

## Review Article

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# Infective endocarditis: call for education of adults with CHD: review of the evidence

Laura H. Hays

*University of Arkansas for Medical Sciences, 4301 West Markham Street, Slot 529, Little Rock, Arkansas 72205, United States of America*

**Abstract** Advanced surgical repair procedures have resulted in the increased survival rate to adulthood of patients with CHD. The resulting new chronic conditions population is greater than one million in the United States of America and >1.2 million in Europe. This review describes the risks and effects of infective endocarditis – a systemic infectious process with high morbidity and mortality – on this population and examines the evidence to determine whether greater patient education on recognition of symptoms and preventative measures is warranted. The literature search included the terms “infective endocarditis” and “adult congenital heart disease”. Search refinement, the addition of articles cited by included articles, as well as addition of supporting articles, resulted in utilisation of 24 articles. Infective endocarditis, defined by the modified Duke Criteria, occurs at a significantly higher rate in the CHD population due to congenitally or surgically altered cardiac anatomies and placement of prosthetic valves. This literature review returned no studies in the past five years assessing knowledge of the definition, recognition of symptoms, and preventative measures of infective endocarditis in the adult CHD population. Existing data are more than 15 years old and show significant knowledge deficits. Studies have consistently shown the need for improved CHD patient knowledge with regard to infective endocarditis, and there is no recent evidence that these knowledge deficits have decreased. It is important to address and decrease knowledge deficits in order to improve patient outcomes and decrease healthcare utilisation and costs.

Keywords: Infective endocarditis; adult; CHD

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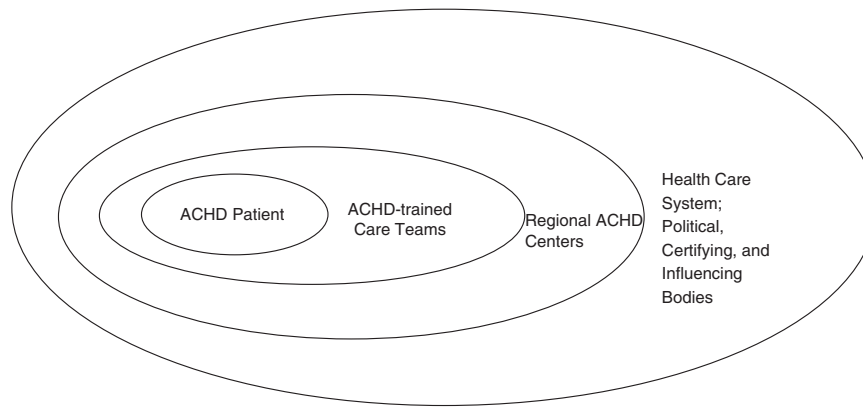
ADVANCES IN SURGICAL REPAIR PROCEDURES OVER the past three decades have resulted in the increased survival rate to adulthood of patients with CHD. This new chronic conditions population is estimated to be greater than one million in the United States of America and >1.2 million in Europe, and will continue to grow.<sup>1</sup> Infective endocarditis is a systemic infectious process with high morbidity and mortality,<sup>2</sup> which poses an increased risk for this population due to the unique cardiovascular anatomies that define the congenital disease.<sup>3–5</sup>

New guidelines on infective endocarditis prophylaxis were released in 2007 by the American Heart Association and in 2009 by the European Society of Cardiology.<sup>6,7</sup> These guidelines introduced new clinical practice standards that emphasise daily oral maintenance and hygiene practices over pre-procedural antibiotic treatment in most instances.<sup>6,7</sup> It is unknown whether the updated guidelines have been disseminated effectively to the affected population.

The purposes of this review were to examine the risks and effects of infective endocarditis on the adult CHD population and to determine whether the current evidence suggests a need for greater patient education on the definition, recognition of symptoms, and preventative measures of this complication. The current literature will be

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Correspondence to: L. H. Hays, MNSc, APRN, CPNP-PC, 4301 West Markham Street, Slot 529, Little Rock, Arkansas 72205, United States of America.  
Tel: 501-827-2540; E-mail: lhays@uams.edu



**Figure 1.**

*Multi-level framework for health systems change adapted from Ferlie and Shortell.<sup>8</sup>*

presented with regard to the impact of infective endocarditis on the adult CHD population, along with current recommendations for this population on prophylactic antibiotic treatment for invasive procedures. The state of patient knowledge will then be evaluated through the literature and assessed in terms of current population needs.

## Materials and methods

### *Literature search*

A literature search was conducted on PubMed with the search terms “infective endocarditis” and “adult congenital heart disease”, which resulted in 628 articles. The search was further refined by limiting the search to studies published in the past five years and on human species, which returned 123 articles. Abstracts of these articles were reviewed for relevance, and articles were excluded if they were written in languages other than English or involved testing of a specific valve brand. A total of 64 articles were retained for full-article review; eighteen articles were strictly case studies and were excluded, and three articles examined diagnostic imaging and were excluded. Other studies that focussed on treatment or on parental or paediatric knowledge of infective endocarditis were excluded. A total of 15 articles were retained for inclusion in this review. Moreover, six additional articles obtained from the reference lists of the included articles and three supporting articles resulted in a total of 24 articles that were included in this review.

### *Framework*

This review is based on a multilevel model for healthcare systems change developed by Ferlie and Shortell.<sup>8</sup> This systems approach to change divides the healthcare system into four levels of distinct focus: (1) the individual or patient; (2) the group or

healthcare team; (3) the overall organisation or infrastructure; and (4) the larger system or environment, often the political system or influencing bodies.<sup>8</sup> This model is based on the belief that individual health habits affect and are affected by multiple levels of influence. Patient education in the context of self-management of chronic disease in adults with CHD can be structured through this multilevel approach as (1) the adult CHD patient with need for information to self-manage the unique medical and social aspects of CHD; (2) the specialised care team trained in the care of adult CHD patients with the ability and training to provide patient education; (3) the regional adult CHD centres with the organisational structure to provide educational materials and self-management training opportunities; and (4) recommendations from committees, organisations, and certifying bodies on the educational and self-management needs of the adult CHD population. See Figure 1. The focal concept for this review is the individual with need for increased knowledge. Future research will show the influence on the individual’s state of knowledge from multiple levels of the healthcare system.

## Results

### *Risks and effects*

Infective endocarditis occurs in the general population at a rate of 1.5 to 6 cases per 100,000 people per year and in the CHD population at a rate of 2300 to 5000 cases per 100,000 people per year.<sup>9</sup> It is clinically defined according to the modified Duke Criteria.<sup>10</sup> These criteria can be found in Tables 1 and 2. Risks to the CHD population are higher due to prosthetic valves and anatomies such as congenital ventricular septal defects in which blood ejection pressure causes tissue injury to the endocardium and creates a more suitable area for vegetation growth.<sup>11</sup>

Table 1. Definition of infective endocarditis according to the modified Duke criteria.<sup>10</sup>


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Definite infective endocarditis
Pathologic criteria
Microorganisms demonstrated by culture or histological examination of a vegetation, a vegetation that has embolised, or an intracardiac abscess specimen; or
Pathologic lesions, vegetation, or intracardiac abscess confirmed by histological examination showing active endocarditis
Clinical criteria*
Two major criteria; or
One major criterion and three minor criteria; or
Five minor criteria
Possible infective endocarditis
One major criterion and one minor criterion; or
Three minor criteria
Rejected
Firm alternate diagnosis explaining evidence of infective endocarditis; or
Resolution of infective endocarditis syndrome with antibiotic therapy for $\leq 4$ days; or
No pathological evidence of infective endocarditis at surgery or autopsy, with antibiotic therapy for $\leq 4$ days; or
Does not meet criteria for possible infective endocarditis, as above

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\*See Table 2 for definitions of major and minor criteria

Table 2. Definition of terms used in the modified Duke criteria for the diagnosis of infective endocarditis.<sup>10</sup>


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Major criteria
Blood culture positive for infective endocarditis
Typical microorganisms consistent with infective endocarditis from two separate blood cultures: <i>Viridans streptococci</i> , <i>Streptococcus bovis</i> , HACEK group, <i>Staphylococcus aureus</i> ; or community-acquired enterococci, in the absence of a primary focus; or
Microorganisms consistent with infective endocarditis from persistently positive blood cultures, defined as follows:
At least two positive cultures of blood samples drawn $>12$ hours apart; or
All of three or a majority of $\geq 4$ separate cultures of blood, with the first and the last sample drawn at least 1 hour apart
Single positive blood culture for <i>Coxiella burnetii</i> or antiphase I IgG antibody titer $>1:800$
Evidence of endocardial involvement
Echocardiogram positive for infective endocarditis – transoesophageal echocardiography recommended in patients with prosthetic valves, rated at least “possible infective endocarditis” by clinical criteria, or complicated infective endocarditis [paravalvular abscess]; transthoracic echocardiography as first test in other patients – defined as follows:
Oscillating intracardiac mass on valve or supporting structures, in the path of regurgitant jets, or on implanted material in the absence of an alternative anatomical explanation; or
Abscess; or
New partial dehiscence of prosthetic valve
New valvular regurgitation – worsening or changing of pre-existing murmur not sufficient
Minor criteria
Predisposition, predisposing heart condition, or injection drug use
Fever, temperature $>38^{\circ}\text{C}$
Vascular phenomena, major arterial emboli, septic pulmonary infarcts, mycotic aneurysm, intracranial haemorrhage, conjunctival haemorrhages, and Janeway’s lesions
Immunologic phenomena: glomerulonephritis, Osler’s nodes, Roth’s spots, and rheumatoid factor
Microbiological evidence: positive blood culture but does not meet a major criterion as noted above* or serological evidence of active infection with organism consistent with infective endocarditis
Echocardiographic minor criteria eliminated

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\*Excludes single positive cultures for coagulase-negative staphylococci and organisms that do not cause endocarditis

Cardiac surgical intervention within the past six months has also been shown to be associated with higher risk for infective endocarditis.<sup>9,12,13</sup>

Right-sided infective endocarditis is most commonly seen in patients with CHD and is most often attributed to streptococci or staphylococci in the United States of America, although pathogens differ by world region.<sup>9,14</sup> Mortality from infective endocarditis has declined over the past 30 years, but

still remains a significant predictor of vascular death,<sup>15</sup> with mortality rate estimates ranging from 4 to 24%.<sup>13,14,16</sup>

Before 2007, patients considered at any increased risk for acquiring infective endocarditis were treated prophylactically before any invasive medical or dental procedure. Guidelines from the American Heart Association in 2007<sup>6</sup> and the European Society of Cardiology in 2009<sup>7</sup> detailed recommendations for

Table 3. Patients with cardiac conditions categorised as highest risk for infective endocarditis by the American Heart Association and European Society of Cardiology.<sup>6,7</sup>

Patients with prosthetic cardiac valve or prosthetic material used for cardiac valve repair\* Patients with previous infective endocarditis\* Patients with the following CHD:

Unrepaired cyanotic, including palliative, shunts and conduits\*

Complete repair with prosthetic material or device, placed by either surgery or catheter procedure, up to 6 months after procedure\*

Residual defect after repair at or adjacent to the site of a prosthetic patch, device, or material placed by either surgery or catheter procedure\*

Patients who have received cardiac transplantation who develop cardiac valvulopathy\*\*

\*Categorised as highest risk by both the American Heart Association and European Society of Cardiology

\*\*Categorised as highest risk by the American Heart Association

prophylaxis for only the highest-risk patients. Under the new guidelines, only patients with the highest risk for infective endocarditis receive prophylactic treatment and only for dental procedures that manipulate the gingival or periapical tissues or perforate the oral mucosa.<sup>6,7</sup> The American Heart Association further recommends prophylactic treatment for higher-risk patients undergoing respiratory tract, infected skin, skin structures, or musculoskeletal tissue procedures.<sup>6</sup> Please see Table 3 for cardiac conditions categorised as highest risk. The committee members charged with preparing the updated guidelines noted the cumulative lifetime risk of daily activities such as chewing and tooth brushing and the lack of evidence supporting the effectiveness of the existing prophylactic antibiotic treatment to prevent infective endocarditis in making their updated recommendations.<sup>6,7</sup>

A cross-sectional survey was conducted in 2008 with paediatric and adult CHD cardiologists to determine the effects of the 2007 American Heart Association guidelines on clinical practice.<sup>17</sup> The results showed significant inconsistency in applying the new guidelines with greater reluctance in the United States of America to discontinue prophylactic treatment.<sup>17</sup>

### Patient knowledge

This review returned no studies that assessed knowledge of the definition, recognition of symptoms, and preventative measures of infective endocarditis in the adult CHD population. Members of the Alliance for Adult Research in Congenital Cardiology used Likert scales in 2009 and 2010 to measure the perception of knowledge before and after an educational intervention, which included perception of infection symptoms knowledge in 520 CHD patients at multiple adult CHD clinics in the United States of America.<sup>18</sup> Although changes in perceptions of knowledge were noted, actual knowledge was not assessed or measured.<sup>18</sup> Ronning et al<sup>19</sup> developed and tested the psychometric properties of the

Knowledge Scale for Adults with Congenitally Malformed Hearts, which is based on the Leuven Knowledge Questionnaire created by Moons et al<sup>20</sup> The scale includes the domain “Endocarditis Prophylaxis”, which contains 13 items and showed an internal consistency reliability of 0.90, with test–re-test correlation of  $r=0.67$ ;<sup>19</sup> however, resulting data from the participants’ answers were not reported.

Other studies have assessed and reported patient knowledge, but most data are more than 15 years old. The Leuven Knowledge Questionnaire for Congenital Heart Diseases was developed by Moons et al<sup>20</sup> in 2001 and is a 33-item instrument that includes the domain “the prevention of complications, including endocarditis”. Results of the assessment of 62 patients with this tool revealed a lack of knowledge of the definition of endocarditis, with 16% answering correctly, and a lack of awareness of typical symptoms of endocarditis, with 8% answering correctly.<sup>20</sup> Kantoch et al<sup>21</sup> reported the correct definition of the terms “endocarditis” and “antibiotic prophylaxis” by 6 and 22%, respectively, of adult participants with CHD in 1997 ( $n=50$ ). In addition, 58% of the participants could identify one risk for cardiac infection in their study.<sup>21</sup> Cetta and Warnes<sup>22</sup> reported similar results in 1995, with 50% of the participants correctly defining endocarditis, and 43% correctly identifying measures for endocarditis prevention ( $n=100$ ).

### Discussion

Although CHD patients are at increased risk for infective endocarditis, significant knowledge gaps have been shown in patients’ knowledge and perceptions of knowledge of the symptoms, risk factors, and preventative measures of this complication.<sup>18,20–22</sup> Historically, studies have shown the need for improved patient knowledge in this regard, with no recent evidence that these knowledge deficits have decreased. It is unclear whether these knowledge deficits are attributable to inconsistencies, and therefore confusion, in application of the prophylactic

guidelines or to lack of the educational processes needed to prepare this patient population for effective self-management.<sup>17,18</sup>

Task Force 5 recommendations stemming from the 32nd Bethesda Conference of the American College of Cardiology focus on access to care and advocacy needs for the adult CHD population.<sup>23</sup> The committee's recommendations include the development of educational materials, more research to determine the economic impact of CHD in the adult population, and advocacy with health insurance companies and legislators.<sup>23</sup> Healthcare systems remain in the developmental stages of preparing to meet the needs of the growing adult CHD population,<sup>24</sup> including provision of teaching and educational materials.

Research to assess current patient knowledge of the aspects of infective endocarditis is needed to identify the gaps in patient knowledge today, so that appropriate and effective teaching methods can be developed to address these gaps. The successful identification of the existing gaps will provide the framework for educational training needed for this population. As rates of infective endocarditis are significantly higher in the adult CHD population, improved education of this population could have a significant impact on patient outcomes, as well as healthcare utilisation and costs.

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## Conflicts of Interest

None.

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