



## The power in being together for young adults who have heart disease – the photoshoot experience



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### ARTICLE INFO

#### Article history:

Received 6 April 2016

Received in revised form

12 February 2017

Accepted 16 February 2017

Available online 31 March 2017

#### Keywords:

Congenital heart disease

Cardiac disease

Automatic implantable cardioverter  
defibrillator (ICD)

Young adult

Experiences

Photoshoot

Social support

### ABSTRACT

**Objectives:** The study aimed to determine perceived motivations and benefits of photoshoot participation for young adults who have heart disease.

**Background:** Feeling isolated and different can have lifelong affects on quality of life in heart disease survivors. Photoshoots, where people create a photographic image of themselves, promote positive interpretation of their cardiac illness experience, but participant experiences remain under-investigated. **Methods:** Young adult heart disease support group members completing a photoshoot were interviewed and data were thematically analyzed.

**Results:** Seven females and one male aged 20–47 years participated. The main theme, *People Like Me*, emphasized feelings of being different, isolated and uncertain due to the heart disease. Other themes related to support gained from people who were not like them, gaining and providing support to their peers. The photoshoot enabled a highly valued collective feeling.

**Conclusions:** For young adult heart disease survivors, the photoshoot provides a fun, social opportunity to reduce isolation and share experiences.

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### Introduction

Approximately 85–90% of the children with congenital heart disease (CHD) are expected to survive to adolescence or adulthood,<sup>1</sup> primarily due to earlier diagnosis and advances in surgical, device and pharmaceutical treatments. Survival is however, accompanied by the need for young people to persist with self-management over a much longer lifespan. CHD survivors must cope with further surgery, treatment sequelae, residual symptoms and uncertainty of outcome as they live increasingly longer lives.<sup>2</sup> Furthermore, new treatments and devices may be developed that

meet the clinical needs of their cardiac condition but can create other issues. This is particularly the case for recipients of an automatic implantable cardioverter defibrillator (ICD).<sup>3</sup> The ICD impact includes scarring and deformity from insertion, as well as anxiety related to fear of an arrhythmia event, which may be witnessed by others.<sup>4</sup>

The health needs of young adults with acquired heart disease and CHD survivors may then include managing physical limitations, clinical symptoms and devices as well as uncertainty about their future.<sup>4,5</sup> Functional status (Atz et al) and exercise capacity is lower than the general population for many patients (Hager et al). Hospital admission for CHD survivors is common, with causes including arrhythmias (34.24%), coronary artery disease (25.85%), heart failure (18.72%), pulmonary hypertension (8.98%) and bacterial endocarditis (1.1%).<sup>6</sup> Many struggle to cope and experience depression (23%), mood and anxiety disorders (30%) as adults.<sup>7</sup> In qualitative studies, common issues faced related to employment and pregnancy,<sup>8</sup> child bearing/rearing, mood disturbances, body

*Abbreviations:* congenital heart disease, CHD; automatic implantable cardioverter defibrillator, ICD.

Conflicts of Interest: None.

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image concerns<sup>9</sup> and sexual functioning, and in ICD recipients anxiety and social isolation primarily due to ICD shocks.<sup>10,11</sup>

Some CHD survivors have additionally found difficulty in identity formation,<sup>12,13</sup> an important developmental task for young people.<sup>9</sup> They can feel different to healthy people due to their scarring and physical limitations, and perceive that they are treated by the community and society as not 'normal',<sup>10,13,14</sup> creating feelings of isolation. CHD survivors' and acquired heart disease patients' scarring also has multiple meanings. Scarring permanently alters appearance, impacts on body image and decreases quality of life and psychosocial functioning.<sup>15,16</sup> While almost half try to conceal their scars and feel a negative impact on their self-esteem and self-confidence, many feel that while disfiguring, the scar/s reinforces that they are currently alive and primarily well.<sup>14</sup> Other studies report similar positive re-interpretations. For instance, a sample of women aged 30 to 79 who had a recent sternotomy for heart surgery, balanced predominantly negative feelings towards their scars by positive perceptions of survival.<sup>17</sup>

Reduction of the impact of these health issues and positive perceptions of scarring can be promoted by support group activities. CHD survivors express interest in support groups both to receive (35%) and provide support (48%), with women and more anxious persons more likely to be interested.<sup>18</sup> However, the potential to meet similar others is limited, as adult CHD is uncommon at 4 cases in 1000.<sup>19</sup> Online support groups, such as Hearts4Heart, have been created to provide this opportunity both for acquired heart disease and CHD survivors.

The photoshoot is used by some support groups for people recovering from or living with an illness to promote positive re-interpretations of the effects of illness is the photoshoot, the most notable of these being for breast cancer patients.<sup>20</sup> The photoshoot is one of many photo-techniques available, but contrasts with photovoice, where participants take photos themselves to highlight an issue.<sup>21</sup> In photoshoots, a professional photographer, often in partnership with participants, produces a series of photos to encourage communities to reinterpret their body image. However, there is very limited research reporting whether patients experience these benefits. In photoshoots for people affected by long term mental illness<sup>22</sup> and severe scarring from war injuries,<sup>23</sup> participants report benefits from the opportunity to choose how they wanted to represent themselves. Often the choice was for the best image possible, and thus contributing to participants' self-esteem and reinforcing the feeling of recovery<sup>22</sup> and creation of a new but more positive identity.<sup>23</sup> While there were indications that the positive outcomes also arose from interacting with others similarly affected,<sup>23</sup> it was difficult to distinguish this given the ongoing interaction with the health

professionals during the projects. One photoshoot for young people with heart disease was found in the public domain and this focussed on CHD survivors, the Scarred For Life project, supported by the Somerville Foundation, an adult heart charity.<sup>24</sup> However, participant's perceptions of benefits could not be determined given the lack of a published evaluation.

The aim of this study was to explore the perceptions of a photoshoot experience for young adults who have a cardiac condition who had volunteered in a photoshoot campaign organized by an online heart disease support group. Participants' motivations to volunteer for the photoshoot in relation to their cardiac condition and any benefits of involvement were investigated.

## Methods

### Study design

This is an interpretive descriptive study using a convenience sample and individual patient interviews, which was conducted in November–December 2015.

### Ethical considerations

The Human Research Ethics Committee of the University of Sydney approved the study (Project No. 2015/847). Participants provided informed consent for the interviews and confidentiality was guaranteed and aliases are used to report results. This investigation conforms with the principles outlined in the Declaration of Helsinki.

### Participants

Participants were members of Hearts4Heart, an online support group for young people with heart disease, both acquired and CHD. Hearts4Heart provides education and information on heart disease, a private Facebook™ platform for peer support and promotes awareness through national events.<sup>25</sup> The Hearts4Heart photoshoot campaign was designed by the support group to extend the normal support provided; to unite and empower members and to raise awareness that heart disease affects Australians of all ages. Hearts4Heart members were advised of the photoshoot campaign through their Facebook™ page emphasizing the opportunity for members to capture and normalize their heart condition experience, including their surgical scarring. Participation in the photoshoot was entirely voluntary, some participated, some did not. Four photoshoots occurred, one each in Sydney, Melbourne, Adelaide and Brisbane, Australia in November 2015. Volunteer professional photographers and make-up artists were present at each photoshoot. The photographer ultimately determined the exact nature of the photoshoots with input from the participants. Examples of the photos produced are available on the website<sup>25</sup> and in illustration 1.

Study eligibility included: 1) membership of Hearts4Heart support group, 2) congenital or acquired heart disease diagnosis, 3) participation in the Hearts4Heart photoshoot, 4) able to understand and speak English sufficient for the informed consent and interview process, 5) over 18 years but under 45 years, and 6) available by Skype or phone for interview. Potential participants were advised of the study following the photoshoot promotion on the Hearts4Heart Facebook™ page. Interested candidates contacted the study personnel and eligibility was then determined, and consent and interview times arranged.

The study sample size was anticipated to be between eight and 12 participants, based on the potential to ensure inclusion by different ages, genders and heart conditions and to achieve data



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