



**'I just can't sit around and do nothing!': Women's experiences of diagnosed with and treated for heart disease in Indonesia – a qualitative study**

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3 ***'I just can't sit around and do nothing!': Women's experiences of diagnosed***  
4 ***with and treated for heart disease in Indonesia – a qualitative study***  
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10 **Abstract**  
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14 Cardiovascular disease has been responsible for 37% of the total death in Indonesia. Research  
15 about cardiovascular disease and its management in Indonesia has heavily emphasised  
16 biomedical aspects of the disease; little is known about experiencing the disease at the  
17 individual's level, especially for those Indonesian women with cardiovascular disease. The aim  
18 of this study was to understand how gender shapes Indonesian women's experiences of living  
19 with heart disease and how it affects their private lives. A feminist-informed qualitative  
20 research design was carried out in the study. The primary method of data collection was semi-  
21 structured interviews. A total of 26 women aged between 30 and 67 years were interviewed  
22 from June to September 2016. Transcribed interviews data were analysed using qualitative  
23 framework analysis. Three major themes were inferred from the data analysis: (1) effect of  
24 CVD on women's day-to-day activities, (2) effects on women's family relationship, and (3)  
25 women's coping strategies. The inability to fulfil the gender expectation of caring for others  
26 had unwittingly managed to undermine or threaten the women's sense of self and their social  
27 identity. Healthcare professionals should be aware of the ethnic and cultural backgrounds of  
28 women with cardiovascular disease, **to enable them to deliver services that meet the social,**  
29 **spiritual, and cultural needs of their patients.**  
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53 **Keywords:** cardiovascular disease, experience, feminist, gender roles, qualitative research,  
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## 1. Introduction

Cardiovascular disease (CVD) is the leading cause of death for women globally (World Health Organisation, 2014). The Centres for Disease Control and Prevention (CDC, 2012) estimates that every one in four deaths of women in the USA is from CVD. The European Heart Network (2015) also reported that CVD causes more than four million deaths in Europe and is the leading cause of death among women in all European countries. A similar phenomenon has been observed in Indonesia, in which ischaemic heart disease (IHD) and stroke have been identified as the leading causes of premature deaths among men and women for the last decade (Mboi et al., 2018). The data from the Global Burden of Disease Study (2016) has also noted a 14.2% increase in deaths due to IHD in Indonesia from 2005 to 2016 (Mboi et al., 2018).

Although heart disease has traditionally been seen as a “man’s disease” (Emslie, 2005; Galick et al., 2015), in fact, it is also a health problem for women. This traditional belief has caused CVD not to be considered as a serious health problem for women of all ages (Lockyer & Bury, 2002). Furthermore, women themselves have thought that they were safe from heart disease until after menopause (LaCharity et al., 1997). The research demonstrates that women suffer from CVD approximately ten years later than men (Anand et al., 2008; Maas & Appelman, 2010); a situation that puts women at high risk of CVD (Worrall-Carter et al., 2011). Therefore, when women do suffer from CVD, they have a higher probability of experiencing poor outcomes, including lower adherence to treatment regimens and poorer quality of life, along with higher morbidity and mortality (Bakhai et al., 2013; Kolandaivelu et al., 2014; Leslie et al., 2018). Although women are at higher risk for negative outcomes related to CVD, women also have lower enrolment in and higher drop-out rates from cardiac rehabilitation programme than men due to family-related obligations or housework (Clark et al., 2013; Resurreccion et al., 2018).

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3 Previous studies into women's experiences of recovering from heart disease showed  
4 that the women experienced the feelings of guilt and shame (Svedlund et al., 2001), insecurity  
5 and uncertainty about life and death (Burstrom et al., 2012; Johansson et al., 2003), changes in  
6 family role and/or relationships (Galick et al., 2015; Smith et al., 2017), as well as fear and  
7 anxiety for the future (Sjostrom-Strand et al., 2011). A meta-synthesis of women's experiences  
8 of recovery after MI (Hildingh et al., 2007) revealed that the recovery was experienced as a  
9 complex process in terms of having to cope with balancing between being oriented towards  
10 themselves and towards other people.  
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21 Due to the androcentric nature of research, women are often viewed as one large  
22 homogenous group (Cosgrove, 2003). However, the reality is the total opposite of that  
23 perspective, in which women's experiences are broad and diverse depending on their social  
24 location (i.e. cultural, economic, religious, etc.). This situation has prompted Crenshaw (1989)  
25 to introduce the concept of intersectionality as a critique to the mainstream (white) feminism  
26 movement that frequently ignored the experience of the black women. However, in the area of  
27 CVD, there has been an increasing trend in the interest of research focusing on women,  
28 although the majority studies were still mainly focused on the experience of the women in the  
29 developed countries and excluded large populations of minority and ethnic groups.  
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42 The exclusion of women, from minority and ethnics groups, from cardiovascular  
43 research indicates a tendency for generalisations of women's experiences and that the  
44 experiences of many women from minority and ethnics groups were not addressed  
45 appropriately. While many similar topics have been the focus of research in a Western context,  
46 no previous study was found that focused on understanding the experiences of women with  
47 heart disease in Indonesia. Much remains to be learned particularly about Indonesian women's  
48 experiences with heart disease, which is still not well understood. Research about CVD and  
49 CVD management in Indonesia has heavily emphasised biomedical aspects of the disease; little  
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3 is known about experiencing the disease at the individual's level, especially for women with  
4 CVD (Maharani & Tampubolon, 2014; Schröders et al., 2017). Scholars suggest that  
5 explorations of day-to-day illness experiences among people from the different sociocultural  
6 background are essential to provide opportunities for an in-depth understanding of a broad  
7 range of contextual factors that influence how people live with chronic disease (Lawton, 2003).  
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### 17 **1.1. Study aim**

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19 The aim of this study was to understand how gender shapes Indonesian women's  
20 experiences with heart disease and how it affects their private lives. The focus of the present  
21 study was not only on ischemic/coronary heart disease but also other heart problems such as  
22 valvular heart disease.  
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## 31 **2. Methods**

### 32 **2.1. Design**

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36 Much of research in CVD has been fairly androcentric (McCormick & Bunting, 2002),  
37 such that there is a pressing need for qualitative research on CVD to adopt a gender-sensitive  
38 approach that considers gendered roles and identities (Emslie, 2005). The main interest of this  
39 study was to investigate how gender shapes women's experiences living with heart disease;  
40 therefore, we used a feminist-informed qualitative research approach. The application of  
41 feminist perspective will provide an alternative view that places the woman at the centre stage.  
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43 One goal that all feminists seem to have in common is the empowerment aspect and 'giving  
44 voice' to women (Ramazanoglu & Holland, 2002). By participating in this study, the women  
45 'gave voice' to their narratives, and this 'voicing' served as a form of empowerment. Feminist  
46 theory was employed during the study's data collection, analysis, interpretation, discussion,  
47 and recommendation. Gender was given considerable attention during the planning,  
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3 implementation, as well as data analysis stage. Further, the women in this study partially  
4 defined themselves with the social roles they performed; mother, wife, housekeeper/carer, for  
5 example, and so an exploration on how social roles can shape the self was also undertaken and  
6 this, again, was informed by feminist theory. In addition, reflective activities were considered  
7 as an integral part of the interpretative process in this study.  
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## 17 **2.2. Participants and setting**

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19 This study was conducted in an outpatient cardiac rehabilitation (CR) centre in the  
20 National Cardiovascular Centre (NCC), Harapan Kita Hospital, Jakarta, Indonesia. A total of  
21 26 women participated in this study. The study participants were selected using a purposive  
22 sampling strategy. The inclusion criteria were: 1) women who were over 18, and 2) **had**  
23 **experience of cardiac event**. There was no limitation regarding the participant's diagnosis. The  
24 participants were approached by CR nurses who were acting as the study gatekeepers. At this  
25 stage, an information package including the participant information sheet, invitation to  
26 participate, and the consent form were provided to potential participants. **Data was considered**  
27 **saturated when no new code could be built. However, we recruited two additional participants**  
28 **to ensure data saturation was achieved**. Out of 31 participants that were approached, 26 of them  
29 agreed to participate in the study. Five participants who declined participation were those who  
30 decided either to not enrol in or drop out of the phase two CR programme. Participants and the  
31 researchers had never met before the conduct of the study.  
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## 51 **2.3. Data collection**

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53 The first author (SS), an Indonesian nurse academic, conducted in-depth interviews  
54 using a semi-structured interview guide between June and September 2016 in 2-6 weeks  
55 following hospital discharge. Twenty-three interviews were carried out in the outpatient CR  
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3 unit and three interviews were conducted by telephone at a date and time, which was entirely  
4 the participant's choice. The duration of the interviews ranged between 15 and 75 minutes  
5 long. Before the actual data collection, the interview guide (see Table 1) was pilot tested  
6 with two women to check the clarity of the questions. Open-ended questions were used to  
7 allow participants to answer in their own words and offer their personal opinions, views, and  
8 experiences. All interviews were conducted in the Indonesian language. Interviews were  
9 audio-recorded and subsequently transcribed verbatim by SS. Following that, each transcript  
10 was checked for error by listening to the audio-recordings of the interviews, whilst  
11 simultaneously reading the transcript. Field notes were written soon after the interview to  
12 capture the context.

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Adhering to the feminist principles, we considered the women as experts regarding their experience of heart disease. It was also essential that we endeavoured to incorporate a collaborative relationship with the study participants. Therefore, we used a more conversational and sharing approach for interviewing women (Oakley, 1981) to invite intimacy as well as to avoid creating a hierarchical relationship between the interviewer and interviewee.

#### 2.4. Data analysis

The data analysis involved a data-driven inductive approach by using a framework analysis approach (Gale et al., 2013; Ritchie & Spencer, 1994). The steps of the framework analysis approach outlined by Ritchie et al. (2014) were followed, including (1) familiarisation with the data; (2) developing an initial thematic framework; (3) indexing the data (i.e. initial thematic framework was applied to the data, labelling sections of text using the existing categories and codes); (4) charting (data summary and display, using a framework matrix); (5) abstraction and interpretation. During the familiarisation process, all authors independently read and re-read

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3 five interview transcripts that were translated into English by SS. To ensure that there were no  
4 changes in meaning during the translation process, back translation from English to Indonesian  
5 was also carried out. Following this, an initial thematic framework based on the emerging  
6 issues arising from the process of familiarisation was developed. The team held regular  
7 meetings to discuss and review this initial thematic framework until consensus was reached.  
8 This initial thematic framework consisting of categories and codes was then applied to the  
9 remaining transcripts by SS. Once all data has been coded, the data was summarised and  
10 arranged into thematic matrices. The next step of the data analysis was data abstraction and  
11 interpretation, in which the participant accounts were compared to find similarities and  
12 differences. At this stage, the authors reviewed the data summaries, mapping the range and  
13 diversity of views and experiences, identifying elements and underlying dimensions, and  
14 proposing key themes that underpin them. Simultaneously, we incorporated the perspective of  
15 intersectionality by continually asking how each individual account was related to broader  
16 social relations structure in dominance and contexts (i.e., age, religion, gender). During the  
17 process of data analysis, NVivo version 11 was used.

## 2.5. Rigor

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22 Rigor or trustworthiness was achieved through credibility, transferability,  
23 dependability, and confirmability as suggested by Lincoln and Guba (1985). To ensure  
24 credibility, the researchers implemented strategies, such as prolonged engagement with  
25 participants and informal member-checking (i.e. through deliberate probing and summarising  
26 or repeating back information back to participants). The participants were also offered an  
27 opportunity to review their interview transcript. In terms of transferability, the detail of the  
28 research setting, methods, participants, as well as the theoretical assumptions underpinning the  
29 study were provided. To enhance dependability, NVivo 11 was used to store and manage the  
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3 data to facilitate audit trail. Lastly, to enhance confirmability, the procedure for checking and  
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5 rechecking the data throughout the study was documented.  
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## 10 **2.6. Ethical considerations**

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12 The research ethic committee at the University of Edinburgh and the local hospital (No:  
13 LB.02.01/II/0859/2016) approved the study. Informed consent was sought from the  
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15 participants who agreed to participate in the study prior to the interview after they received  
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17 written and verbal information. The participants were also assured that they could withdraw  
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19 from the study at any time without any consequence.  
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## 26 **3. Results**

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28 A total of 26 Indonesian women participated in this study. The women who took part  
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30 in this study varied in terms of age, diagnosis, education level, ethnicities, working situations,  
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32 and marital status. However, all the women in this study had undergone cardiac surgery. Details  
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34 of the participants interviewed are outlined in Table 2.  
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38 Participants' narratives about their illness linked experiences, including the causes of  
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40 heart disease and its effect on their day-to-day lives were all strongly influenced by their  
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42 cultural values and traditions that framed their health beliefs and behaviour towards heart  
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44 disease. Hence, complex interplays between cultural values/ethnic affiliation, religion and age  
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46 produced participants' gender position and helped them to articulate the effect of CVD on their  
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48 day-to-day lives as a woman within Indonesian society. From the data analysis, the following  
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50 three main themes were identified: 1) effect of CVD on women's day-to-day activities, 2) effect  
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52 of CVD on women's family relationship, and 3) women's coping strategy.  
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### 59 **3.1. Effect of CVD on women's day-to-day activities: loss of control**

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3 All the women in this study identified a lack of autonomy and control as the most  
4 significant impact of the physical impairment and functional limitations associated with the  
5 disease. The women spoke of how the illness caused disruptions in many aspects of their lives.  
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7 Heart disease had a significant impact on their ability to carry out normal role functions as a  
8 mother, a wife, and a member of society. The women reported a sense of ‘not being in control  
9 of their bodies and daily activities’, as well as out of control within the home due to their  
10 inability to maintain normal domestic standards.  
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### 22 **3.1.1 Housework: “everything has changed”**

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24 Consistently, the women in this study stated that “everything has changed” since  
25 experiencing heart disease. The inability to carry out their domestic tasks caused the women to  
26 feel profound guilt. They felt this way because the participants considered housework as solely  
27 their responsibility, so that they could not imagine anyone else, particularly their husband,  
28 carrying out the task. These situations created uncomfortable feelings for women, resulting in  
29 them feeling less useful than before their heart disease; or as some of the participants said:  
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31 “useless”. One woman described:  
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40 *“...I feel troubled because I can’t do the housework. [...] My son helped to*  
41 *sweep the floor, but you know, ‘a man is a man’, right? Indeed, he swept the*  
42 *floor, but ‘just like that’. So yeah, it troubled me a lot, because I cannot do it on*  
43 *my own”. (P3)*  
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### 51 **3.1.2 Social withdrawal**

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53 Some participants in the study described that when their symptoms deteriorated they  
54 had to withdraw from participating in social activities. One participant described that she was  
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3 actively involved in several organisations. However, she was no longer able to remain  
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5 involved, particularly after she got married and was then diagnosed with CVD. She explained:

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7 *“I used to be an activist. I participated in many social activities [...] Everything*  
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9 *has changed since I suffered from heart disease. If I wanted to do an activity*  
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11 *outside, I had to go with my husband. I had to wait for him from work so he*  
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13 *could accompany me.” (P8)*  
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### 19 **3.1.3 Giving up job/employment**

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21 Some of the women in this study used to be financially independent by working outside  
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23 of the house, but they had to voluntarily give up their job due to their illness. One participant  
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25 who acted as the primary earner in the family stated that she felt uncomfortable giving up her  
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27 job since she has suffered from heart disease. She experienced a conflict between providing  
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29 care for others (particularly her father and her son) and providing care for herself in day-to-day  
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31 life. She felt guilty about not doing enough for her father even though she was had a condition  
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33 that also required care.  
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## 40 **3.2. Effect on women’s family relationship**

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42 Throughout the interviews participants reported that heart disease challenges family  
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44 harmony, particularly with regards family’s habits/routines, as well as imposing burden on  
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46 their family members. One of the main consequences of physical incapacity was the reduced  
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48 ability of the participants to perform their social roles. Since experiencing illness, many of the  
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50 women suggested that their previous social roles began to change or even ceased altogether.  
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### 57 **3.2.1. Changing relationship pattern (from a caregiver to a care receiver)**

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3 Many women portrayed themselves as self-reliant, socially and physically active, and  
4 who previously had occupied a central role in the family as the key caregivers instead of, as  
5 now, care receivers. As the women were no longer able to perform their normal functions and  
6 roles, due to their illness, that perceived demotion posed a threat to their identity. Furthermore,  
7 the women also expressed that their illness had caused arduous and continuous obligations to  
8 family members. One participant stated:  
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19 *“I feel like I am burdening my family a lot. I feel pity for them. I should be able*  
20 *to help my parents or help my husband. Now my husband is always helping me*  
21 *to do everything, taking care of me. I am so grateful that he doesn't complain*  
22 *at all.” (P17)*  
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### 31 **3.2.2. Separation**

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33 Most women with young children in this study had to live separately from their  
34 children, due to their degenerating physical condition that required them to focus on their  
35 treatment. They asked their parents or relatives to look after their children during their  
36 treatment period. One participant described her experience:  
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42 *“I was separated from them [the children] when the small one was only eight*  
43 *months, so, I wasn't able to breastfeed her anymore, right? It has been around*  
44 *a year I haven't seen my daughter. [...] She has been taken care of by my parent-*  
45 *in-law...” (P18)*  
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54 Leaving their children under the supervision of others was a difficult decision for the  
55 participants; at the same time, they felt that they had no other choice. For the participants, the  
56 role of caregiver for children was most important, thus for the young women with relatively  
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3 young children, they found it very hard to accept their diagnosis and condition. For this reason,  
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5 participants also expressed feelings of guilt about not being able to look after their children  
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7 properly, since they could not fulfil their roles as a good mother.  
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### 12 **3.2.3. Marital conflicts**

14 Although most participants described that they received a great deal of support from  
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16 their spouses, children, or extended family members, some participants revealed information  
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18 suggesting disrupted relationships, such as marital conflict, or communication issues with  
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20 family members. One participant explained that since being diagnosed with congenital heart  
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22 disease, she experienced conflicts with her (now ex) husband. She described:  
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26 *“...he cheated on me, and then he married again to another woman. From 2008*  
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28 *to 2014, he just didn't care when my illness relapsed many times. He said I just*  
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30 *dramatized the situation. So yeah, finally I asked for a divorce.” (P20)*  
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### 35 **3.2.4. Over-protective family**

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37 The women frequently described that the lessened freedom and independence were not  
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39 a mere consequence of their illness, but also came from their families that tended to be  
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41 overprotective. One woman described her frustration when her husband told her to stop her  
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43 usual task of cleaning the house when she thought still able to manage it. She explained,  
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47 *“They get mad at me if I did it... “Later you can do it, but not now”, for God*  
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49 *sake, it was only sweeping the floor... I could not just sit down all day doing*  
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51 *nothing [...] I think it's okay as long as I don't lift heavy stuff...” (P10)*  
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## 56 **3.3. Women's coping strategies: Maintaining harmony**

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3 The participants expressed that one of their central roles was as the caregiver of the  
4 family. Therefore, when the lead caregiver of the family was ill, established roles and norms  
5 in the family were challenged; hence it was quite likely that the harmony in the family could  
6 no longer be sustained. In this study, the strategies employed by the women to maintain  
7 harmony in the family included: 'I just can't sit around and do nothing!' and 'I keep it secret!'  
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### 17 **3.3.1. 'I just can't sit around and do nothing!'**

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22 All the women in this study, despite difficulties, tried to maintain their role as wife,  
23 mother, or grandmother to protect their families from being overly concerned about their  
24 condition. They viewed housekeeping duties as something they were used to doing and which  
25 brought a feeling of normality into their lives. A common theme that we heard from the women  
26 in this study was: "*I just can't sit around and do nothing*". From the participants' narrative, it  
27 was important for them to show that they still had the strength and energy to perform their duty  
28 as a mother. One woman decided not to ask for help and managed the household tasks and  
29 childcare duties on her own, despite her deteriorating symptoms. She expressed that it was not  
30 good or convenient to be dependent on other people, or imposing burdens on her family. She  
31 described:  
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“...and ever since they were babies, we never asked our parents to help us with  
the kids. We did everything on our own, so it was only recently, because my  
condition got worse and I had to go for some intensive treatment, I asked my  
parents to help us with childcare.” (P8)

### 3.3.2. *'I'll keep it a secret!'*

Participants perceived the heart as the centre of their life. Therefore, they defined heart disease as a severe illness with an immediate threat to life; thus revealing the illness to their family members would make them worry. They were concerned that their symptoms would interfere with household duties and caring for others. Revealing the illness to the family would also significantly disrupt family harmony. One woman stated:

*"When my husband asked what's wrong with me, I told him that maybe my cholesterol level was increased. [...] I didn't want him to worry about me. Because the heart is the centre of our lives... if he knew it, I was afraid that it would be burdening him"* (P16)

## 4. Discussion

In this study, we described how gender shapes women's experience of heart disease and how it affected their private lives. The results demonstrated that heart disease not only created functional limitations for the women but more importantly, had a significant effect on their sense of self. They perceived heart disease altered their daily lives and their feminine identity; specifically their internalised norms and perceptions about what it is to be an ideal woman in their context (Bird & Rieker, 1999). The women felt that heart disease intertwined with, and altered the gendered expectations of, caring for others, which they perceived as central to their identity as a woman. At the same time, as cardiac patients, they were aware of the limitations imposed on them by the disease. Their very limited ability to carry out normal roles as a mother/wife meant they were no longer able to fulfil gendered expectations, mainly doing the household chores and caring for the family. These limitations caused the women to feel like a burden to their families, and thus threatened their sense of self. The feeling of being a burden to others contradicts the ideal characteristic of a 'good woman', as well as

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3 undermining the traditional feminine role of family caregiver in Indonesian society. As  
4 Charmaz (1983) noted, becoming a burden typically degrades identity because the sick person  
5 has little power over their situations and the quality of their existences.  
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10 The women interviewed reported that since experiencing heart disease, they were 'not  
11 able to do anything like before' in the sense of performing domestic duties and caring for the  
12 family, including the wife role. This finding concurs with several other studies from both a  
13 Western (Pihl et al., 2011) and Asian perspective (Seah et al., 2016). These studies reported  
14 that the reduced physical ability as the result of heart disease often created various restrictions  
15 on many aspects of the individuals' lives. Being unable to fulfil their previous social roles, as  
16 wives or mothers, caused the participants to experience psychological discomfort. Hildingh et  
17 al. (2007) suggest that women patients experience a greater sense of loss and frustration than  
18 do male patients, due to women's greater domestic roles in their normal situations.  
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30 Most of the women in this study explained situations that related to a sense of social  
31 displacement, in which heart disease had prevented their full engagement in activities that were  
32 connected with their former identities. The participants were concerned about losing standing  
33 in front of others who, it should be stressed were not ill. The woman's status would be lost, or  
34 significantly reduced, if they failed to live up to expectations for a person in a certain role or  
35 of a certain status. Dalal and Biswas (2009) assert that being unable to provide support to family  
36 and friends can relatively quickly lead to an erosion of self-worth.  
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47 Maintaining family harmony was noted as an important finding in this study. The  
48 women interviewed demonstrated the continuous efforts to maintain their roles as wife, mother,  
49 or grandmothers to protect their families from being overly concerned about their condition,  
50 so that harmony in the family would be sustained. Many participants developed strategies that  
51 allowed them to balance their needs with the needs of others, to give them a sense of control  
52 over their daily activities. This is similar to what Sulik (2007) described as the 'balancing act'  
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3 **which is used as a vital coping strategy developed by the women with breast cancer in the US.**

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6 The participants explained that they sincerely accepted the illness but at the same time they did  
7  
8 not want to abandon their obligations to the family and society. These findings align with the  
9  
10 study from Schou et al. (2008) who reported that the women fought to maintain their role in  
11  
12 their families as wives, mothers, or grandmothers.

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15 The emphasis that women in this study placed on their roles as wives and mothers also  
16  
17 concurs with another study, whereby the authors found that women presented themselves as a  
18  
19 ‘good housewife’ despite their pain, in order to maintain a positive identity, reinforced by  
20  
21 continuing to perform their traditional gender roles (Richardson, 2005). Although performing  
22  
23 household tasks aggravated their health condition, the women stated that it also helped to  
24  
25 improve their sense of usefulness in the family. This is also similar to the research by Baker et  
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27 al. (2016) who reported that being able to perform previous routines became an important  
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29 aspect of maintaining normality or continuity from the past.  
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33 The women preferred to hide their illness from those they did not want to disclose to,  
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35 particularly from outsiders. One of the women concealed her heart problems from her family  
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37 out of fear of being a burden and source of stress for others. This concurs with other research  
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39 in Western contexts, which reported women deliberately hid their illness, particularly if the  
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41 symptoms interfered with household duties and caring for others (Currie & Wiesenberg, 2003;  
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43 Galick et al., 2015) or if they assumed they would become a burden to their family (Davidson  
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45 et al., 2008; Medved & Brockmeier, 2011).  
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### 51 **Implication for Nursing Practice**

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53 **This study offers a deeper understanding of female patients’ experience of living with**  
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55 **heart disease.** Despite the diversity in characteristics of study participants’ cultural background,  
56  
57 age, and socioeconomic status, people affected by heart disease share similar experiences of  
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3 emotional, psychological, social, relational, and physical consequences. The findings of this  
4 study provide health professionals, service providers, and policy makers with broad insights  
5 into common elements of people's experiences of heart disease and potential options for  
6 improving their health and wellbeing. It thus has the potential to enhance implementation of  
7 patient-centred care as well as collaborative approaches. Cardiac nurses or other healthcare  
8 professionals should have intercultural competence skills, to enable them to deliver services  
9 that meet the social, spiritual, and cultural needs of their patients. Healthcare professionals  
10 should be aware of the ethnic and cultural backgrounds of the patients so they would be able  
11 to determine the different behaviour of the patients with CVD. In addition, when providing  
12 lifestyle recommendations to the women, a sociocultural context within which patients are  
13 encouraged to make behavioural changes needs to be considered. Lastly, the psychosocial  
14 aspects of care must also be addressed to optimise care for women with heart disease.

### 33 **Limitations**

34  
35 Since this study was only conducted in one single setting in Indonesia, the experience  
36 of the women in this study might not reflect a larger Indonesia perspective. For this reason, we  
37 must be cautious in generalising the findings of this study. However, we made an effort to  
38 contextualise the results so that that the reader can evaluate to what extent our results might be  
39 applicable to other settings. Another limitation of this study lies in the fact that only women  
40 who had undergone cardiac surgery participated in this study. Therefore, the experiences of the  
41 women in this study might be different with the women whose heart disease is medically  
42 managed.

## 56 **5. Conclusion**

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3 As the female patients in this study experienced a combination of reduced physical  
4 capacity, lack of autonomy and control, and inability to perform former roles as mothers/wives,  
5 these conditions had unwittingly managed to threaten the women's sense of self and their social  
6 identity. This study showed how internalised norms and values, as well as expectations from  
7 others, shaped women's experiences with heart disease. The women are expected to perform  
8 the roles of a good mother and/or wife, to place the needs of others before their own, or to  
9 manage the household affairs. For this reason, the women in this study continuously tried to  
10 fulfil what society expected of them regardless of their medical condition. The study findings  
11 extend the literature on women's experiences with heart diseases in which women experienced  
12 the feelings of ambivalence, uncertainty, vulnerability, and how they struggled between  
13 striving to preserve their self, and at the same time they were strongly oriented toward other  
14 people. Further research should be directed to investigate how cultural and spiritual values  
15 affect women's recovery rates from heart disease. Moreover, future research that compare  
16 men's and women's experiences as well as investigate how gender interplays with ethnic or  
17 religious backgrounds and how masculinity and femininity influence illness experiences  
18 should also be conducted.  
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### 43 **Author contribution**

44  
45 Study design: SS, FC, AH

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47 Data collection: SS

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49 Data analysis: SS, FC, AH

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51 Manuscript writing and revisions for important intellectual content: SS, FC, AH  
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## List of tables

Table 1. Interview questions

No	Question
1	<i>Could you describe the events that led up to your admission to the hospital?</i>
2	<i>What was going on in your life after knowing that you suffered from heart disease?</i>
3	<i>What changes (positive and negative) have occurred in your life since experiencing heart disease?</i>
4	<i>How was your typical day before and after you were diagnosed with heart disease?</i>
5	<i>How do you describe the person you are now?</i>
6	<i>What helps to cope with your condition?</i>
7	<i>How have you changed as a person since experiencing heart disease?</i>

Table 2. Participants' characteristics

No	Age	Ethnicity	Marital status	Occupation Status	Religion	Diagnosis*
1	44	Sundanese	Married	Full-time	Islam	MR severe
2	41	Sundanese	Married	Part-time	Islam	MR severe
3	66	Batak	Widowed	Part-time	Christian	MI
4	62	Betawi	Widowed	Part-time	Islam	MI
5	32	Betawi	Divorced	Unemployed	Islam	MI
6	44	Javanese	Married	Unemployed	Islam	MR severe
7	43	Sundanese	Married	Full-time	Islam	MR severe
8	36	Minahasan	Married	Unemployed	Christian	Aortic stenosis
9	54	Javanese	Widowed	Unemployed	Christian	MI
10	44	South Sumatra	Married	Unemployed	Islam	MR severe
11	33	Javanese	Married	Unemployed	Islam	MR severe
12	61	Minangkabau	Widowed	Retired	Islam	MI
13	58	West Nusa Tenggara	Widowed	Part-time	Christian	MR severe
14	53	Javanese	Married	Full-time	Islam	MI
15	36	East Nusa Tenggara	Married	Unemployed	Christian	MR severe
16	42	Batak	Married	Part-time	Christian	Tetralogy of Fallot
17	36	Sundanese	Married	Unemployed	Islam	MI
18	30	Javanese	Married	Unemployed	Islam	MR severe
19	30	Javanese	Married	Unemployed	Islam	MR severe
20	36	Javanese	Married	Full-time	Islam	ASD
21	58	Minangkabau	Married	Part-time	Islam	MI
22	46	Banjarese	Married	Part-time	Christian	ASD
23	55	South Sumatra	Married	Full-time	Islam	MR moderate
24	58	Minangkabau	Married	Unemployed	Islam	ASD
25	55	South Sumatra	Married	Full-time	Islam	MR moderate
26	49	Javanese	Married	Unemployed	Christian	MI

\*MR = Mitral Regurgitation; MI = Myocardial infarction; ASD = Atrial Septal Defect

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"For Peer Review"



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26	49	Javanese	Married	Unemployed	Christian	MI

\*MR = Mitral Regurgitation; MI = Myocardial infarction; ASD = Atrial Septal Defect

Reviewer Comments	Response from authors
Reviewer 1	
<p>You provide a good case for the need to examine heart disease in women. Have previous studies in other countries examined women's experiences of heart disease?</p>	<p>Yes, we have now included some previous studies that examine women's experiences of heart disease in the literature review.</p>
<p>As a reader, I would like to know more information so that I better understand what is known about women's perception of their experience with heart disease, what is not known, and how this study fills the gap. Some of the literature is cited in the discussion section of the manuscript but also should have been included in the review of the literature section of the manuscript.</p>	<p>We have added this information on the introduction section of the study on page 3.</p>
<p>Explain more what you mean about feminists' perspective? How is that perspective applied to the research study?</p>	<p>We added information about feminist perspective on p. 4-5 (study design) and p. 6-7 (data collection and data analysis section). Using this perspective, gender was given considerable attention during the planning, implementation, and data analysis stage.</p>
<p>Why were only women admitted for cardiac surgery eligible to participate in the study? What about women whose heart disease is medically managed? How did this limitation in the sample influence your results and conclusions?</p>	<p>This study was part of a larger study (Sutantri, Cuthill, &amp; Holloway, 2019) to explore women's attendance in cardiac rehabilitation (CR) programme in Indonesia. Due to the limited capacity of the CR centre only women who had undergone cardiac surgery eligible to attend the programme. Hence, this study focused only on women with cardiac surgery. We have added this as one of the limitations of this study. The limitation in the sample might affect the results in the way that the women who participated in this study were in a more severe cardiac condition. This finding might be different if we included the women whose heart disease is medically managed.</p>
<p>How was the feminist framework used to analyze the data?</p>	<p>We incorporated the perspective of intersectionality by continually asking how each individual account was related to broader social relations structure in dominance and contexts (i.e., age, religion,</p>

	gender). We have added this information on p. 7
Your sample size was determined by the number of participants who consented and not by the determination of data saturation. It is important to point this fact out to the reader.	The sample size was based on the data saturation (we have included this information on p. 5)
What was the range and mean number of days post-operative for the participants?	Between 14-days and 48-days post-operative
I think the manuscript should have a separate section titled "Limitations: and a section titled "Future Research." Also, I think a section titled "Implications for Nursing Practice" would be helpful.	Thank you for the suggestions. We have now added these sections.
Reviewer: 2	
The article has potential to make a solid contribution to the field, given its international perspective and feminist commitment. The reporting of IRB authorization and research on Indonesian culture was thorough. The translation protocol seemed reasonable (thought it should be made explicit who on the team performed the translation).	Thank you.
The introduction should more directly address intersectionality. The studies cited on page 3 lines 20 to 37 excluded large populations of minorities and other ethnicities. The intro provides sufficient literature on the Indonesian context, but it should also acknowledge the generalizations about the "women's experience" in the existing literature that differ from developed vs. developing countries.	We have added information about the intersectionality as well as provided the previous studies into women experiences that mostly conducted in developed countries on p. 3
Feminist qualitative methods were not specified. The paper cites framework analysis as the governing model. Feminist qualitative methods would more overtly reflexivity (on the part of researchers and participants), collaboration, power analysis, and advocacy. For example, it would involve member checking during the manuscript drafting stage in addition to the interviewing stage (page 8 lines 14 to 21). See Olesen et al. 2010, Hesse-Biber 2013,	We applied feminist perspective in the stages of our research process: from the planning, the implementation, and the analysis, including reflexivity. We offered the women an opportunity to review their interview transcript (p.7). In terms of collaboration, we incorporated a collaborative approach during the interview with the women to avoid creating a hierarchical relationship (p. 6)

McHugh 2014.	
<p>Since numbers of quotes were not used to justify themes presented in the results, a more detailed explanation of what determined and confirmed which codes or themes were most important--consensus? member checking? saturation? Why were the themes chosen that were chosen other than they seemed to answer the questions on their face? It was unclear from the methods whether inductive or deductive coding analysis was employed. As the results are presented currently, they appear to be a content analysis (deductive) searching for themes that correspond to the research question. The methods should state the approach specifically. It seems that the methods did not include a selective or axial coding stage where codes were combined into themes and overarching concepts in a model. For example, problems with physical limitations (its own code) seem equivalent to or pervasive in housework, social participation, and job employment. The relationship is not indicated in the results. Rather, all are treated as codes equivalent to physical limitations without the model demonstrating the clear relationship between those codes. The section on family relationship effects was better--it identified unique and distinct dimension of changes within women's family relationships. However, the subsection should provide a summary or description of the interrelationship between the themes as a preface before the first sub-code (3.2.1).</p>	<p>We have added the information regarding this on the manuscript p. 7.</p> <p>We made sure that the research process was both structured and iterative, moving from micro to macro data. The iterative process ensured that the overall context of the data was not lost in fragmentation, and also that all of the data was finely examined.</p> <p>The data analysis involved a data-driven inductive approach by using a framework analysis approach. One of the steps of data analysis was data abstraction and interpretation. The stage of mapping and interpretation involves the process of analysing the similarities and differences of the key characteristics, as laid out in the framework matrix. To interpret the data, we followed the steps that have been outlined by Ritchie, Lewis, McNaughton Nicholls, and Ormston (2014).</p> <p>Initially, we read through a few data summaries relating to a theme or subtheme that were produced using the framework to map and interpret the identified differences and similarities. Then we listed the elements that characterise and differentiate the responses. Once elements had been identified, we sorted the elements that fitted together according to the underlying dimensions. Following that, we examined the data again, combined elements into different types of responses in order to produce a set of categories that is able to discriminate different manifestations of the data. Each emerged category was given a label reflecting its contents.</p>
<p>The narrative should also explain the codes in relationship to the condition diagnosis and treatment. The dimensions coded reflect responses to condition treatment and maintenance. However the literature review describes clinical problems or differences between men and women with disease symptom presentation. Both are individual level, but one is pre-diagnosis or during</p>	<p>We have revised our literature review accordingly, so that the focus of this study is the condition of treatment and recovery instead of diagnosis and treatment.</p>

<p>diagnosis, and the other involves issues of adherence and maintenance. For this reason, the literature review should focus on statistics and research on treatment adherence and survivorship quality of life for women diagnosed with and treated for CVD, rather than stats about prevalence or diagnosis differences.</p>	
<p>The conclusion should also contain a discussion about intersectionality. In particular, it should describe how the manuscript's findings extend the literature on quality of life for women diagnosed with and treated for CVD. How do the particular pressures of Indonesian culture on women make their experience managing CVD different than women in developing cultures, which is the focus of most if not all of the existing literature? (See also, in addition to the studies cited, PMID 19811254 and 17371474.) The conclusion does a solid job of presenting evidence about Indonesian culture and how it might be seen as informing participants' survivorship experiences. However, it should include a discussion drawing distinctions and differences between managing these same or similar dimensions in Western contexts.</p>	<p>We have revised accordingly. The study findings extend the literature on women's experiences with heart diseases in which women experienced the feelings of ambivalence, uncertainty, vulnerability, and how they struggled between striving to preserve their self, and at the same time they were strongly oriented toward other people.</p>
<p>The conclusion should also discuss more limitations. For example, it was unclear whether the sample of participants represented (employment status, age) the population of women in Indonesia who are typically diagnosed with CVD. Also, the conclusion should explicitly mention directions for future research in addition to clinical suggestions. There were misspellings and punctuation issues, so another round of proofreading is also in order.</p>	<p>We added a separate section that listed all the limitations of the study. The direction of the future research has also been added to the conclusion section. We also have already done another round of proofreading to check the spellings and punctuations.</p>

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16 Sutantri, S., Cuthill, F., & Holloway, A. (2019). 'A bridge to normal': a qualitative study of  
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