception and experience of this vital role.

For this reason, along with the writers’ personal interest on transition for adolescents with CHD and the nurses’ role in this process, this research proposal will endeavour to identify nurses’ experience and perceptions of transition for adolescents with CHD with particular emphasis on education of the adolescent and their family.
1.3 LITERATURE REVIEW

Introduction

Congenital Heart Disease (CHD) is a broad term used for any deformity or malformation of the heart which occurs when the foetus is developing (Alderman 2000). Malformations can range from simple to complex and can occur as an isolated irregularity or linked to a genetic disorder (Deanfield et al. 2003). CHD is diagnosed in approximately 1 in every hundred live births in Ireland making it one of the most common congenital defect (Heart Children Ireland 2010).

Due to advances in cardiology over the last 4 decades, the percentage of children with CHD reaching adulthood has risen from 15% to 90% (Deanfield et al. 2003). It is suggested that in the next decade 1 in 150 adults will be living with CHD (Warnes et al. 2008). Whilst life expectancy has increased significantly, a high incidence of co-morbidities is evident in adults with CHD (Billet et al. 2008). Co-morbidities and residual effects for this increasingly new population, include: endocarditis, arrhythmias, congestive heart failure and sudden death (Engelfriet et al. 2005). Owing to this increase in mortality, coupled with the high risk of complications seen in adults with CHD, it is fast becoming one of the most common chronic conditions in adults worldwide (Billet et al. 2008).

The provision of a structured transition program tailored to suit individual needs and maturity, emphasising the importance of continuity of care and regular follow up in the adults services, is seen as an absolute requisite by international cardiology associations including ESC (Deanfield et al. 2003), Department of Health UK (DOH 2006) and the ACC/AHA (Warnes et al. 2008). Cardiology Associations also identify the nurse, and in particular the Cardiac Nurse Specialists, as having a pivotal role in transition programs, the education of patients with CHD and the successful transfer of these patients to adult services.

The aim of this literature review is to evaluate the link between effective and continuous education during transition programs and successful transfer to adult CHD services, for patients with CHD. This will be achieved by exploring research on transition in CHD over
the last 10 years. Critical to this review is an examination the nurses’ role of educator during the transition process.

Literature, for this review, was retrieved by an electronic search of databases including Proquest, Science Direct, Ovid and Cinahl. This search was limited to the last 10 years and by the following keywords: – Transition, transfer, adolescents and congenital heart disease.

The majority of the literature retrieved was from Canada, USA, UK and Belgium. Literature gathered included qualitative and quantitative studies along with anecdotal articles and literature reviews (see appendix 1).

Whilst the literature produced many themes for the purpose of this review the following themes will be explored:-

1) Education required during transition and the role of the nurse in education:-
   - Their heart defect, medications and treatment.
   - Co morbidities associated with CHD
   - Pregnancy, contraception, lifestyle and health behaviour

2) The implication to the CHD patients lost to follow up.

**Explanation of key terms:**

**Adolescence:-** The age when adolescences takes place varies throughout literature, however, the World Health Organisation (WHO 2002) defines adolescence as between the ages of 10 and 19. Conversely it is argued that adolescence is not an age but a developmental phase of significant physical and psychological change when an individual develops a sense of personal identity. It is a period where a person is no longer a child but not yet an adult (Wong et al. 2010).

**Transition:-** “A purposeful planned process that addresses the medical, psychological and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems” (Blum et al. 1993, p.570). Successful transition programs culminate in the
transfer, to the adult services, of an informed and autonomous adolescent who is confident in taking responsibility of their health.

Guidelines on transition issued by the ESC, recommend that discussions on transition begin before 12 years old and continue until successful transfer to adult services takes place at around 18 years (Deanfield et al. 2003). However these guidelines also highlight the importance of tailoring this timeline to suit the individual and their needs.

*Transfer:* An event resulting in the successful move of a patient from the paediatric services to the adult services. A successful transfer usually happens at the end of a structured transition programme.

*Education of the CHD patient during transition programs*

Nurses are central to the smooth and successful management of education in children with CHD and their parents, during the transition process (Deanfield et al. 2003, Claessens et al. 2005). Crucial to the success of transition programs is initiation and continuation of education from time of diagnosis through to successful transfer, tailoring of education to individual needs and provision of written information to reinforce verbal information (Kennedy 2008).

In order to foster independence in adolescents with CHD and enable them to become autonomous in their health care needs, it is vital they are educated on all aspects of their illness and provided with the tools to help them cope with the implication of their disease on their quality of life (Reid et al. 2006). Nurses’ are fundamental in this education process as they place the person coping and living with a disease central to their nursing care (Moons et al. 2006, Kikkenborg Berg & Hertz 2007). In their qualitative study, Clarizia et al. (2009) found a direct correlation between adolescents’ knowledge of their disease and their understanding of the importance of follow up. Whilst it is important to include parents in all aspects of their child’s care, in order to prepare the adolescent to take ownership of their disease provision must be made (by the nurse) to meet with the adolescent in private, as overprotection by parents is seen to hinder social maturity and independence (Simko et al. 2006). Furthermore, the rationale for this should be explained to the parents.
Heart defect, treatment and medication

A qualitative study by Veldtman et al. (2000) on 63 adolescents with CHD, deduced that adolescents who fully understand their condition appear to have a better quality of life with less stress and more compliance with medication and follow up. This study also revealed that while a third of participants had a good understanding of their heart disease and could show the location of their defect on a diagram, 33% had an incorrect understanding. Conversely, Moons et al. (2001) quantitative study of 62 adults with CHD found that 61% had a good understanding of their defect. Participants in both studies were actively attending specialist CHD centres.

Both Veltman et al. (2000) and Moons et al. (2001) found that whilst 90% of their participants had a good knowledge of their past treatments Moons et al. (2001) study deduced that 25% were unaware of the potential side effects of their medication. Quantitative studies of parents of children with CHD by Cheuk et al. (2004), Chessa et al. (2005) and Reid et al. (2006), found similar patterns of knowledge; however, they also deduced that more than 60% of parents had little knowledge or understanding of the prognosis of their child’s disease.

Co-morbidities associated with CHD

According to Horner et al. (2000) up to 86% of adults with complex CHD develop complications such as heart failure, arrhythmias and endocarditis. Engelfriet et al. (2005) carried out the largest quantitative study in Europe which addressed morbidity and mortality in 4110 CHD patients over 5 years. During this time this study revealed that 6% experienced endocarditis, 19% underwent surgery, 20% developed arrhythmias, and over half were started on chronic medications. Although studies show a high risk of morbidity, less than 50% of adults with CHD could recognise symptoms of heart failure and only 10% identified the main symptoms of endocarditis (Moons et al. 2001).
Due in part to poor education and advice on the risks associated with pregnancy, CHD is currently the most common cause of morbidity and mortality during pregnancy. However, with good planning, assessment and communication this statistic can be reduced and many female adults with CHD can have a successful pregnancy (Sommerville 2002, Thorne et al. 2006). Moons et al. (2001) found 87% of female participants were naive to the complications of pregnancy and only 25% of these correctly identified forms of contraception that were contraindicated for them. Although studies show a lack of knowledge in this area, Simko et al. (2006) and Ronning et al. (2008) deduced that females with CHD sought after more information regarding contraception and pregnancy.

The need to address the issues of pregnancy and contraception, along with other sensitive and personal issues, further highlights the importance of providing the adolescent with CHD the opportunity to discuss these issues with a nurse in private and without their parents present (Simko et al. 2006).

Reid et al. (2006) found risk taking behaviour in adolescents with CHD correlates with that of their healthy peers, however, adolescents with CHD were unaware of the added risks to their disease associated with an unhealthy lifestyle. The results of an anonymous self assessment questionnaire by Swan and Hillis (2000) revealed that while most adults with CHD can engage in moderate exercise, only 30% of the participants received any advice on exercise and the majority of the advice given was prohibitive. The benefits of education programs in CHD was evident in a study by Moons et al. (2006) which identified an increase in awareness of exercise capabilities and recognition of symptoms of overexertion in their cohort of adults with CHD.

**Summary of education**
Research on CHD shows a direct correlation exists between the level of a patients’ knowledge and their compliance with follow up appointments in adult services (Clarizia et al. 2009, Moons et al. 2009). As discussed previously, patients’ with CHD show a shortfall in the knowledge of their disease and the associated risks along with the importance of follow up in adult services. Due to the high risk of complications and co-morbidities, the importance of ensuring this group of patients are followed up in adult services is highlighted throughout literature (Hilderson et al. 2008, Gibson et al. 2009). Lack of education is seen as one of the key reasons for over 50% of adults with CHD ‘lost to follow up’ Moons et al. (2008).

*The Lost CHD patient*

“Transition programs that inform patients about the rationale for ongoing follow-up and that teach them how to navigate the medical system can prevent another lost generation” (Moons et al. 2008, p.262)

A quantitative study undertaken in Canada by Reid et al. (2004) consisting of 360 CHD patients aged between 19 and 21, chronicled an unsatisfactory rate of 47% of patients successfully transferring to an adult centre. Wacker et al. (2005) found that 76%, of over 10,000 CHD patients studied, did not attend a follow up appointment within 5 years. In this study additional questionnaires were sent to the cohort of patients not followed up in an attempt to gauge their health status. Whilst only 25% replied, 35% of respondents had concerns about their health. Both studies concluded by highlighting the need to educate patients on their disease and the importance of follow up and were subsequently supported in this conclusion by Gatzoulis (2006) and Moons et al. (2008).

A qualitative study, by Yeung et al. (2008) of adults with CHD, found that lack of follow up increased the risk of complications associated with the disease and tripled the chance of patients requiring cardiac intervention. During interviews participants cited a deficiency in information and knowledge on the importance of attending follow up appointment as the main reason for not attending. Due to the increase risk of morbidity in patients lost to follow up, Danish media described this group as ‘ticking time-bombs’ in 2005.
**Implications to research**

Research on the CHD population is not without limitations. The first challenge arises due to the multitude of variations of CHD, ranging from mild to severe, and the ambiguity surrounding the definition and classification of CHD. Caution needs to be taken when comparing studies due to this ambiguity along with the exclusion of a large percentage of the population from studies. Several studies mentioned so far, not limited to but including: Veltman et al. 2000, Moons et al. 2001, Reid et al. 2004 and Billet et al. 2007 exclude patients with associated syndromes, Intellectual Disabilities and mild lesions.

Additionally, most studies on CHD are limited to patients actively receiving care in a specialised centre and, as discussed earlier, a large proportion of the adult CHD population are lost to follow up and therefore excluded from research. A popular method of sampling in research on CHD is non-probability and convenience sampling CHD which does not offer a true representation of the population (Polit & Beck 2006) and therefore caution should be taken when interpreting the results.

Finally, implementation of databases on patients with CHD is a relatively new phenomenon resulting in a dearth of statistics on the actual number of patients lost to follow up, living their lives free from complications associated with the disease and patients who have passed away as a result of their disease (Moons et al. 2008).

**Adult and Paediatric Services for CHD in Ireland**

As discussed throughout this review “Congenital heart defects are extremely varied, can occur in a number of combinations and cover a spectrum of severity” (Kennedy 2008, p.154) and put the CHD patient at significant risk of developing various complications in adulthood. In order to manage this new patient group effectively, specialised centres along with nurses and cardiologist trained in CHD are required (Somerville, 2002) however research shows that health services in Europe lack these resources.
Whilst the paediatric sector in Ireland has 5 paediatric cardiologists along with 5 specialist cardiac nurses (all of whom work full-time), the adult CHD centre in the Mater hospital has only one adult congenital heart nurse specialist and no full time CHD specialist cardiologist (Rogers 2010, personal communication). Furthermore, to date no database is kept on children with CHD in Ireland (Rogers 2010).

**Conclusion**

Due to major advances in cardiology, patients with CHD are living well into their adult years. This has resulted in a rapidly increasing and comparatively new group of patients attending adult healthcare services. However, whilst the mortality of this patient group has increase they are at risk of requiring further cardiac interventions and developing co-morbidities due to their disease. Alarmingly research has shown that education of this patient group is lacking resulting in over half of them being lost to follow-up. Lapse of care is linked to an increase in the risk of complications.

Whilst research on CHD is still lacking, the last decade has seen an increase resulting in of the emergence of guidelines on the management of CHD. These guidelines all highlight the importance of developing transition programs which educate adolescents with CHD, and their parents, on their disease and the importance of regular and continuous follow up of care. Transition programs should be individualised and result in successful transfer, of the adolescent, from paediatric to adult services at a time tailored to them and not to age.

Literature on transition and education of adolescents with CHD places Childrens’ nurse in a pivotal position to initiate and continue education from the time of diagnosis through to successful transfer. A key aim of transition is to empower the adolescent to take ownership of their illness by providing them with all the information they need to successfully achieve this. This information should provide them with complete knowledge of their disease, how to recognise complications associated with their disease and the importance of making good lifestyle choices and attending for follow up care.

As discussed in section 1.2 above, a dearth of research studies exists on Nurses’ perceptions and experiences of their role in transition of adolescents with CHD. The
following research proposal aims to look at this gap in the literature by exploring the Nurses’ perceptions and experiences of their role in transition of adolescents with CHD.
1.4 RESEARCH QUESTION

According to Brink and Wood (2001) a research question confronts, investigates and challenges a specific dilemma or topic in order to generate constructive and informative information. Research questions are fundamental in the research process as they direct the researchers’ attention to the specific query under investigation (Parahoo 2006).

What are nurses’ perceptions and experiences of transition for adolescents with congenital heart disease?

1.5 AIM OF STUDY.

The aim of this research is to gain insight into nurses’ experiences of transition for patients with CHD, with particular emphasis on education of patients and their parents.

1.6 RESEARCH OBJECTIVES

The main objectives of this study are:-

- To gain an understanding of nurses’ experiences and knowledge of transition and CHD.
- To explore the experience of nurses in relation to educating patients with CHD (and their parents) on transition and CHD.
- To ascertain nurses views of their role in transition.
- To uncover any barriers, that may exist within practice, to successful transition.
CHAPTER 2

Research Methodology

According to Burns and Grove (2001) the total approach of a study, from recognising a question or problem, to developing a plan for answering the question is known as research methodology. This includes selecting participants, data collection, data analysis and dissemination.

2.1 DESIGN / PROPOSED METHOD

As previously discussed, the aim of this research is to gain insight into nurses’ perceptions and experiences of transition for patients with CHD, with particular emphasis on their role in educating patients. It is proposed to adopt a qualitative approach to gather this information.

Qualitative methods are particularly suitable for exploring individuals knowledge and experience of health issues (LoBiondo-Wood & Haber 2002) and are favoured when the aim of the study is to encapsulate the dynamic human experience in its entirety (Polit and Beck 2006).

This study will follow a qualitative phenomenology design as this approach is preferable when a study looks to obtain insight into the lived experience of the participants (Burns and Grove 2009). In research a topic is explored using a qualitative approach if the aim of the research is to understand the behaviour and acuity of the participants (Parahoo 2006). A phenomenology approach highlights, in each participants own words, their unique understanding of the research topic and any experiences they may have encountered (Parahoo, 2006:68). Phenomenology is relevant when the researcher wishes to gather data of life experiences from participants who have lived them (Gerrish and Lacey 2006).
As this proposal seeks nurses’ perceptions and experiences of transition for adolescents with CHD a qualitative phenomenology approach was chosen as it is the best method to explore this topic and gain insight into each nurses’ unique experiences and perceptions.

2.2 **POPULATION SAMPLE**

Population can be defined as the total group of people that meet the requirements for a particular research study (Polit and Beck 2006). A sample, or study population, is the portion of the population selected for the study (Gerrish and Lacey 2006). In this case the sample consists of registered Childrens’ nurses (RCN), employed in a paediatric cardiac unit of a Leinster hospital meeting the criteria listed below.

Small samples, very carefully and prudently selected, are preferable in qualitative research due to the detailed nature of the research and the comprehensive analysis of data required (Carr 1994). Purposive sampling is used in order to gain access to RCNs with sufficient knowledge and experience in the area being researched (Parahoo 2006). According to Burns and Grove (2001) purposive samples are particularly suitable to newly explored topics for research. A small purposive sample of 10 RCNs’ will be recruited for this research. Two participants will be randomly selected, from this sample, for a pilot study, the reason for this will be outlined further in section 2.3.

Inclusion criteria, the attributes required for defining members of the population (Burns and Grove 2001), are:-

1. Nurses must be Registered Childrens’ Nurses (RCN) working, in a paediatric cardiology ward for a minimum of 6 months.

2. Nurses must be native English speakers to reduce the risk of ambiguity and misunderstanding during data analysis.

Exclusion criteria: Agency nurses, student nurses and newly qualified nurses (i.e. qualified within 6 months prior to the start of the study)

Permission to gain access to participants will first be sought from the Research Ethics Committee in Trinity College Dublin and the Hospital Ethics Board (appendix 2).
Following this it is proposed to seek approval for the study from the Director of Nursing at the hospital (appendix 3) and the manager of the cardiology ward (appendix 4).

Once permission is granted it is proposed to erect a letter of invitation (appendix 6) in the nurses’ station on the cardiac ward and in the nurses’ break room. This letter will outline the research aims and offer assurance of both confidentiality and anonymity. It is intended to send a separate letter (appendix 5) to the Cardiac Nurse Specialist (CNS) seeking their assistance to encourage nurses on the ward to read this letter of invitation.

The invitation letter will also direct potential participants to a box of information packs (appendix 7) available for all nurses’ to read and take one if they wish. Each pack will contain a more detailed letter of invitation thanking the participant for their interest in the study (appendix 7.1), a form for contact details (appendix 7.2) and a copy of a consent form (appendix 7.3) which will be explained and signed at the time of the interview. It is intended to give extra copies of this pack to the CNS and to ask their assistance to hand them out if needed.

It is proposed to place a red box marked ‘Research Study’ in the nurses’ station. The invitation letter will direct potential participants to complete their contact information form (appendix 7.2) and place it in this red box before the date mentioned on the invitation letter. This box will be collected, by the proposed researcher after the date stated. A stamped addressed envelope, with the proposed researchers address, will be included in each information pack to allow potential participants an alternative way to return their contact form.

2.3 **DATA COLLECTION**

Data will be collected using face to face, semi structured interviews. This means that the interview topic is predetermined but the questions are open ended. Semi structured interviews offer a degree of flexibility to explore issues not anticipated, by allowing the researcher to reword the question while keeping the same meaning. However, it also prevents the researcher from relinquishing control and direction of the interview (Gerrish and Lacey 2006, Parahoo 2006).
Each interview will be taped on a dictaphone, this will be explained to the participant and their consent sought prior to starting the recording. A field journal will also be used to take written notes of any observations made by the interviewer. All data collected will be stored in accordance with the Data Protection Act (Government of Ireland 2003) and destroyed once results have been formulated and written up.

In semi-structured qualitative research every interview will differ slightly as the questions and probes the researcher asks are guided by the response of the interviewee (Parahoo 2006). The aim of qualitative research is to gain insight into all eventualities of experience and perceptions of the topic being study (Parahoo 2006). In this case information retrieved in each interview is built on during the next interview (Parahoo 2006).

The researcher will transcribe all interviews verbatim, from the dictaphone onto paper. This will ensue immediately after the interview and any notes taken throughout the interview, e.g. the tone of the participants voice, will be entered into the margin of the transcript. This is to allow the researcher to identify areas which may need to be explored more in the next interview (Parahoo 2006). While interview questions will not be omitted or adjusted the researcher can ask probes such as ‘can you elaborate on that point further’ to thoroughly explore the topic.

In order to build a rapport and trust with the participants, the researcher needs to be involved in the interview process and should have knowledge of the topic being researched. However, to ensure that the researcher obtains an accurate insight of the issues and to prevent any personal bias from affecting the research it is proposed to use ‘bracketing’ and continuous reflexivity, i.e. putting their assumptions aside during data collection and analysis in order to accurately identify and report the participants true experiences (Aherne 1999). Reflexivity is a similar process to reflection and can include keeping a field journal of what was said, how it was said and what was seen (Gerrish and Lacey 2006). This information is used, along with the audio tape, to interpret the experiences and perceptions of the participants.

Permission will be sought, from the Director of Nursing and the ward manager, for interviews to take place during the participants working shift. Prior to arranging interview times consultation will be made, with the ward manager, regarding times causing the least disruption to the ward routine. It is proposed to facilitate participants who wish to attend the interview outside working hours by arranging the interview at a time convenient for them. Scheduling of interviews will take place upon receipt of contact information forms.
It is anticipated that permission will be obtained to hold interviews in a quiet, comfortable, well ventilated and appropriate room within the hospital but outside the paediatric cardiac ward. A DO NOT DISTURB sign will be placed on the door to ensure no interruptions. It is proposed that each interview will last 45 - 60 minutes. A full interview schedule is outlined in appendix 7.

2.4 PILOT STUDY

A pilot study will take place prior to the research study. Two participants from the sample of 10 will be randomly selected for this pilot study. The pilot study will test the proposed study as participants are from the same sample, interviews will take the same format and be held in the same room, and the data collection and analysis will be done in the same way as proposed for the study (Burns & Grove 2009). This will allow the researcher to review all the variables and methods of the proposed study and ensure they are valid.

The purpose of this pilot study is to test the research method, to ensure the interview schedule and questions are both feasible and comprehensible. Pilot studies are also required to ensure the research question are understood and answerable, to test the validity and reliability of the methodology and the sample selected for the research (LoBiondo-Wood and Haber 2002).

Additionally, pilot studies are included in the research process to ensure all research tools and equipment are working properly. The researcher is one of the main tools in qualitative research and the pilot studies allows examination of the researchers ability to bracket and reflect in order to ensure results are accurate and assess if the interview process time scale is accurate. Data obtained during this pilot study can be used to test the data analysis process however none of this data will be used in the findings or outcomes of the main study.

All data from the pilot study will be held in accordance with the Data Protection Act (Government of Ireland 2003) and destroyed upon completion of the study.
2.5 **RIGOR AND TRUSTWORTHINESS OF STUDY**

Qualitative research, using interview methods, involves asking participants questions about the chosen topics. The interviewer is one of the main tools in this process. Each interview is unique. In order to ensure rigor and trustworthiness the researcher proposes the following:

As discussed in section 2.3 the researcher will endeavour to use bracketing and continuous reflexivity during data collection and analysis to minimise the risk of their own bias distorting the outcome of the research.

All interviews will be transcribed verbatim from audio tape and details such as tone of voice and field notes will be noted in the margins. These field notes will be included when analysing the data and will add to the results of the study. It is proposed to solicit randomly selected participants, to read their own transcript to ensure their views are accurately portrayed.

The use of a pilot study, outlined in section 2.3, is also a tool to ensure rigor and trustworthiness of the study.

2.6 **DATA ANALYSIS**

Data analysis of phenomenology studies aims to discover the true meaning of the phenomenon being studied. It is proposed to use Colaizzi (1978) seven steps method to identify and conceptualise the views and perceptions of participants.

These steps are as follows (Parahoo 2006, Polit & Beck 2006)

1. The researcher thoroughly reads all transcripts to develop an understanding and feeling for them.
2. ‘Significant statements’ are taken from each transcript.
3. ‘Formulated meanings’ are taken from each significant statement.
4. Meanings are grouped into themes to reveal common patterns in data.
5. All results obtained in steps 1-4 are integrated into an ‘exhaustive description’ of the phenomenon being studied.

6. Create a detailed description of the phenomenon being studied in as explicit a statement of identification as possible.

7. Participants are asked to validate the findings to ensure nothing is omitted and they accurately portray their views.

As discussed previously bracketing and reflexivity will continue throughout the analysis process to reduce the risk of the researchers preunderstanding and prior knowledge about the phenomenon affecting the results of the study.

It is proposed that this research will identify generalised views from nurses who have experienced transition of adolescents with CHD. During analysis the researcher will endeavour to differentiate between views pertinent to all participants and those that apply to particular participants only. Although individual views are fundamental to identify with the participants lived experience, they have limited use when looking at the views of a population (Ayres et al. 2003).

2.7 ETHICAL CONSIDERATIONS

In order to safeguard participants and their human rights, the proposed research will only commence when written approval is received from the appropriate ethics boards. Basic human rights which need to be protected in research include, the right to:- self determination, respect, privacy and dignity, protection from harm, protection from exploitation, confidentiality and anonymity, full disclosure to allow informed voluntary consent and the right to fair treatment (Polit & Beck 2006).

It is proposed to obtain ethical consent for this study from the college and hospitals’ Ethics Research Board, the Director of Nursing at the hospital and the ward manager. A signed informed consent form will be acquired from all participants prior to interview and interviews will be held in the hospital as this is where the phenomenon takes place and should be a place where participants feel safe. The aims and objectives of the research, and the format of the interview process, will be explained to ensure each participant can
give informed consent. Moreover all participants will be assured that they can opt out of the research at any stage without any explanation.

Informed consent forms will be completed by participants before the interview is started. According to Polit & Beck (2006) informed consent is routed within the ethical belief of respect for human dignity and total disclosure. Each participant will be treated with the utmost of respect during the study and they will have total control on what to say or whether to refuse to partake at any given time.

In order to protect participant’s anonymity it is proposed that pseudonyms will be used in all findings and the name of the hospital will not be mentioned in results. Confidentiality will be maintained by keeping all paperwork, tapes and journals safe and restricting access of same to the researcher. As discussed previously data will be held in accordance with the Data Protection Act (Government of Ireland 2003) and will be destroyed once results have been gathered and written up.

Throughout the interview process the researcher will endeavour to avoid interruptions and show respect to the participant at all times.
CHAPTER 3

3.1 PROPOSED OUTCOME OF THE STUDY

It is proposed to produce a written report outlining the findings and highlighting nurses’ views of their experiences of transition for adolescents with CHD. It is hoped that this report will provide details of nurses’ perceptions of their role in the transition process, any factors which inhibit or promote transition and any support required to allow nurses to provide transition services for adolescents with CHD.

Moreover, it is proposed that this study will form the basis of future studies, on this topic, in Ireland and further highlight previous research which identifies the importance of structured transition programs for CHD patients. The researcher anticipates that the results of this study may facilitate the introduction of education for nurses, which will be facilitated by Cardiac Nurse Specialist, on transition for adolescents with CHD.

It is predicted that findings from this study will be disseminated in the following way

- Presented at national and international nursing conferences,
- Published in acclaimed nursing journals,
- Highlights of the report published in Heart Children Ireland’s publication which is issued to families of children with CHD and adults with CHD,
- Presented to Cardiac Nurse Specialist and nurses working on cardiac wards,
- Creating a poster outlining the highlights of the study and placing it on cardiology wards.

3.2 TIME SCALE FOR RESEARCH

The proposed time scale this research is eighteen months. The details of this time scale are outlined on the Gantt scale in appendix 8.
3.3 **BUDGET**

The proposed budget for this research is outlined in appendix 9. In order to apply for funding it is important to define an approximate budget. Moreover, by having a budget in place the researcher can plan their study around allocated resources (Polit and Beck 2006).
Reference List


Department of Health UK (2006) Adult Congenital Heart Disease: A commissioning guide for services for young people and grown-ups with Congenital Heart Disease (GUCH). Retrieved from


from pediatric cardiology to and adult congenital heart disease program. *Journal of Adolescent Health* **44**(4), 316-322.


APPENDICES
Appendix 1

Summary of literature used in literature review
APPENDIX 2

Letter to the Research Ethics Committee
Dear Mr Chairman,

My name is XXXXX and I am in fourth year of a BSc (cur) in General and Childrens’ nursing at Trinity College, Dublin. One of the requirements for this course is to conduct a research proposal. I am proposing to carry out a qualitative research study on: ‘Nurses’ perceptions and experiences of transition for adolescents with congenital heart disease’. I have enclosed a copy of the research proposal for your attention and I am seeking your approval to conduct this research in XXXX hospital.

I hope to conduct 10 semi structured interviews, the first 2 will form a pilot study which is proposed to take place one month before the actual study. It is anticipated that each interview will take 45 - 60 minutes, and the entire interview will be audio recorded, transcribed verbatim and the data collected and sorted into themes and written up. I hope that the results of this research will be disseminated at nursing conferences and lectures, in nursing journals and through posters placed in hospitals. Furthermore, it is hoped that this study will assist future research, practice development and nurse education. All data gathered during the study will be held in accordance with the Data Protection Act 2003 and destroyed once findings are concluded and written up. Ethical approval will be sought prior to conducting any interview.

Participants in this study will be English speaking Registered Childrens’ nurses working full-time on a paediatric cardiac ward. I would like to seek approval to conduct interviews during the participants shift and in a suitable quiet and private room within the hospital. Prior to setting times for the interviews I will consult with the ward manager to obtain suitable times which will cause the least disruption to the ward.

I hope to solicit the assistance of the Cardiac Nurse Specialist to encourage nurses’ to read the invitation letter and take a information pack if they are interested in finding out more information. A copy of this pack is enclosed and it contains a letter thanking the nurse for their interest and an outline of the study, a form for their contact details and availability for interview and a copy of an informed consent form (this will be explained and filled on the day of interview). The letter of invitation will show that confidentiality and anonymity will be upheld at all times and the participants will be assured that they can opt out of the study at any time.

I would like to thank you for taking the time to read the enclosed proposal and would greatly appreciate it if you would consent to this research. If you have any questions or require any further information do not hesitate to contact me at the above address.

Yours sincerely,

_____________

XXXXX XXXX
APPENDIX 3

Letter to the Director of Nursing
21/02/2011

Dear Director of Nursing

My name is XXXXX and I am in fourth year of a BSc (cur) in General and Childrens’ nursing at Trinity College, Dublin. One of the requirements for this course is to conduct a research proposal. I am proposing to carry out a qualitative research study on: ‘Nurses’ perceptions and experiences of transition for adolescents with congenital heart disease’.

I have enclosed a copy of the research proposal for your attention and I am seeking your approval to conduct this research in your hospital.

I hope to conduct 10 semi structured interviews, the first 2 will form a pilot study which is proposed to take place one month before the actual study. It is anticipated that each interview will take 45 - 60 minutes, and the entire interview will be audio recorded, transcribed verbatim and the data collected, sorted into themes and results written up. I anticipate that the results of this research will be disseminated at nursing conferences and lectures, in nursing journals and through posters placed in hospitals.

Furthermore, it is hoped that this study will assist future research, practice development and nurse education. All data gathered during the study will be held in accordance with the Data Protection Act 2003 and destroyed once findings are concluded and written up. Ethical approval will be sought prior to conducting any interview.

Participants in this study will be English speaking Registered Childrens’ Nurses working full-time on the paediatric cardiac ward. I would like to seek approval to conduct interviews during the participants shift and in a suitable quiet and private room within the hospital. Prior to setting times for the interviews I will consult with the ward manager to obtain suitable times which will cause the least disruption to the ward.

I hope to solicit the assistance of the Cardiac Nurse Specialist to encourage nurses’ to read the invitation letter and take a information pack if they are interested in finding out more information. A copy of this pack is enclosed and it contains a letter thanking the nurse for their interest and an outline of the study, a form for their contact details and availability for interview and a copy of an informed consent form (this will be explained and filled on the day of interview). The letter of invitation will show that confidentiality and anonymity will be upheld at all times and the participants will be assured that they can opt out of the study at any time.

I would like to thank you for taking the time to read the enclosed proposal and would greatly appreciate it if you would consent to this research. If you have any questions or require any further information do not hesitate to contact me at the above address.

Yours sincerely

____________________

XXXXXXXXX XXXXXX
APPENDIX 4
Letter to the Manager of the cardiology ward
Dear XXXXXX

My name is XXXXX and I am in fourth year of a BSc (cur) in General and Childrens’ nursing at Trinity College, Dublin. One of the requirements for this course is to conduct a research proposal. I am proposing to carry out a qualitative research study on: ‘Nurses’ perceptions and experiences of transition for adolescents with congenital heart disease’. I have enclosed a copy of the research proposal for your attention and I am seeking your approval to conduct this research with nurses on your ward.

I hope to conduct 10 semi structured interviews, the first 2 will form a pilot study which is proposed to take place one month before the actual study. It is anticipated that each interview will take 45 - 60 minutes, and the entire interview will be audio recorded, transcribed verbatim and the data collected, sorted into themes and written up. I anticipate that the results of this research will be disseminated at nursing conferences and lectures, in nursing journals and through posters placed in hospitals. Furthermore, it is hoped that this study will assist future research, practice development and nurse education. All data gathered during the study will be held in accordance with the Data Protection Act 2003 and destroyed once findings are concluded and written up. Ethical approval will be sought prior to conducting any interview.

Participants in this study will be English speaking, Registered Childrens’ Nurses working full-time on the cardiac ward. I would like to seek approval to conduct interviews during the participants shift and in a suitable quiet and private room within the hospital. Prior to setting times for the interviews I will consult with you to obtain suitable times which will cause the least disruption to the ward.

I hope to solicit the assistance of the Cardiac Nurse Specialist to encourage nurses’ to read the invitation letter and take an information pack if they are interested in finding out more information. A copy of this pack is enclosed and it contains a letter thanking the nurse for their interest and an outline of the study, a form for their contact details and availability for interview and a copy of an informed consent form (this will be explained and filled on the day of interview). The letter of invitation will show that confidentiality and anonymity will be upheld at all times and the participants will be assured that they can opt out of the study at any time.

I would like to thank you for taking the time to read the enclosed proposal and would greatly appreciate it if you would consent to this research. If you have any questions or require any further information do not hesitate to contact me at the above address.

Yours sincerely

________________

XXXXX XXXXX
APPENDIX 5

Letter to the Cardiac Nurse Specialist
Dear XXXXXX

My name is XXXXX and I am in fourth year of a BSc (cur) in General and Childrens’ nursing at Trinity College, Dublin. One of the requirements for this course is to conduct a research proposal. I am proposing to carry out a qualitative research study on: ‘Nurses’ perceptions and experiences of transition for adolescents with congenital heart disease’. I have enclosed a copy of the research proposal for your attention and I am seeking your assistance to encourage nurses to read the invitation letter at either the nurses’ station or the break room and to take an information pack if they wish to participate in this study or require more information.

I hope to conduct 10 semi structured interviews, the first 2 will form a pilot study which is proposed to take place one month before the actual study. It is anticipated that each interview will take 45 - 60 minutes, and the entire interview will be audio recorded, transcribed verbatim and the data collected, sorted into themes and results written up. I anticipate that the results of this research will be disseminated at nursing conferences and lectures, in nursing journals and through posters placed in hospitals. Furthermore, it is hoped that this study will assist future research, practice development and nurse education. All data gathered during the study will be held in accordance with the Data Protection Act 2003 and destroyed once findings are concluded and written up. Ethical approval will be sought prior to conducting any interview.

Participants in this study will be native English speaking registered childrens’ nurses working fulltime on the cardiac ward for a minimum of six months. Due to potential lack of experience, agency and nurses qualified within the last 6 months will be excluded. I hope to gain approval to conduct interviews during the participants shift and in a suitable quiet and private room within the hospital.

I have enclosed a sample information pack containing a letter thanking the nurse for their interest and inviting them to participate in the study, an outline of the study, a form for their contact details and availability for interview, and a copy of informed consent form that will be explained and filled on the day of interview. The letter of invitation shows that confidentiality and anonymity will be upheld at all times and the participants will be assured that they can opt out of the study at any time. It is hoped that this study will assist future research and practice development.

I would like to thank you for taking the time to read the enclosed proposal and I would greatly appreciate your help with this study. Feel free to contact me with any queries on the proposed study.

Yours sincerely

______________

XXXXXXXX XXXXXX
APPENDIX 6

Letter of invite to the participant
Re participation in study

My name is XXXXX and I am in fourth year of a BSc (cur) in General and Childrens’ nursing at Trinity College, Dublin. One of the requirements for this course is to conduct a research proposal. I am proposing to carry out a qualitative research study on: ‘Nurses’ perceptions and experiences of transition for adolescents with congenital heart disease’, and I am seeking your participation in this study. An information pack, with further details on the study, is available in the nurses’ station for anyone who wishes to have more information (the Cardiac Nurse Specialist has extra copies if required).

I am writing to invite you to participate in this research. Participation in the study will involve partaking in a 45-60 minute semi-structured interviews (I hope to gain permission, from the ward manager, to carry out interviews during a day you are on duty). The purpose of this interview is to gain an insight into your experiences and perceptions of transition for adolescents with congenital heart disease and also your role in this transition. The entire interview will be audio recorded, transcribed verbatim and the data collected sorted into themes and written up. The results will be disseminated in nursing journals, at nursing conferences and discussed with all participants along with nursing staff in cardiology units nationwide. It is anticipated that the results of this study will contribute to future research in this area and assist the development of nurse education and practise development. Ethical approval will be sought prior to conducting any interview.

Confidentiality and anonymity will be upheld at all times. Pseudonyms will be used and your name or the hospitals name will only be known to the researcher. All data gathered during the study will be held in accordance with the Data Protection Act 2003 and destroyed once findings are concluded and written up. If you decide to participate you can choose to withdraw from the study at any time.

If you wish to participate in this study, or if you require further details, please feel free to take an information pack, located in the nurses’ station, fill out your contact details on the enclosed form and place it in the red box marked ‘Research Study’ in the nurses’ station before DD/MM/YY. Following receipt of this form, I will contact you to answer any further queries you may have. I will then organise an interview at a time convenient for you and within the times agreed with the ward manager for the interviews. However, if you would prefer to do the interview outside your working day this can also be arranged.

I would like to thank you for taking the time to read the enclosed information and would greatly appreciate your participation in this study. Feel free to contact me with any queries on the proposed study.

Yours sincerely

____________________

XXXXX XXXXX
APPENDIX 7
Information Pack for potential Participants

This consists of

7.1 Letter of invitation and thanks.

7.2 Form for contact details

7.3 Consent Form
APPENDIX 7.1

Letter of invitation and thanks.
21/02/2011

Dear XX

Thank you for taking the time to read the information on this study and also for your interest in participating. I hope that you will participate as I feel this research study is pertinent to your area of work. Please find below a brief background on why I feel this study is important and also an outline of the proposed study.

**Background to this study:**

Research shows that over 50% of adolescents with congenital heart disease (CHD) will experience sequelae and complications due to their disease. These include arrhythmias, endocarditis, congestive heart failure, pulmonary vascular disease and sudden death. Owing to this high risk of complications, education of adolescents with congenital heart disease (CHD) on their disease and the importance of follow up care as adults is vital. Alarming research has also shown that education, and effective transition programs, for this patient group is lacking resulting in less than 50% of adolescents with CHD being successfully transferred to adult services.

While education is highlighted as a fundamental attribute of transition programs and nurses’ are identified as being in a prime position to offer this education, a dearth of research exists on nurses’ opinions of their perception and experience of this vital role. For this reason, this research proposal will endeavour to identify nurses’ experience and perceptions of transition for adolescents with CHD with particular emphasis on education of patients and their parents.

**Brief Outline:**

The main objectives of this study are:-

- To gain an understanding of nurses’ experiences and knowledge of transition and CHD.
- To explore the experience of nurses in relation to educating patients with CHD (and their parents) on transition and CHD.
- To ascertain nurses views of their role in transition
- To uncover any barriers, that may exist within practice, to successful transition.
Method: The methodology chosen to explore this topic is a qualitative phenomenology approach. Data collection will take the form of semi-structured, face-to-face interviews. An audio recording of each interview will take place and the researcher will also keep a field journal with written notes (all data and notes will be held in accordance with the Data Protection Act 2003 and destroyed once results are written up).

Sample – It is proposed that a purposive sample of 10 registered nurses, working on a paediatric cardiology ward in a large teaching hospital in Leinster, will be recruited. Confidentiality and anonymity will be upheld at all times. Pseudonyms will be used and your name or the hospital’s name will only be known to the researcher. Ethics approval will be sought prior to starting this research and informed consent obtained from each participant.

Data Analysis - It is proposed that data collection and analysis will occur simultaneously. The researcher will endeavour to continuously reflect on their own participation in interview processes along with randomly selecting participants to read transcripts of interviews in order to ensure rigour and trustworthiness is maintained. Data will be analysed using Colaizzi (1978) method of analysing interview transcripts in qualitative research.

Findings - It is proposed that findings will identify nurses’ experiences and perceptions of transition and that these findings will assist with future research, nurse education and practice development for nurses working with adolescents with CHD.

I have put my email address and phone number at the top of this letter and please feel free to contact me on either if you have any further queries. If you want to participate you can contact me by email or phone listed above or alternatively fill out your contact details on the enclosed form and place it in the red box marked ‘Research Study’ in the nurses’ station before DD/MM/YY. I will organise the interview at a time convenient for you and within the times agreed with the ward manager for the interviews. However, if you would prefer to do the interview outside your working day this can also be arranged.

I hope this letter answers any queries you may have and it will encourage you to participate in this study. Just to reiterate that if you decide to participate you can choose to withdraw from the study at any time with no questions asked. I would like to thank you again for taking the time to read the enclosed information and would greatly appreciate your participation in this study.

Yours sincerely

__________________________

XXXXXX XXXXX
APPENDIX 7.2 –

Form for contact details
Contact Information

Name:___________________________________________________

Phone Number:______________ (mobile) _____________ (home)

Email address:____________________________________________

Ward:________________________________________________________

Current Position (e.g staff nurse, manager, cardiac nurse specialist)
________________________________________________________

Length of time qualified: _____(months)  _____ (years)

Length of time working on cardiac ward: ____ (months)  _____ (years)

Please tick appropriate box for following questions:-

1. Are you employed Fulltime?     Yes ☐     No ☐

2. Is your position           Permanent ☐      Temporary ☐      Bank ☐

3. Are you a native English speaker?     Yes ☐     No ☐

4. Would you prefer to attend for interview

During working hours    ☐    Outside working hours    ☐

It is proposed that interviews will take place during the month of xxxxxx. If you wish to attend for interview during your working day and you know your roster for this month can you please provide dates available

_________ / ___________ / ___________ / ___________ / ___________

Alternatively if you would prefer to attend outside work please provide a list of days which are convenient for you.
APPENDIX 7.3

Informed Consent
Consent Form

I have received your invitation to participate in your qualitative study on Nurses’ experiences and perceptions of transition for adolescents with Congenital Heart Disease. I understand all the information and feel I am adequately informed on the aims of your research and the interview process. I also understand that all interviews will be taped and subsequently transcribed and all information I offer will be kept confidential and securely by the researcher. I have been informed that my anonymity will be protected by the use of pseudonyms.

It has been explained to me that my participation is voluntary and I can opt out of the study at all times and that there are no risks or benefits to participation in this study.

I ___________________ have read the above invitation and believe I fit the criteria and wish to partake in your study on “Nurses’ experiences and perceptions of transition for adolescents with Congenital Heart Disease.”

I understand that by signing this form I am ensured my anonymity will be upheld and all information furnished will be totally voluntary and confidential.

I understand that I can withdraw from this study at any given time if I wish to do so.

Signature of Participant ________________________________

Signature of interviewer ________________________________

Date ________________________________
APPENDIX 8

Interview Schedule
Location:- quiet, comfortable and well ventilated room. Sign – ‘Do Not Disturb – interview in process’ placed on outside of door,

Expected Length of interview – 60 – 90 minutes

Opening the interview – Introductions, welcome the participant, thank them and build rapport and trust to relax them. Advise on consent, anonymity and options to opt out at any time. Offer refreshments and ask if they have any questions.

Explain that questions are open ended and semi structured to allow for discussion and exploration of topics of interest which may arise during interview. Each question should take approx 20-30 minutes.

Question 1 – What is your understanding of transition for adolescents with CHD?

Probes: - difference between transfer and transition
  
  At what age should it start?
  
  Who is responsible for transition programs? (CNS / CLN / all nurses / All healthcare staff)
  
  What are the aims of transition?

Question 2 - Can you share with me your experience of transition for adolescents with CHD

Probes:- what level of priority in nursing care?
  
  Your comfort level/knowledge level on CHD and transition
  
  How much time is required / part of every encounter with patients with CHD?
  
  Adolescents level of knowledge/autonomy and parents knowledge?
  
  One to one with adolescent or parent and adolescent together?

Question 3 – What do you perceive as your role in transition?

Probes:- Educator - disease, lifestyle, complications
  
  Facilitator - for follow up in adult services, (you mentioned follow up, can you elaborate on that?)
  
  Encourager – encouraging adolescents to take ownership of their health
  
  Learner – your level of knowledge, level of support and training available

Question 4 – In your experience what factors can affect successful transition

Probes:- Factors which may inhibit or enhance success of transition
  
  Parents protective of children?
  
  Environment – busy ward environment - time available, suitable location
  
  Nurses knowledge level – accurate information

Conclude Interview –

Thank the participant for their time and input.

Ask them if they are happy with their input and if there is anything else they would like to add.

Enquire if they would be available to look over the findings of the study, prior to disseminating results, to confirm them.
APPENDIX 9

Time scale
**Time Scale – 18months Gantt scale in appendices**

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<th>Literature Review</th>
<th>Research Design</th>
<th>Ethical Approval</th>
<th>Sample Recruitment</th>
<th>Pilot Study</th>
<th>Data Collection</th>
<th>Data Analysis</th>
<th>Findings</th>
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APPENDIX 10

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