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Description and initial evaluation of an educational and psychosocial support model for adults with congenitally malformed hearts

Short title: Education and psychosocial support for congenitally malformed hearts

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Keywords: Patient education, information, hospital outpatient clinic, nursing, computer-based education, Competence based education

Abstract

Objective: Various programmes for adults with congenitally malformed hearts have been developed, but detailed descriptions of content, rationale and goals are often missing. The aim of this study was to describe and make an initial evaluation of a follow-up model for adults with congenitally malformed hearts, focusing on education and psychosocial support by a multidisciplinary team (EPS).

Methods: The model is described in steps and evaluated with regards to perceptions of knowledge, anxiety and satisfaction.

Results: The EPS model included a polyclinic visit to the physician/nurse (medical consultation, computer-based and individual education face-to-face as well as psychosocial support) and a 1-month telephone follow-up. Fifty-five adults (mean age 34, 29 women) with the nine most common forms of congenitally malformed hearts participated in the EPS model as well as the 3-months follow-up. Knowledge about congenital heart malformation had increased in 40% of the participants at the 3-months follow-up.

Conclusion: This study describes and evaluates a model that combines a multidisciplinary approach and computer-based education for follow-up of adults with congenitally malformed hearts. The EPS model was found to increase self-estimated knowledge, but further evaluations need to be conducted to prove patient-centred outcomes over time.

Practice implications: The model is now ready to be implemented in adults with congenitally malformed hearts.

1. Introduction

Adults with congenitally malformed hearts often have a poor level of knowledge about various aspects of their cardiac condition and there is a lack of educational materials for this group¹⁻⁵. To date, education has often been given as verbal information, complemented with pictures of the heart and copies from medical charts, provided by the responsible cardiologist⁶. Patient education/computer-based education has been shown to increase knowledge and/or management of the disease in people with chronic diseases⁷⁻¹⁰. We have constructed a follow-up model for adults with congenitally malformed hearts that contains medical consultation, education and psychosocial support by a multidisciplinary team (EPS). The aim of this study was to describe and make an initial evaluation of a follow-up model for adults with congenitally malformed hearts, focusing on education and psychosocial support by a multidisciplinary team (EPS).

2. Methods

Adults with uncomplicated congenitally malformed hearts (ventricular septal defect, atrial septal defect, coarctation of the aortae, aortic valve stenosis) and complicated congenitally malformed hearts (tetralogy of Fallot, complete transposition of the great arteries, congenitally corrected transposition of the great arteries, Ebstein anomaly and Eisenmenger syndrome) can be offered the EPS model. The EPS model is described in steps including a visit to the physician/nurse and 1-month telephone follow-up (Table 1). Data were collected from the participants regarding perceptions of knowledge, anxiety and satisfaction related to the EPS model before and after the different steps (Table 2).

Please insert Table 1 and 2 here

3. Results

3.1. Part 1: Visit to the physician

Before the participants received the EPS model, they completed a questionnaire to test their degree of knowledge regarding their cardiac condition; the Knowledge scale for Adults with Congenitally Malformed Hearts (KnoCoMH) (developed from the Leuven Knowledge Scale⁴) and a questionnaire to investigate symptoms of anxiety and depression, Hospital Anxiety and Depression Scale, (HADS)¹¹. The instruments were analysed and the results used in the participant's individual education in part two.

During the visit they underwent clinical evaluations and/or echocardiography and/or exercise tests. Following the evaluations, the physician provided the participants with the results, allowing time for questions.

3.2. Part 2: Visit to the specialised nurse

The next step was the visit to the nurse. First, the education was provided through a computer-based educational program followed by individual education face-to face and psychosocial support.

3.2.1. The computer-based educational program

The computer-based educational program for adults with the ten most common forms of congenitally malformed hearts has been developed and evaluated by a multidisciplinary team and adults suffering from these diseases (table 3). The program was developed as a complement to verbal information in order to gain a more complete understanding of congenitally malformed hearts. All of the ten malformations in the program have their own module. Each module consists of eight main areas and subheadings (Table 4).

The nurse introduced the participant to the computer-based educational program containing information about their particular congenital cardiac malformation. This information was downloaded to a CD. The participant and the nurse started by looking at the cover (Picture 1) and the contents list detailed on the back (Table 4).

On the inside of the cover was the name of the cardiac malformation, the name and year of any surgery, or if they had been recommended endocarditis prophylactics. The physician's or nurse's phone number was also on the cover. The participant then started the computer-based educational program and the nurse demonstrated how to navigate through the main areas (Picture 2) and subheadings (Picture 3). They also looked at an example of the self-conducted test (Picture 4) that ended every main area (Table 4). The participant then ran the entire program on his/her own. Depending on the physician's recommendations of endocarditis prophylactics, the participants included or excluded the main area Endocarditis Prophylactics. The nurse was still around to provide any assistance during the 60 minutes when the participant ran the program

Please insert Table 3 and 4 and Pictures 1-4 here
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3.2.2. Individual education and psychosocial support

The nurse and the participant looked through the results of the knowledge questionnaire, KnoCoMH that had been completed before visiting the physician. They discussed the contents of the computer-based educational program and the questions in the KnoCoMH from the participant's perspective. Through this procedure both the participant and the nurse gained an understanding of the participant's understanding of their malformation and knowledge gaps. The KnoCoMH dealt with areas such as general knowledge about the cardiac condition (name, symptoms, cause/heredity, physical activity) and specific knowledge such as medication, endocarditis prophylactics, contraceptives and pregnancy. The participant's individual need for knowledge was registered by the nurse during the discussion regarding the KnoCoMH and the computer-based educational program.

The next step was to evaluate the need for psychosocial support. This was achieved through 26 questions previously used by Kampuis et al ¹². The questions covered different subjects such as life/health insurance, education, employment, sport, and other daily activities (Table

5). The questions were discussed with the participant and if there were problems the nurse asked if they were related to the malformation. Only problems related to the cardiac condition were registered. The discussion around the participant's situation, cardiac malformation and new knowledge contributed to a willingness and motivation to improve self-care. Individual goals were set, and an individual care plan was developed to reach the goal. All participants were given a contact card for the nurse. The next step was the 1-month follow-up.

If the results of the HADS questionnaire showed symptoms of anxiety/depression (scale score 8-10 = borderline for symptoms of anxiety/depression, >11 clinically significant anxiety/depression ¹¹) the nurse addressed this with the participant and contacted the social worker in the multidisciplinary team. This team consisted of a physiotherapist, dietician, hospital social worker, cardiologist, gynaecologist, anesthesiologist, obstetrician and pediatrician. If needed, the nurse contacted participants in the multidisciplinary team to organise an appointment. The member of the multidisciplinary team who was contacted, was responsible to follow up the participant's goal.

Everyone in the multidisciplinary team remained in contact with the physician in charge in case there were questions regarding the participant's situation in relation to the congenitally malformed heart.

Please insert Table 4 here

3.2.3. One-month follow-up

The nurse phoned the participants as a follow-up one month after the visit to the hospital outpatient clinic. The reason for this follow-up was to check if the participants had any questions, if the goal set had been reached and how to plan for the future. The participants could also make contact with the nurse if needed. Further follow-up was planned according to the participants' situation

3.3. Initial evaluation

Fifty-five adults have passed the EPS model. Mean age was 34 years (range 19-74). Twenty-nine participants were women. Before passing the EPS model, 47 % (25/53) perceived their knowledge of their cardiac condition to be “good” or “excellent”, three months later these numbers had increased to 89 % (41/46). Regarding symptoms of anxiety, 38% (20/52) perceived “some anxiety” or “much anxiety” in connection with their cardiac condition before the EPS model. After three months this remained unchanged (39 % , 18/ 46). Directly after passing the EPS model, 88 % (45/51) perceived their satisfaction with the combination of the visit to the physician and the nurse to be “very good” or “excellent” but after three months this number had decreased to 75 % (33/44) (Table 6).

Please insert Table 6 here

4. Discussion and conclusion

4.1. Discussion

Education and/or psychosocial support have previously been studied in connection with chronic diseases such as heart failure¹³, asthma¹⁴, ischemic heart disease¹⁵) as well as in adults with congenitally malformed hearts¹⁶. Computer-based education and psychosocial support have shown to improve effects in education and self-management programmes¹⁷⁻¹⁸. To the best of our knowledge a model like EPS has never been described before. The EPS model is developed from the theory of constructivism¹⁹⁻²⁰ using a competence-based course design²¹ that includes computer-based, individual education face-to-face and psychosocial support. In accordance with the educational theory of constructivism, the focus of the EPS model is to support adults with congenitally malformed hearts in understanding their cardiac condition, by building the education and psychosocial support on relevance and prior knowledge (competence-based course design)¹⁹⁻²¹. To promote learning and self-management it is important to engage the participant by taking the individual’s perspective rather than the disease perspective^{6 17 22}. The computer-based educational program used in the EPS model

has been developed and tested in accordance with the cognitive theory of multimedia learning and the theory of cognitive load perspective²³⁻²⁴. This means that the program use an easy language text, pictures, animations and sounds to engage the participants in understanding their malformed hearts.

The strengths with our study are: 1) The content of our EPS model is described in detailed to allow thorough understanding of the content and theoretical framework of the intervention and 2) The participants' perceptions are assessed before and 3 months after the EPS model 3) The participants' knowledge is evaluated before the EPS model and 4) The individual education is based on the knowledge evaluation. The psychosocial support was developed from the person's own perspective, i.e. the education and psychosocial support was individually targeted to the personal view. One weakness of our approach was that only adults with the ten most common diagnoses in congenitally malformed hearts could participate in the model. The reason for this was that we chose to start developing the computer-based educational program only for ventricular septal defect, atrial septal defect, coarctation of the aortae, aortic valve stenosis, tetralogy of Fallot, complete transposition of the great arteries, congenitally corrected transposition of the great arteries, single ventricle, Ebstein anomaly and Eisenmenger syndrome.

4.2. Conclusions

This is the first study to describe and evaluate a model combining a multidisciplinary approach and computer-based education as follow-up for adults with congenitally malformed hearts. Our EPS model fulfils the recommendations of international guidelines. Further studies are needed to test the outcomes of the EPS model regarding long-term increase in knowledge and other patient- centred outcomes.

4.3. Practice implications

The model is now ready to be implemented in adults with congenitally malformed hearts.

Competing interests

The authors declare that they have no conflicts of interest.

Authors' contributions

HR initiated and planned the study and drafted the manuscript. ES, AS, and NN participated in the planning of the study and writing the manuscript. All authors read and approved the final manuscript.

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I confirm that all personal identifiers have been removed or disguised so that the person described is not identifiable and cannot be identified through the details of the story.

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Table 1

The flow in the EPS model

Part 1: Visit to the physician
Part 2: Visit to the specialised nurse
The computer-based educational program
Individual education and psychosocial support

EPS model = Education and Psychosocial Support by multidisciplinary team

Table 2

Questions about the participants own perception about their knowledge, anxiety and satisfaction.

How do you perceive your knowledge about your cardiac condition? ^{a,b}

How do you perceive your current anxiety with regards to your cardiac condition? ^{a,b}

How do you perceive your current satisfaction regarding your meeting with a physician and a nurse? ^{c,b}

^a Baseline before EPS model.

^b 3 months.

^c Baseline after visit at the physician/nurse.

Table 3

Modules in the Computer-based Educational Program.

Ventricular septal defect
Atrial septal defect
Coarctation of the aortae
Aortic valve stenosis
Tetralogy of Fallot
Complete transposition of the great arteries
Congenitally corrected transposition of the great arteries
Single ventricle
Ebstein anomaly
Eisenmenger syndrome

Table 4

Eight main areas and their subheadings in each of the 10 modules in the Computer-Based Educational Program

Main areas/Subheadings	Main areas/Subheadings
MY CONGENITAL CARDIAC MALFORMATION	ENDOCARDITIS PROPHYLACTICS
<ul style="list-style-type: none"> - The normal heart - appearance - The normal heart - function - What does my congenital cardiac malformation look like? - How many people have the same congenital cardiac malformation? - Does my congenital cardiac malformation give symptoms? 	<ul style="list-style-type: none"> - What is endocarditis? - I – risk for endocarditis? - When – risk for endocarditis? - How to avoid endocarditis? - What are the symptoms of endocarditis?
Test your knowledge	Test your knowledge
CAUSE AND HEREDITY	MEDICAL AND SURGICAL TREATMENT
<ul style="list-style-type: none"> - Why do I have congenital cardiac malformation? - Is my congenital cardiac malformation hereditary? - Where can I meet other people with congenitally malformed hearts? 	<ul style="list-style-type: none"> - Medical treatment – my congenital cardiac malformation? - Can I stop the medication? - Surgical treatment – my congenital cardiac malformation? - Other treatments for my congenital cardiac malformation?
Test your knowledge	Test your knowledge
CONTRACEPTIVES AND PREGNANCY	EMPLOYMENT AND SPARE TIME
<ul style="list-style-type: none"> - What to think about with regard to contraceptives - Issues when planning a pregnancy - Pregnancy 	<ul style="list-style-type: none"> - Can I do all types of work? - Sport/spare time activities - Risk for my heart when flying? - To think about – when travelling?
Test your knowledge	Test your knowledge
MEDICAL CONSULTATION AND SUPERVISION	SEXUAL ASPECTS AND HEALTH CARE
<ul style="list-style-type: none"> - Why regular check-ups? - Why not operate the congenital cardiac malformation now? - Postoperative check-ups? - When should I contact the doctor? 	<ul style="list-style-type: none"> - Sex life/life together - effects of my congenital cardiac malformation? - My congenital cardiac malformation –self-care issues? - Alcohol, drugs, smoking and moist snuff
Test your knowledge	Test your knowledge

Table 5. Questions during Phase 2; Difficulties in daily life related to the congenital cardiac malformation.

Did you ever feel restricted in your choice of

- educational course?
- job?
- sport?
- hobby?
- house?
- holiday destination

Did you ever give up

- an educational course?
- a job?
- a sport?
- a hobby?
- a holiday?

Did your physician ever advise you not to have children?

Did you ever think it was better not to have children

Were you ever excluded from

- an educational course?
- a job?
- a possible promotion?
- a job after medical examination?
- sports after medical examination?

Were you ever prevented from

- applying for a driving licence?
- taking out a mortgage policy?
- taking out a life insurance policy?
- taking out a health insurance policy?

Did you ever have to pay a higher premium than other people for

- a mortgage?
- a life insurance?
- a health insurance?

Table 6

Perceptions about knowledge, anxiety before/after the EPS model and satisfaction with EPS model at baseline and after 3 months, presented in numbers and percentage.

How do you perceive your knowledge about your cardiac condition?							
	Excellent	Very good	Good	Fairly good	Poor	Very poor	Total
Baseline ^a	2 (3,8)	9 (17,0)	14 (26,4)	21 (39,6)	5 (9,4)	2 (3,8)	53
3 months	5 (10,9)	22 (47,8)	14 (30,4)	5 (10,9)	0	0	46
How do you perceive your current anxiety with regards to your cardiac condition?							
	No anxiety at all	Very little anxiety	Some anxiety	Moderate anxiety	Very much anxiety		Total
Baseline ^a	11 (21,2)	21 (40,4)	12 (23,1)	6 (11,5)	2 (3,8)		52
3 months	13 (28,3)	15 (32,6)	17 (37)	1 (2,2)	0		46
How do you perceive your current satisfaction regarding your meeting with a physician and a nurse?							
	Excellent	Very good	Good	Fairly good	Poor	Very poor	Total
Baseline ^b	15 (29,4)	30 (58,8)	6 (11,8)	0	0	0	51
3 months	10 (22,7)	23 (52,3)	10 (22,7)	1 (2,3)	0	0	44

() = percentage.

^a = before the EPS model.

^b =after visit at the physician/nurse.



Picture 1: Cover of the Computer-based Educational Program.

Information för vuxna med medfött hjärtfel

1. Mitt hjärtfel

Hjärtats normala utseende
Hjärtats normala funktion
Hur ser mitt hjärtfel ut?
Hur många har mitt hjärtfel?
Brukar mitt hjärtfel ge symptom?
Testa dina kunskaper

3. Preventivmedel, graviditet

Att tänka på vid preventivmedel
Vad händer om jag vill ha barn?
Graviditet
Testa dina kunskaper

5. Endokardit profylax

Vad är endokardit?
Jag - risk för endokardit?
När - risk för endokardit?
Hur undvika endokardit?
Vilka symptom ger endokardit?
Testa dina kunskaper

7. Arbete och fritid

Kan jag arbeta med vad jag vill?
Sport/fritidsaktiviteter
Risk för mitt hjärta vid flygning
Att dränka på - vid resor
Testa dina kunskaper

2. Orsak / ärftlighet

Varför fick jag ett medfött hjärtfel?
Är mitt hjärtfel ärftligt?
Var kan jag träffa andra?
Testa dina kunskaper

4. Läkarkontakt och kontroller

Varför regelbundna kontroller?
Varför inte operera hjärtfelet nu?
Efter operation - slutkontrollerat?
När ska jag kontakta läkare?
Testa dina kunskaper

6. Behandling

Medicinsk behandling - mitt hjärtfel
Kan jag sluta med medicinen?
Kirurgisk behandling - mitt hjärtfel
Andra behandlingar för mitt hjärtfel
Testa dina kunskaper

8. Sex och samliv, friskvård

Påverkas sex/samliv av mitt hjärtfel?
Mitt hjärtfel - vad kan jag göra?
Alkohol, droger, rökning och snus
Testa dina kunskaper

Information för vuxna med medfött hjärtfel



Information för vuxna med medfött Hjärtfel

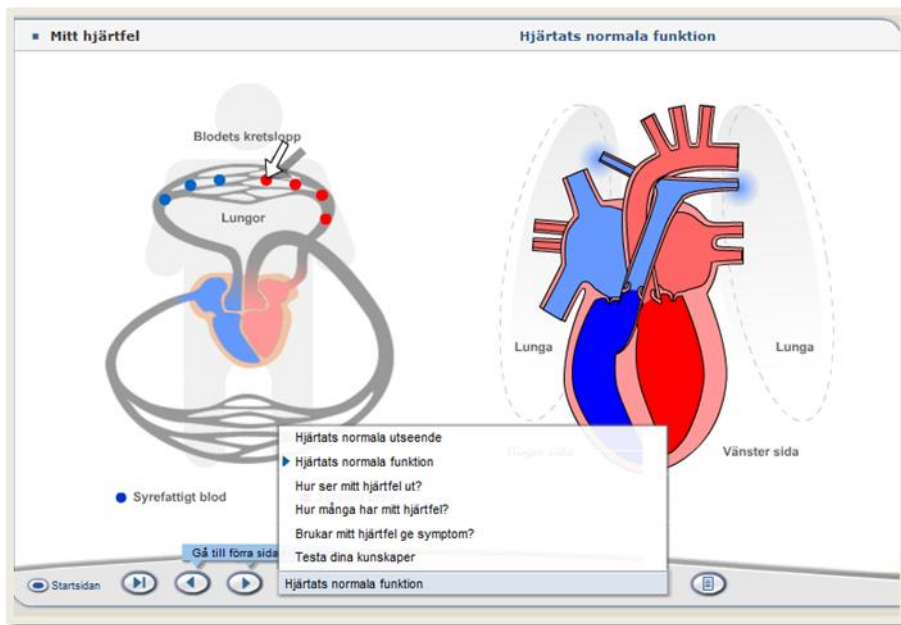
Fallosts tetrad

- Mitt Hjärtfel
- Orsak, ärftlighet
- Preventivmedel, graviditet
- Läkarkontakt och kontroller
- Endokardit profylax
- Behandling
- Arbete och fritid
- Sex och samliv, friskvård
 - Öppna artikeln för ditt hjärtfel

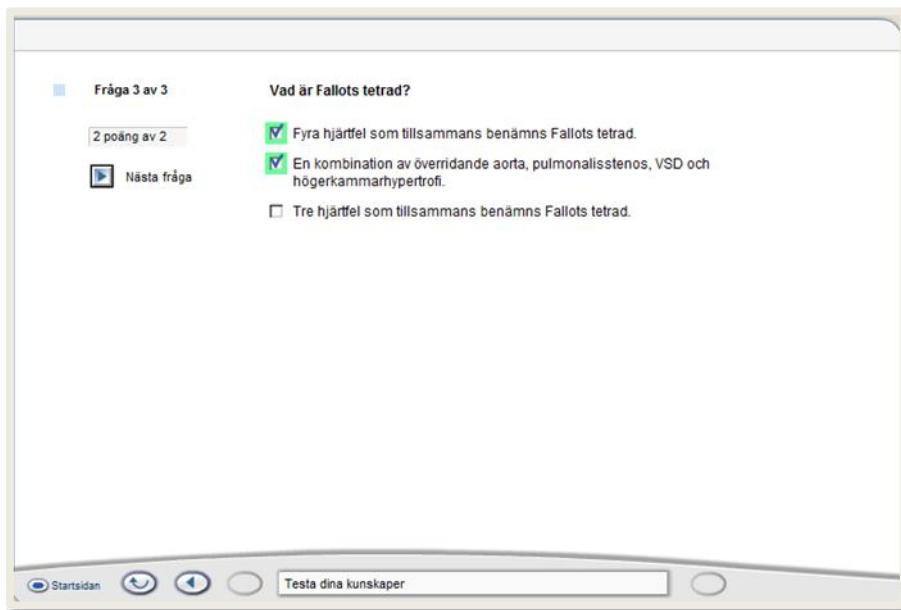
■ Hjälp ■ Om Programmet



Picture 2: The main areas in the Computer-based Educational Program.



Picture 3: Example of how to navigate in the subheadings in the Computer-based Educational Program.



Picture 4: Example of the self-conducted test in the Computer-based Educational Program.