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‘A bridge to normal’: A qualitative study of Indonesian women’s attendance in a phase two cardiac rehabilitation programme

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ABSTRACT

Background. Cardiac rehabilitation (CR) is effective in reducing mortality and morbidity, in improving life expectancy and quality of life for people with cardiovascular disease. Despite these recognised benefits, women's attendance rates in cardiac rehabilitation programmes remain sub-optimal.

Aims. This paper details the study that explored factors that influence women's attendance of a phase two CR programme in Indonesia

Methods. An exploratory qualitative research design was carried out in the study. Semi-structured interviews were used as the main method of data collection. Data were collected from June to September 2016. Twenty-three women aged between 30 and 66 years were interviewed. Transcribed interviews data were analysed using a qualitative framework analysis.

Results. Three major themes were inferred from the analysis: (1) a bridge to normal, (2) connecting with others and (3) contextual factors. The first theme is illustrated by two subthemes: 'making my heart works again' and 'performing social roles'. The second theme was illustrated by the following subthemes: 'exchanging knowledge and experience' and 'developing a give-and-take relationship'. The third theme was illustrated by three subthemes: 'recommendations from the staff', 'family support', and 'availability of health insurance'.

Conclusion. Women's attendance in CR in Indonesia is mainly influenced by their expectations and desire to be able to resume their previous social roles in the family and society. The findings of this study can assist healthcare professionals to better understand the needs of women and the fit between women's needs and existing CR programmes.

Such understanding could provide direction for more effective approaches to the CR programmes that are currently offered in Indonesia.

Key words: women, cardiac rehabilitation, cardiovascular disease, rehabilitation, gender roles, qualitative

1. Introduction

Although traditionally cardiovascular disease (CVD) has been commonly perceived as a male disease (1, 2), it is a leading cause of death for both men and women worldwide (3, 4). The World Health Organisation (WHO) reported that approximately 17.5 million people died from CVDs in 2012, which contributed to one-third of total deaths worldwide (4). The WHO reported that roughly a third of the total deaths in Indonesia are attributable to CVD (5), with stroke and coronary heart disease (CHD) being the leading cause of deaths in the country (6).

A cardiac rehabilitation (CR) programme can offer a coordinated and multifaceted intervention, including: a) exercise-based training, b) patient education, c) psychological intervention, d) interdisciplinary support, and e) risk reduction to promote secondary prevention (7). Numerous studies have demonstrated that CR is effective in improving the prognosis and the quality of life for patients with CVD (8-10). Due to its effectiveness, CR has been recommended as a Class IA recommendation for CVD patients (11). Despite the acknowledged benefits, attendance rates at CR remain poor globally, ranging from only 20% to 50% (12-16). In addition, although men and women receive similar benefits from CR intervention (17), women were still less likely than men to participate in the CR programmes on offer to them (18, 19). The reasons for women's lower participation in CR programmes are multifactorial, including patient-level factors (i.e. work- and family-related obligations)(20), practical factors (i.e. distance and transportation issue)(21, 22), health-system/provider factors (i.e. lack of referral) (23).

There is a lack of understanding or evidence regarding women's participation in CR programmes in Indonesia. Although there has been an awareness of the women's

lower participation in CR in a Western context for more than two decades, there is still a scarcity of research that has provided insight into Indonesian women's actual experiences of CR. In Indonesia, women are often perceived as 'inferior to men' within cultural, religious, and political contexts (24). Indonesian women also face distinctive challenge as they are expected to be responsible for maintaining and preserving harmony in the family (25); a context in which women are required to submit, keep quiet, and make sacrifices for the family. This condition might influence women's decision to follow intensive treatment in the hospital, such as CR programme. Tod et al. (26) reported the potential influence of culture on CR attendance, which indicated that research should include the variable of a different cultural background. As such, this study aims to explore the factors that influence women's attendance in a phase two CR programme in Indonesia; factors which are neither well understood nor well documented in the existing literature. Hopefully, insights will be gained into ways to improve CR programmes that can then be implemented in other countries. To the best of our knowledge, this qualitative study will be the first study in this area of research to be conducted within an Indonesian context.

2. Methods

2.1. Design

An exploratory qualitative research design using semi-structured interviews was employed to investigate women's participation in a phase two CR programme. The epistemological stance supporting this research was based on social constructionism, which assumes that social reality is socially constructed through sustained social interactions and relationships (27).

2.2. Setting and sample

The study was conducted in an outpatient CR centre in the National Cardiovascular Centre (NCC), in Jakarta, Indonesia. The CR programme was carried out in a mixed-gender setting for both men and women (see Table 1 for the overview of the CR). Phase two CR is the early outpatient phase of CR, during which the patients participate in a structured and closely monitored programme of physical activity, psycho-education activities, and counselling.

A purposive sampling method was adopted to select study participants. A total of 23 adult women aged between 30 and 66 years participated in this research (Table 2). The criteria for selection of the participants were (1) women who were over 18, (2) had experienced a 'cardiac event', (3) were referred to and enrolled in the phase two CR programme for the first time within the last three months prior to data collection. There was no limitation concerning the participant's diagnosis. The CR nurses who were acting as the study's gatekeepers approached the patients about the possibility of participating in the study. None of the participants that were approached refused to participate in the study. The study participants came from different locations in Indonesia, with 11 of them living in Jakarta city. The other group members came from more rural areas such as Sumatra, Kalimantan, Sulawesi, Java, and Nusa Tenggara. Participants and interviewer had not met before the women were recruited to the research.

2.3. Data collection

One to one interviews were carried out between June and September, 2016 in the hospital setting at a date and time which were entirely the participant's choice. The interviews were conducted after the women had at least completed their sixth session

(half of the programme). The first author (SS), an Indonesian academic hence familiar with the cultural discourse espoused by the study participants, conducted the interviews using a semi-structured interview guide and probing techniques in the Indonesian language. All authors are experienced in qualitative research. The interview guide was pilot tested with two women to check the clarity of the questions. The duration of the interviews ranged from 30 to 75 minutes. The following interview questions were used: a) ‘what did you know about CR programme?’, b) ‘what was your motivation of attending the programme?’, c) ‘how did you decide to attend CR programme?’, d) ‘what did you expect from attending this programme?’, and e) ‘what facilitators and barriers of attending the programme?’. All the interviews were audio-recorded and transcribed verbatim. Field notes were written soon after the interview to capture the context.

2.4. Data analysis

Data were analysed using a framework analysis method developed in the 1980s by Jane Ritchie and Liz Spencer at the National Centre for Social Research in the UK (28). There were five stages of analysis in this study: (1) familiarisation with the data (i.e. read and re-read transcripts, listened back to the audio recorded interviews) to increase familiarity; (2) constructing an initial thematic framework (i.e. emergent issues arose from the process of familiarisation); (3) indexing and sorting the data (i.e. initial thematic framework was applied to the data); (4) charting (i.e. the data is rearranged according to appropriate themes in the framework matrix with summary of the participants’ quotes); and (5) mapping and interpreting the data (i.e. the participant accounts were compared to find differences and similarities). All authors independently read and re-read five of the interview transcripts that were translated into English by SS to develop an initial thematic

framework. This initial thematic framework was then discussed with the team during the regular team meetings to review the list of the themes and initial memos to check for inconsistencies, clarifications, or missing themes. After the initial thematic framework was constructed, SS then coded the rest of the data. Throughout this process, the authors continued to hold regular meetings to refine the analysis, reach a consensus, and thus finalise the extracted themes. Also involved was a computer-assisted qualitative data analysis, NVivo version 11 that offered a framework matrix feature.

2.5. Ethical considerations

Ethical permission for the study was obtained from the Research Ethics Committee at the University of Edinburgh and the local hospital in Indonesia. The research conformed to the principles outlined in the Declaration of Helsinki (29). All participants received thorough information about the study and were informed that their participation was voluntary and that they could withdraw from the study at any time with no consequences. Informed consent was obtained from all the participants who agreed to participate in the study. To ensure confidentiality, all identifiable information about individuals was removed from all published data extracts. Rigour was achieved through credibility, transferability, dependability, and confirmability as outlined by Lincoln and Guba (30) (Table 3).

3. Findings

The inductive analysis resulted in the identification of three major themes related to factors that influence women's attendance in the CR programme: (1) 'a bridge to

normal’, (2) ‘connecting with others’, and 3) ‘contextual factors’. Original quotations from participants are presented to support the findings.

Theme 1: A bridge to normal

This theme illustrate how CR programme were perceived by the women as an important step that helped them to regain their self-confidence, which ultimately facilitated them to resume their position within the family and community. In this light, CR has become a bridge across which the women can access competence and knowledge so as to re-engage with their former activities, including family, friendships, and employment. Hence, two sub-themes that fell under this main theme were: (i) ‘making my heart works again’, and (ii) performing social roles.

Subtheme 1.1. ‘Making my heart works again’

Throughout the interviews, the participants explicitly stated that their primary goal for participating in the CR programme was to be able to achieve similar levels of activity and well-being that they had enjoyed prior to their diagnosis. The women stressed the importance of being physically fit again so that they would be able to perform their social roles in the family and society. One participant stated:

“Well, I think it is a must. We must participate in the rehab programme, right? For us, this is also to make our heart to work again, that’s good, right? [...] I want my body to be fit, after the surgery... so my heart will be normal again.” (P18)

Subtheme 1.2. Performing social roles

Throughout the interviews participants reported that heart disease challenges family harmony, particularly in the aspect of family’s habits/routines, as well as imposing

burdens on their family members. For the women who participated in this study, the significant impact of their illness had prevented them from being able to perform their normal role functions as spouses, mothers or grandmothers. Since domestic functions and caring roles were of high value and a central component of the participants' sense of self, being unable to perform those functions had created a high degree of emotional turmoil for the women.

“I want to be healthy again, so I will have more energy to do my daily activities. I also need to be healthy for my family so that I would be able to serve my husband better. [...] I wish that I could take care of my family again. Because I believe that, a wife is the anchor of the family, right?” (P10)

By attending CR, the women expected that they would be able to restore their former roles in the family that has been disrupted by their recent cardiac event. Many participants stated that what made them continue their participation in CR programme was wanting to return to their family and be able to perform the household tasks again.

“I want to make my husband and children happy. More importantly, I want to take care of my husband. Due to my illness, it's been several years that I couldn't fulfil my duty as a good wife. I want to do that again.” (P7)

“I want to have a fast recovery. [...] I want to work again. At least I can contribute to the family income, to get some pocket money for our children.” (P2)

Theme 2: Connecting with others: being in the same boat

Participants explained that one of their primary reason to attend and continue their participation in the CR programme was because they had the opportunity to meet and interact with other patients on a regular basis. They described that meeting other patients with a similar condition helped them to reduce the feelings of alienation and gave them a sense of normality. Further, they stated that the interaction, discussion and exchanges

with peers became a source of moral support to them. Many of them described the social support given by other participants as the feelings of *'being in the same boat'*.

Subtheme 2.1. Exchanging knowledge and experience

Being able to exchange information with other patients who had a similar cardiac experience was cited by the participants as another reason for their attendance in the CR programme. In this way, camaraderie with other patients became a source of comfort as the women disclosed their struggles of living with heart disease. One woman stated:

"I decided to join because here I have many friends, people that had gone through the same thing. So, I think it's good. It gives me spirit. It's better to join. If I only stay at home, what am I going to do? That's it. I feel better here, joining rehab, good for my body." (P9)

Another participant echoed the above statement by stating:

"I could share the experience with other participants so I didn't feel like the only person who went through this hardship." (P8)

The above narratives illustrate how the CR programme provided women with reassurance and a sense of comfort, once they realised that they were not alone in their concerns and challenges.

Subtheme 2.2. 'Developing a give-and-take relationship'

The mutual give-and-take emotional process with other participants through problems sharing, support, and encouragement was identified as an important factor that influenced women's continued attendance in their CR programme. These activities have helped the women to feel less of a burden because they had the opportunity to help others with a similar condition to their own. In return, the women also described how they

became more open to receive support and encouragement from others. One participant stated:

“[...] It’s really nice to be here. I think it really helped other patients. Because we support and motivate each other. [...] I feel like I found a new family; I found sisters. Like that. We do everything together. We joke with each other. The togetherness makes us happy, so we are not feeling alone. It is much better than just staying at home and doing nothing.” (P7)

The data show that interacting with other women in the CR programme, was useful to alleviate participants’ anxiety and loneliness. They found comfort in the process of exchanging experiences, fears, and frustrations with others. In contrast, one participant who decided to withdraw from the CR programme described that she felt different from others since she was affected by hemiparesis (weakness in the left-side of the body). Hence, she felt embarrassed as she could not exercise at the same level as the other patients in the programme.

Theme 3: Contextual factors

This theme presents the contextual factors that influence women’s attendance in CR: a) recommendations from the staff, b) support from family, and c) availability of health insurance.

Subtheme 3.1. Recommendations from the staff

Recommendations from a physician or other allied health professionals were reported as an essential reason for the women to enrol in the CR programme in this study. All participants explained that the hospital staff visited them while they were still in the hospital, prior to their discharge. The staff explained all aspects of the CR programme to them, including: a) the components of the programme, b) the purpose of CR, c) the

programme's duration, and d) what was expected of them as 'the clients'. The benefits of CR, as well as the negative consequences of not following the programme, were also explained.

"When I was still in the ward, mm, someone came to me. [...] Then he brought me to the rehabilitation unit, and I got counselling about the programme." (P3)

"Well, the doctors told me to do so. I just followed it. Because, since the beginning, my intention was to get treatment from here, so I should obey all their suggestions to me." (P6)

Subtheme 3.2. Support from family

A large majority of the participants explained that they received a great deal of support from their spouse and family members, following their cardiac event. In fact, almost all the participants that were interviewed in the CR centre came to the programme accompanied by a family member. However, one participant had to make an early exit from the CR programme since she had no family member to stay with her in Jakarta since the rest of the family lived in a different island.

"Yeah my children supported me a lot. Sometimes, I feel lazy to attend the session, they told me to keep continuing it. They asked whether I was exhausted or not. I said no, so they pushed me to come to the session. Everything comes from my children actually, because you know, they supported me financially, they paid for everything." (P4)

The women in this study also expressed their appreciation and gratitude not only for the material and emotional support given by their family and friends, but they also cited spiritual support as extremely important for them. One participant shared:

"The most important support is prayer. Although my friends and neighbours could not come to see me in the hospital, all of them sent their prayers for me so that I could recover and be normal again." (P7)

Subtheme 3.3. Availability of health insurance

From the perspective of cost, the availability of insurance to cover the cost of the programme became a significant factor that influenced women's participation in the CR programme. One participant commented:

“I feel so grateful with this insurance coverage from the government. Without it, I don't think that I would have made it so far.” (P21)

The data indicate that all participants in this study were protected by the government insurance scheme that covers all medical costs including the CR fee. One participant affirmed:

“Yes everything has been covered by the government insurance scheme. We just spend money on our personal expenses, such as food and accommodation. So, my rehab is also being covered by insurance. I think the service is excellent!” (P7)

3. Discussion

This is the first study within an Indonesian setting that has explored the factors that influence women's participation in CR. The study revealed that the participants' expectations of the benefits of CR became one of the main reasons for their enrolment in the phase two CR. They believed that the programme could help them to 'become a normal woman' again, as prescribed by the Indonesian sociocultural system. Maintaining harmony in the family has been recognised as an important responsibility for a woman within Indonesian society (25). This aim would be achieved by firstly regaining their physical health, which in turn will restore their social standing in front of family and others. Based on the cultural expectations and social norms in Indonesia, women are expected to fulfil gendered expectations, such as: a) being the caregiver in the family, b) doing household chores, c) serving her husband, d) contributing to community

development and e) to fulfil social obligations at the community level (31). Belief in benefits from CR was also identified as one of the personal enablers for CR participation in Western countries (32).

Dewi et al. (33), in their study of the perceptions of CVD among Javanese people (Indonesia), found that balance and harmony are central to the participants' understandings about their disease and ways of managing cardiovascular illness. In this study, the ultimate goal of each woman's recovery was to be able to be part of their family again, as well as to reclaim their previous social roles as a mother and a wife. Being able to re-engage with what traditionally has been seen as 'female' household tasks was the most critical driver of participants' attendance in the CR programme. In this sense, the findings suggest that women considered CR as a *bridge* to prepare them to return to their 'normal' lives, as well as restoring them to their 'correct' social position. This conclusion resonates with the findings of previous studies in the US and Canada which reported that the intrinsic motivation of the women's attendance in their CR programme was to reclaim their independence so as not to be a burden to their family (34). More importantly, the central concern of participants' attendance in the CR programme was to restore their social dignity within other fields that had been affected by their illness, such as: family, home, employment, and social life (35).

A qualitative study on men and women's experiences following a cardiac incident found that women felt more isolated as compared to men in their experience of heart disease (36). The women in this current study clearly stated that the opportunity to meet and interact with other patients on a regular basis became one crucial factor that facilitated their continued attendance in the CR. Participants found a unique two-way connection with other patients as they shared a similar experience of living with heart disease. The

relationship with other women was identified as equal and non-hierarchical which in contrast with their experience in the medical provider-patient relationship (37). Making friendships was a significant phenomenon that was considered by participants as empowering and which facilitated the process of recovery following the cardiac event. The feelings of being less of a burden and having the opportunity to help others with a similar cardiac condition helped the women to regain a sense of normalcy in their lives. In this sense, phase two CR is a bridge where the women developed mutual relationships, as well as a forum where they can share their concerns and experiences. However, the findings also demonstrate that the issue of feeling different from one's peers has been seen as a significant barrier to continued CR participation.

Many participants in this study decided to take the rehabilitation programme because of recommendations from the NCC staff. A vast number of studies have consistently identified referral or recommendation from healthcare professionals as an enabling factor in CR enrolment for both men and women (38-41). Culturally, Indonesian society generally holds health care professionals, particularly physicians, in high regard. This general notion is also common among other South Asian countries. South Asians view a physician as an authoritative and knowledgeable person that rarely makes mistakes, as well as a person who has a deep and thorough understanding of the patients' conditions (42).

The collectivist culture in Indonesia gave an advantage to the women in this study as they could easily receive support from the nuclear/extended families or friends. Support from family became a significant factor that led to women's participation and completion in the CR programme. This support not only helped them to cope with the immediate impact of their illness but also positively influenced their decision to attend

the CR programme. However, healthcare providers should not assume the presence of a family network as synonymous with family support (43). Being surrounded by family members, or having spouses or partners, does not necessarily guarantee that women receive the kind of support that they need (44). Furthermore, the pragmatic consideration of medical insurance availability to cover the cost of the programme has also been cited by the participants as another critical factor regarding their attendance in the CR programme.

Although many studies suggest social roles associated with childcare, housework, and family life as barriers to women's participation in the CR programme (20, 26, 45-47), almost all the women in this study managed to complete the phase two CR. However, since this study was only conducted in one single unit of CR in Indonesia, the authors are aware that the evidence from this study may not reflect the larger perspective. Although the 23 women interviewed in this study came from diverse cultural and ethnic backgrounds, their experiences still cannot be considered as representative of all women in Indonesia; therefore, generalising the findings from this study is not possible. Another limitation of this study was related to the study's participants; the focus was on female participants in a CR programme. Hence, the findings might be greatly different to the experience of the women who were not attending CR. In addition, all the women in this study had undergone cardiac surgery; non-cardiac surgery patients were ineligible for this particular CR programme, and so were excluded. Therefore, the women in this study were all in a serious medical and physical condition, which may also have influenced both their illness experiences and subsequent decisions to attend the CR programme.

4. Conclusion

Having a particular understanding of Indonesian women's experiences, where the concept womanhood revolves around a woman's primary roles as a mother and a wife, provides a practical insight into improving women's participation in CR. This study revealed that Indonesian women's decisions to attend a CR programme were mainly influenced by their expectation and desire to restore themselves to a pre-cardiac event level. Such a recovery would mean they would once again be able to resume their social roles in the family. The study also highlighted the importance of social connections and relationships with other patients in the CR programme as being one of the most critical factors that facilitate the women's continued attendance in CR. The findings of this study can assist healthcare professionals to better understand the needs of women and the fit between women's needs and existing CR programmes. Therefore, future work to increase CR attendance in Indonesia should be both gender- and culturally-sensitive to the needs of female CVD patients. In addition, future research would be best directed at investigating the reasons for women's non-participation in, or dropping out from, CR programmes in Indonesia or other Asian countries.

5. Implications for practice

- The implementation of a recovery-focused approach with a holistic perspective on health to assist CVD women in their transition to recovery.
- The inclusion of the family and close friends in the planning of women's care should be considered in any initiatives designed to improve the uptake of CR.
- Development of women's support groups in CR as well as providing an effective insurance scheme would probably be beneficial in facilitating women's participation in an Indonesian context.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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LIST OF TABLE

Table 1. Overview of the phase two CR programme delivery in the hospital

Phase 2	<p>Intensive physical exercise delivered in the outpatient CR centre (duration: 2-4 weeks, delivered in daily mode for the patients living in the outside of Jakarta, and three times per week for patients living in Jakarta city, 60 min duration each session, total: 12 session. Content of the session:</p> <ul style="list-style-type: none"> - 10 min warm up - 10 min static bike with a gradual increase of intensity - 20 walking with a gradual increase of distance - 15-20 min treadmill <p>Educational activities 2-3 times per week Psychological counselling</p>
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Table 2. Participants' characteristics

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

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

Table 3 Rigour of the research

Credibility	Prolonged engagement with participants, informal member-checking strategies, and peer-debriefing were carried out.
Transferability	A detailed description of the research setting, methods, participants, as well as the theoretical assumptions underpinning the study were provided
Dependability	The used of NVivo 11 to store and manage the data was aimed to facilitate audit trail in order to enhance dependability.
Confirmability	To enhance confirmability, the procedure for checking and rechecking the data throughout the study was documented. Throughout the analysis process, interpretations were constantly shared and discussed between the research team.
