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ORIGINAL RESEARCH

Education and support needs of the older adult with congenital heart disease

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Abstract

Aim. This article is a report of a study exploring health-related quality of life in adults with congenital heart disease and the extent to which it is associated with patients' illness beliefs and emotional health.

Background. A reduction in mortality in patients with congenital heart disease has led to an increasingly older population that faces new challenges. Studies in a younger adult population have reported inconsistent findings regarding health-related quality of life. Factors such as, the complexity of the congenital heart defect, have not been found to be associated with quality of life. The association between illness beliefs and health-related quality of life has not previously been reported.

Method. A cross-sectional questionnaire study of adults with congenital heart disease attending an outpatient clinic in a specialist centre in the United Kingdom between October 2007 and May 2008.

Results. The mean age of the study population was 37·2 years. Participants reported poorer physical functioning, role functioning and general health than a general population. High levels of anxiety were reported in 38% and high levels of depression in 17%. In multivariate analysis, higher levels of anxiety and depression were associated with poorer mental functioning and higher levels of depression with poorer physical quality of life.

Conclusion. We have reported that high levels of anxiety and depression in an older population of patients with congenital heart disease are associated with poorer quality of life. This highlights the need to routinely assess anxiety and depression in this patient group and to provide psychological support appropriately.

Keywords: adult congenital heart disease, health-related quality of life, illness beliefs, nursing, psychosocial support

Introduction

The incidence of congenital heart disease (CHD) across the United Kingdom (UK), Europe and North America is estimated at between 0·5% and 0·8% of live births (Dolk *et al.* 2011). Such estimates suggest that around 1 million children are born each year with CHD worldwide(European

Society of Cardiology, 2010). The majority of these defects are diagnosed during infancy with a minority diagnosed during childhood or even adulthood (Deanfield *et al.* 2009). In countries that routinely provide foetal imaging services, such defects are then increasingly diagnosed during the prenatal period.

Advances in cardiac surgery and intensive care management have improved the survival of children living in Europe and North America for several decades. Increasingly such interventions are available more widely. Where children can access such health care, then around 90% with a simple lesion (such as, an atrial septal defect (ASD)) will live to adulthood. They can expect a similar life expectancy to that of the general population. Around 80% of babies born with more complex lesions (such as double-outlet right ventricle) can now expect to live to adulthood (Petersen *et al.* 2003). The average lifespan has therefore increased and healthcare services have been developed that focus on the care of the adult with CHD (ACHD). An important focus of nursing is to help patients live with the consequences of their illness. Nurses working in ACHD units have therefore adopted the role of giving patient education and support to assist the transition from child to adult hood. Much of this have emphasized the specific challenges associated with adolescence. However, the age of the ACHD population (population with congenital heart disease aged over 16 years) is increasing. Exploring the health-related quality of life (HRQoL) of adults with CHD will therefore provide important information to ensure that education and support remains appropriate to the needs of this changing patient population.

Background

Health-related quality of life refers to the person's interpretation of their health status compared with their expectations; a poor quality of life indicates that a patient's perceived health status is below that which they expect. HRQoL is a multi-dimensional concept comprised of physical factors (such as pain), functional status, emotional status and general well-being. The importance people place on each of these domains is influenced by context and culture. Therefore, there is likely to be some variation across countries. For example, in the UK, where families are typically geographically separated, people place a relatively high importance on physical functioning and independence in activities of daily living. HRQoL is reported to be slightly higher in countries of Northern Europe when compared with the UK, although it follows a similar trend in terms of the relative importance placed on each domain (Norman *et al.* 2009).

Previous studies, largely reporting on study populations in Europe and North America, have reported inconsistent findings regarding the HRQoL of adults with CHD. Studies have reported that HRQoL is similar or even better when compared with that of a general population (Moons *et al.* 2005, 2009, Loup *et al.* 2009, Berghammer *et al.* 2011). However, others have reported poorer quality of life (Kamphuis *et al.* 2002, Lane *et al.* 2002, Rose *et al.* 2005, Gratz *et al.* 2009).

Patient's perception of their health status may depend on clinical factors, such as the severity of the heart defect and their capacity to exercise. For example, in a study of 111 adults with a mean age of 32 years, Rose *et al.* (2005) reported that patients with more complex lesions or with limited exercise capacity have a poorer physical quality of life than a general population but reported no difference in social or mental functioning. Similarly, Lane *et al.* (2002) in a study of patients with a median age of 31 years reported that patients with an inoperable condition or chronic hypoxia (cyanotic heart disease) had significantly poorer physical quality of life than the general population. They also reported poorer quality of life in patients who were surgically cured (such as those treated for an ASD or Ventricular septal defect). However, they reported that HRQoL was similar to the general population in patients who had undergone a surgically palliative procedure or who were managed medically. These results suggest that HRQoL may be influenced by more than the severity of the heart defect. Patient's beliefs about their illness and the results of its management may also influence expectations of their health status.

Congenital heart disease is a life-time condition and adults face new challenges from later complications, such as heart rhythm problems, heart failure or other end-organ failure (Baek *et al.* 2010). With increasing age, many will also require further surgery, such as replacement of a prosthetic valve. Alongside, these adults face psychosocial challenges related to employment and family life. All these have the potential to decrease their HRQoL. Nurses play a key role in promoting quality of life. However, there is limited understanding of how CHD has an impact on the lives of older adults and consequently, little to direct the development of these strategies.

Illness representation

The illness representation model is a self-regulation model based on the assumption that patients have a rational basis to how they interpret an event or illness and this influences how they construct their subsequent responses and actions (Leventhal *et al.* 1984). This interpretation or illness belief is

therefore individual to each person. In the ACHD such beliefs probably arise from childhood experiences, parental influences, contact with healthcare professionals and current employment issues.

There is a developing body of research in patients with acquired heart disease that suggests that patient's beliefs about their illness, including the extent to which it can be controlled through treatment or through their own behaviour, influences outcome. Molloy *et al.* (2009) explored the illness beliefs of older people with heart failure and reported that greater beliefs about the negative consequences of the illness and its long-term nature were associated with poorer self-care behaviours. Using qualitative analysis of interviews with heart failure patients Horowitz *et al.* (2004) also identified that patients' beliefs about the acute or chronic nature of their heart failure influenced their self-management behaviour. Previously, we have explored the influence of these beliefs on the perception of quality of life in adults with coronary heart disease (Lau-Walker *et al.* 2009). In a 3-year follow-up study we reported that patients' perceptions of their symptoms and belief in their personal ability to control their illness at the time of hospital discharge were strongly associated with better physical quality of life 3 years later. Knowledge of illness beliefs has influenced the design of interventions for education and support in adults with heart failure and with cardiovascular disease (Zaphiriou *et al.* 2006, Brodie *et al.* 2008). However, to our knowledge, illness beliefs have not previously been explored in a population born with a congenital heart defect. Interventions designed to assist them live with their illness have not therefore benefited from identifying potentially modifiable factors in these beliefs.

The study

Aim

This study was designed to explore HRQoL in adults with CHD and to determine the extent to which it is associated with patients' illness beliefs and emotional health (anxiety and depression). It was anticipated that this information would be used to develop effective strategies for education and support.

Design and setting

This was a cross-sectional study of adults with CHD attending an outpatient clinic in a specialist hospital in central London, UK.

Sample

Patients were recruited from an outpatient follow-up clinic for CHD. Those who met the inclusion criteria were invited to participate in the study. For this, they had to be aged above 16 years. We defined CHD according to the definition used by European Society of Cardiology, and therefore included patients with Marfan's syndrome (Baumgartner *et al.* 2010). We did not include patients with pulmonary hypertension, where the origin of their disease was not confirmed as a congenital heart defect.

Data collection

All patients who attended the outpatient clinic between October 2007 and May 2008 were approached by a research nurse, who invited them to participate in the study. They were given a patient information sheet and consent form. Patients who agreed to take part in the study were then given a pack of three questionnaires and a stamp-addressed envelope for their return. The questionnaires were: the medical outcomes short-form 36 (SF36v2) (Ware *et al.* 1993), the illness perception questionnaire (revised) (IPQ-R) (Moss-Morris *et al.* 2002) and the hospital anxiety and depression scale (HAD) (Zigmond & Snaith 1983).

The patient notes were reviewed for demographic and clinical characteristics.

Background socio-demographic data were collected from the hospital records.

Ethical considerations

All participants were given an information sheet which outlined the purpose of the study. If they agreed to take part, then they signed a consent form. All data were anonymized and entered onto a secure data-base. It was therefore not possible to identify specific patients with high levels of anxiety and depression. However, all participants continued to receive usual care and were referred for support under the usual hospital arrangements if a clinical need was identified.

Research Ethics Committee approval for the study was granted from the relevant NHS ethics committee. Reference No:07/H0708/78. The study conformed to the Declaration of Helskinki.

Data analysis

Descriptive statistics were used to describe the demographics and clinical characteristics. Variables of continuous data

were assessed for normality using probability plots. These variables were reported as mean and standard deviation (SD) if normally distributed or as median and interquartile range if skewed. Categorical data were expressed as frequency and per cent.

All questionnaires were scored using their instruction manual.

Scores on the SF 36 were compared to data from a representative population of people from the registers of General Practitioners in four counties in England (Jenkinson *et al.* 1999). We used these as the UK reference group. We used the *z*-test to assess whether the mean scores from our study population were significantly different from the UK norm. Significance was accepted at the 5% level ($P \leq 0{\cdot}05$).

We undertook univariate linear regression analysis to test the association between HRQoL (summary scores for physical (PCS) and mental (MCS)) and our independent variables of age, gender, education, lesion complexity, anxiety, depression and the dimensions of the IPQ-R questionnaire.

We used a multiple linear regression model to test which of the variables were independently associated with HRQoL (PCS and MCS). Variables that were statistically significant at the 1% level ($P \leq 0{\cdot}01$) in the univariate analysis were included in this model.

Missing data on the three questionnaires were handled according to the individual questionnaire manuals. Less than 5% of the values were missing and these were imputed using a Markov Chain Monte Carlo (MCMC) method. This method creates multiple imputations by using simulations from a Bayesian prediction distribution for normal data assuming that the data are from a multivariate normal distribution (Schafer 1997). We used bootstrap regression to assess the robustness of our results following our multiple imputations. The 'bootstrap model' showed no difference in outcome to the analysis of the raw scores. This confirmed the robustness of the reported associations and thereafter only the results of the analysis using the raw scores are reported. Two patients did not complete the SF 36 questionnaire. This was our dependent variable and so these patients' data were not included in the analysis.

Data were analysed using the statistical software package STATA (version 10·1).

Reliability and validity

The questionnaires used in this study were all validated, self-administered tools. All had previously been used in cardiac populations (Lewin *et al.* 2002, Lau-Walker *et al.* 2009).

Short-form 36

Health-related quality of life was measured by the medical outcomes study, 36 item short-form (SF36v2) (Ware *et al.* 1993). The questionnaire is multidimensional and scored in eight domains; physical function, role limitations due to physical function (role function), bodily pain, general health, vitality, social function, role limitations because of emotional problems (role emotion) and mental health. The responses to each item are combined to generate a score from 0 to 100 for each domain, with higher scores reflecting better QoL. The eight domains can be combined to provide overall summary scores for physical (PCS) and mental (MCS) health states. The questionnaire is a generic HRQoL assessment tool. An advantage of such generic tools is that they enable comparison of results across patient groups. However, they are more likely to be insensitive to changes caused by a specific disease state, especially, where patients have difficulty distinguishing the effects of multiple comorbidities. It was anticipated that due to the age of the study population, few would have comorbid conditions and the SF-36 v2 would therefore provide information on the effect of CHD on patients' mental and physical functioning.

Illness Perception Questionnaire

The IPQ-R (Moss-Morris *et al.* 2002) was used to assess patient's beliefs about their illness. The questionnaire is a 38 item tool that measures the following illness beliefs: beliefs about the symptoms they experience that are related to their illness (identity); the chronic nature of the illness (timeline); perceived consequences (consequences) and the ability to control these (personal control and treatment control), the understanding of their illness (illness coherence), emotional beliefs (emotional representation); and beliefs about the causes of the illness. The questionnaire includes two additional scales; one reports the symptoms patients believe are related to their illness (identity) and the other their belief about its causes (causal dimension).

Hospital Anxiety and Depression Scale

The HAD (Zigmond & Snaith 1983) is a common measure for anxiety and depression and was used as a measure of psychological well-being. The 14 item questionnaire has two sub-scales: a seven item anxiety scale (HAD-A) and a seven item depression scale (HAD-D). The tool measures the participants' current 'state' of anxiety and depression rather than an existing 'trait' and asks participants to indicate how they have felt in the past week. Test–retest reliability is high up to 2 weeks ($r > 0{\cdot}8$) but over longer time periods, it is less stable. Transient state changes should therefore not influence the results. There is no clear cutoff score although values ≥7

or 8 are generally suggestive of a possible state of anxiety or depression whereas a cutoff value ≥11 or 12 are suggestive of a probable state of anxiety (Zigmond & Snaith 1983, Bjelland *et al.* 2002). In this study, scores of HAD-A ≥ 8 and HAD-D ≥ 8 were used to report a possible state of clinically significant anxiety or depression. Scores on the HAD-A ≥ 8 and HAD-D ≥ 8 were used to report a probable state of clinically significant anxiety or depression.

Lesion complexity

We categorized the complexity of the congenital heart defect according to the criteria suggested by Billet *et al.* (2008): simple, moderate or complex. Where the defect did not fit the criteria, then clinicians in the steering group (JPR, HH, MRC) reached a consensus decision. For example, a patient with an ASD was classified as having a simple lesion in line with the classification system. However, when this defect was complicated by an absent inferior vena cava then it was classified as a moderate lesion. We categorized patients with Marfan's syndrome as having a 'simple' lesion.

Results

Patient characteristics

Ninety nine patients with a confirmed diagnosis of CHD were recruited over an 8-month period between October 2007 and May 2008.

The mean age of the study population was 37·2 years with an age range of 17–67 years. Forty three participants (43%) were aged above 40 years and twelve (12%) were aged above 50 years (Figure 1). Fifty four (55%) were male. Fifty seven (53%) of the participants who provided these data (89/99 of the total study population) were educated to degree level or above and 67 ((85%) of the 79/99 participants who completed this data) were in full or part-time employment. Only six (6%) participants were attending the specialist centre for the first time.

Thirty participants (30%) were classified with a simple lesion, 55 (56%) with a moderate lesion and 14 (14%) with a complex lesion. As a few participants only were classified with a complex lesion, subsequent data are analysed with the subgroups, moderate and complex combined (see Table 1).

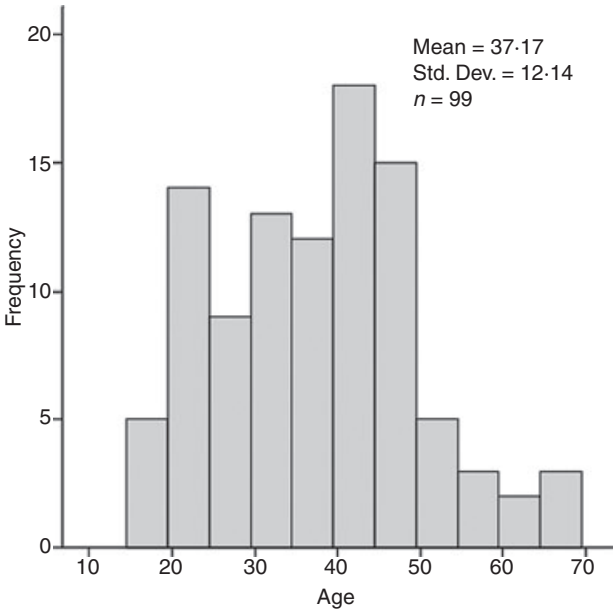

Figure 1 Age distribution of the study population.

Table 1 Demographic and clinical characteristics of the study population

Variable	*N* = 99
Age mean (range)	37·2 years (17–67)
Male *n* (%)	54 (55)
Ethnicity : Caucasian *n* (%)	99 (99)
Education level : (Data 89/99)	
Below degree level *n* (%)	42 (47)
Degree or above *n* (%)	57 (53)
Employment (data available on 79/99)	
Full-time *n* (%)	51 (66)
Part-time *n* (%)	16 (20)
Casual *n* (%)	2 (3)
Other *n* (%)	10 (13)
Lesion Severity	
Simple *n* (%)	30 (30)
Moderate *n* (%)	55 (56)
Complex n (%)	14 (14)

Illness perception

Illness belief- casual dimension

Results of the illness perception questionnaire reported that the majority of participants (64 (65%)) believed that their CHD was caused by 'chance or bad luck'. Nineteen (19%) believed it was hereditary and 15 (15%) believed it was caused by a 'germ or virus'. Some believed that contributory causes of their CHD were stress or worry (22 (22%)), or lifestyle behaviours, such as smoking (10 (10%)) and diet (14 (14%)).

Illness belief- identity dimension

Participants experienced a mean of four symptoms that are associated with their CHD during the 4 weeks prior to their outpatient visit. The most common symptoms were; palpitation (44 (44%)), breathlessness (42 (42%)),

fatigue (33 (33%)), chest pain (28 (28%)) and dizziness (28 (28%)).

Illness belief- illness representations

The mean score on the illness representation domains of the IPQ-R reported that a high number of participants held a strong belief that their illness would last a long time (timeline acute/chronic: example question, 'I expect to have this illness the rest of my life'). They also held a strong belief that their illness could be controlled by their medical management (treatment control: example, question 'The negative effects of my illness can be avoided by my treatment') and by themselves (personal control: example question, 'There is a lot which I can do to control my illness').

Participants also believed that their illness had a negative impact on both themselves and their families and this included negative financial implications (consequences: example questions, 'My illness has major consequences on my life' and 'My illness has serious financial consequences'). (Table 2).

Anxiety and depression

Data from the HAD reported that 38 participants (38%) had at least possible levels of clinically significant anxiety. Thirteen (13%) had a HAD-A score ≥ 12, suggestive of probable clinically significant levels of anxiety. Seventeen participants (17%) had a HAD-D ≥ 8 suggestive of at least possible clinically significant depression and 5 (5%) had a HAD-D ≥ 12, suggestive of probable clinically significant depression.

Health-related quality of life

The mean score on the physical component summary score was 48·18 (SD 9·65), and the mean score on the mental component summary score was 47·93 (SD 12·96).

Table 2 Illness beliefs as reported by scores on the illness perception questionnaire-revised (IPQ-R)

Variable	Mean (SD)
Timeline (acute/chronic) (6–30)	17·63 (3·25)
Consequences (6–30)	17·27 (4·44)
Personal control (6–30)	16·64 (3·64)
Treatment control (5–25)	14·01 (2·79)
Illness coherence (5–25)	11·53 (3·06)
Timeline cyclical (4–20)	9·48 (3·64)
Emotional representation (6–30)	15·64 (4·38)

Results from the *z*-test reported that when compared with a UK reference group (Jenkinson *et al.* 1999) participants in this study reported worse HRQoL in three domains: physical functioning, role functioning and general health ($P < 0·05$). There was a trend towards a reduction, also in social functioning ($P = 0·06$). (see Table 3).

Influences on health-related quality of life

Physical functioning

Univariate linear regression analysis reported that physical quality of life was not associated with the complexity of the CHD lesion (coefficient −0·46, $P = 0·83$), gender (coefficient 0·39, $P = 0·84$), or level of education (coefficient 1·32, $P = 0·32$).

Four variables made a statistically significant contribution to physical functioning and were entered into the multiple linear regression model; anxiety ($P < 0·001$), depression ($P < 0·001$), consequences ($P < 0·001$) and timeline cyclical ($P = 0·001$). Multiple linear regression reported that lower physical quality of life was associated with higher levels of anxiety and depression, stronger beliefs in the negative consequences of their illness (consequences) and greater beliefs that their symptoms varied over time (timeline cyclical). There was a weak association between these variables and physical quality of life that accounted for 23% of the variance. There was a statistically significant association between depression and physical quality of life; higher depression scores as shown on the HAD-D were

Table 3 Analysis of health-related quality of life as reported by the Short-Form 36 version 2 (SF-36, v2) in the study population compared with the UK norm

	ACHD study ($n = 99$)	UK norm ($n = 8869$)	
Variable	Mean (SD)	Mean (SD)	*P* value
Physical functioning	74·60 (28·91)	87·99 (19·65)	< 0·0001*
Role functioning	80·66 (27·52)	87·17 (22·01)	0·019*
Bodily pain	79·06 (24·29)	78·80 (23·01)	0·92
General Health	54·81 (17·84)	71·06 (20·43)	< 0·0001*
Vitality/Energy	59·41 (24·20)	58·04 (19·60)	0·57
Social functioning	77·27 (29·58)	82·77 (23·24)	0·06
Role emotion	81·27 (28·04)	85·75 (21·18)	0·11
Mental Health	72·16 (18·83)	71·92 (18·15)	0·90

*$P \leq 0·05$.

Data analysis using *z*-test.

associated with lower physical quality of life (coefficient −5·17, $P = 0·05$) (Table 4).

Mental functioning

Results from the univariate linear analysis reported no association between lesion complexity (coefficient 1·81, $P = 0·23$) or level of education (co-efficient 1·64, $P = 0·53$) and mental functioning.

Univariate linear regression analysis indicated that five variables were associated with mental quality of life. Poorer mental functioning was associated with higher levels of anxiety and depression (as measured by the HAD-A ($P < 0·001$), HAD-D ($P < 0·001$) and IPQ-R emotional representation ($P < 0·001$)) and stronger beliefs in the negative consequences ($P = 0·001$) and cyclical nature of the illness ($P = 0·001$).These variables were entered into the multiple linear regression model.

Multiple linear regression analysis reported that higher levels of anxiety and depression were significantly associated with lower mental functioning ($P < 0·001$). The model including all the variables explained 58% of the variance in the model. (Table 5)

Discussion

Limitations of the study

There were some limitations to our study. The study design and use of multiple regression analysis does not enable us to identify predictors of HRQoL. However, it does enable us to identify the strength of association between the variables we examined and patient's physical and mental functioning. Participants in this study were also predominantly caucasian (99%) and the majority were educated to degree level or above (53%). They were followed up in specialist centre where a clinical nurse specialist was employed in the outpatient clinic to provide them with information. We are therefore cautious not to over generalize the study findings to a general ACHD population that may not receive this same level of care.

Discussion of results

A distinctive feature of our study results was that the mean age of our population was 37·2 years and 43% were aged above 40. This represents an older population than previously reported, even after excluding those studies that included adolescents with CHD. Lane *et al.* (2002) reported a median age of 31 years (IQR 26–36) in a UK-based study recruiting patients from a specialist centre in the middle of England. Similar studies from Germany (Rose *et al.* 2005) and Asia (Chen *et al.* 2011) have reported on an adult CHD population with a mean age of 33 years; still younger than that reported in our study. The overall number of adults with CHD is increasing. This study therefore provides important information related to the challenges faced by the older adult with CHD and factors influencing their HRQoL.

The majority of participants (58 (56%) in this study had a good understanding of their illness. They identified the symptoms of palpitation, breathlessness and fatigue as related to their heart disease and understood the causes of their CHD. The majority also (64 (65%)) believed their

Table 4 Regression analysis for emotional health, illness perception, demographic and clinical characteristics on the physical component summary score of the SF 36 v2

Linear regression (univariate)				Multiple linear regression		
Variable	Coefficient (95% CI)	*P* value	R-Squared	Coefficient (95% CI)	*P* value	R-squared
Consequences	−0·85 (−1·26, −0·43)	< 0·001**	0·15	−0·43 (−0·91, 0·04)	0·074	0·23
HAD-D	−9·03 (−13·83, −4·23)	< 0·001**	0·13	−5·17 (−10·36, 0·01)	0·05*	
HAD-A	−6·65 (−10·40, −2·91)	< 0·001**	0·12	−1·94 (−6·20, 2·33)	0·37	
Timeline cyclical	−0·85 (−1·35, −0·35)	0·001**	0·11	−0·35 (−0·93, 0·23)	0·23	
Emotional representation	−0·55 (−0·97, −0·12)	0·012	0·07			
Illness coherence	−0·75 (−1·36, −0·14)	0·017	0·06			
Education	1·32 (−1·32,3·96)	0·32	0·012			
Personal control	0·15 (−0·40, 0·69)	0·59	0·003			
Timeline	−0·07 (−0·67,0·52)	0·81	0·0006			
Complexity of lesion	−0·46 (−4·73,3·81)	0·83	0·0005			
Treatment control	−0·07 (−0·76,0·63)	0·84	0·0004			
Gender	0·39 (−3·54, −4·32)	0·84	0·0004			
Age	−0·02 (−0·19, −0·14)	0·78	0			

*$P \leq 0·05$; **$P \leq 0·01$.

Table 5 Regression analysis for emotional health, illness perception, demographic and clinical characteristics on the mental component summary score of the SF 36 v2

Linear regression (univariate)				Multiple linear regression		
Variable	Coefficient (95% CI)	*P* value	R-squared	Coefficient (95% CI)	*P* value	R-squared
HAD-D	−20·05 (−24·79, −15·30)	< 0·001*	0·43	−14·95 (−19·72, −10·18)	< 0·001*	0·575
HAD-A	−13·93 (−17·87, −9·99)	< 0·001*	0·34	−8,27 (−12·27, −4·26)	< 0·001*	
Emotional representation	−1·00 (−1·50, −0·51)	< 0·001*	0·146	−0·17 (−0·64, 0·31)	0·49	
Consequences	−0·86 (−1·37, −0·35)	0·001*	0·10	0·07 (−0·14, 0·55)	0·76	
Timeline cyclical	−1·02 (−1·63, −0·40)	0·001*	0·10	−0·14 (−0·68, 0·40)	0·60	
Illness coherence	−0·76 (−1·52, 0·009)	0·047	0·041			
Treatment control	−0·57 (−1·42, 0·28)	0·18	0·019			
Education	1·81 (−1·19, 4·80)	0·23	0·017			
Gender	−2·09 (−6·87, 2·67)	0·39	0·008			
Complexity of lesion	1·64 (−3·55, 6·83)	0·53	0·004			
Age	0·03 (−0·17, 0·23)	0·78	0·0009			
Timeline	−0·04 (−0·78, 0·69)	0·90	0·0002			
Personal control	−0·03 (−0·70, 0·64)	0·93	0·0001			

*$P \leq 0{\cdot}01$.

CHD was due to chance or bad luck with 19 (19%) believing it was hereditary and 15 (15%) that it was caused by a germ or virus. CHD is a birth defect for which frequently there is no identifiable cause. However, in some circumstances it may be related to maternal drug or alcohol consumption, genetic diseases such as Marfan's syndrome or a maternal virus infection during pregnancy, of which rubella is the most common. Results of the illness belief questionnaire also showed that participants perceived CHD to be a long-term illness that could be managed both by medical treatment and by their personal actions. In multivariate analysis, we did not detect any association between these illness beliefs and physical or mental functioning. This finding contrasts with our earlier study in an adult cardiac population, albeit in patients with acquired heart disease (Lau-Walker *et al.* 2009). The findings of this earlier study reported that patients had a low perception of their sense of control of their illness at time of hospital discharge and this was significantly associated with their HRQoL 3 years later. Possible explanations for this difference may relate to the congenital nature of their illness. Adults in this study had been born with a heart defect and for the majority, this was diagnosed in infancy. The majority were known to the specialist centre, reviewed regularly in the outpatient clinic and seen individually by a clinical nurse specialist, who provided them with relevant patient education. Our findings would support that participants' understanding had developed from this close contact with a healthcare professional over a lengthy time-span during which they received and sought information and reflected on their own experience.

However, our study population reported high levels of anxiety and depression. Thirty eight per cent of participants had possible clinically significant anxiety and 17% possible clinically significant levels of depression. Previous research in a congenital heart disease population has similarly reported high levels of 'state' anxiety and depression. Kovacs *et al.* (2009) in a study of outpatients in North America reported that 26% of their study population had high levels of anxiety and 33% high levels of depression. In our study, these high levels of anxiety and depression were strongly associated with poorer mental functioning and high levels of depression were associated with poorer physical functioning. This finding suggests that participants may benefit from the assessment of anxiety and depression during routine clinical assessment.

We also report poorer quality of life in physical and role functioning when compared with a general UK population. These results contrast with others that have reported near normal levels of quality of life (Moons *et al.* 2005, Moons *et al.* 2009, Loup *et al.* 2009) albeit in studies of a younger population with a mean age at least 10 years below that of our sample. The challenges of the transition to adulthood have previously been emphasized in international guidelines. Both European and American guidelines have emphasized the need for patient education around issues of employment, contraception, pregnancy and genetic counselling (Warnes *et al.* 2008, Baumgartner *et al.* 2010). Although such topics potentially increase patient understanding of their illness, they are primarily of relevance to the younger female population. We did not report that gender was independently associated with either physical or mental functioning. How-

What is already known about this topic

- Adults with congenital heart disease are living longer and many require regular follow-up, life-long medication and repeated surgery.
- Nurses have developed roles to provide patient education and to support the transition from childhood to adulthood.
- Studies of younger adult patients with congenital heart disease have reported similar or better health-related quality of life than a general population.

What this paper adds

- Older adults with congenital heart disease have good levels of knowledge about their illness but high levels of anxiety and depression.
- High levels of anxiety and depression are associated with poorer mental functioning and high levels of depression with poorer physical functioning.
- Routine assessment of anxiety and depression will enable early identification of unmet need and appropriate intervention.

Implications for practice and/or policy

- Clinical practice settings should ensure the routine assessment of anxiety and depression in adults with congenital heart disease.
- Interventions should be designed that focus on improving health-related quality of life.
- Interventional studies of strategies for psychological support are needed.

ever, 43% of our study population were aged above 40 years and faced challenges that are not necessarily found amongst an adolescent or younger adult CHD population. This older patient population may have started to develop later complications of CHD and its earlier treatment such as arrhythmias, heart failure or other organ failure (Baek *et al.* 2010), all of which will require further medical or surgical management. Equally, they are more likely to have concerns about on-going employment, home mortgages, life and health insurance. All these issues may have influenced their HRQoL. Our results have important implications as the overall age of the CHD population increases and suggest that the provision of education that is individualized to address the changing circumstances of the older adult is of particular relevance.

Exercise is encouraged in patients with CHD and younger patients benefit from access to special exercise-based rehabilitation programmes (Moons *et al.* 2004, Moalla *et al.* 2006, Takken *et al.* 2007). In adults with CHD such programmes have similarly been shown to improve outcome (Quintana *et al.* 2010) but frequently are not available, even in specialist centres. Therefore, designing interventions to support exercise may avoid unnecessary limitations in physical functioning and improve the HRQoL of this older adult CHD population.

Conclusion

In summary, this study showed that HRQoL is reduced in this older adult UK population with CHD. From multivariate analysis, we reported that greater beliefs in the negative consequences and cyclical nature of their illness and high levels of anxiety and depression were associated with poorer physical and mental functioning. In addition, we reported high levels of anxiety and depression. These findings have several implications for nursing care.

First, nurses should routinely assess anxiety and depression in patients with CHD during each follow-up clinic visit. Where participants are identified with probable clinically significant levels of anxiety and depression, then nurses specialized in the care and management of patients with ACHD can address specific issues. Patients with more extreme psychological comorbidity can then be appropriately referred to specialists in psychological management. Second, interventions that include effective psychological support combined with an emphasis on exercise should be designed. Such an approach would be likely to increase participants' HRQoL both in terms of their physical and mental functioning.

For researchers, there is a need for further exploration of factors influencing the high levels of anxiety and depression seen in this study population. In addition, there is a need for interventional studies to determine effective components of programmes that focus on improving the HRQoL of this ageing patient population.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

MAG, MLW & MRC were responsible for the study conception and design. HH & MLW performed the data collection. JPR, HH, WB & MRC performed the data analysis. JPR, HH, WB, MAG, MLW & MRC were responsible for the drafting of the manuscript. JPR, MLW & MRC made critical revisions to the paper for important intellectual content. WB provided statistical expertise. MAG, MLW & MRC obtained funding. JPR & MRC supervised the study.

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