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A qualitative study on the challenges cardiac patients face in their life during the perioperative phase of their open heart surgery

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Abstract

Background. Despite becoming more and more successful in saving lives, open heart surgery is often experienced as a life threatening event and is associated with fear and depression. While research and treatments focusing on improving mental states in cardiac patients are rising, research focusing on patients' experiences regarding de period surrounding cardiac surgery is mostly unexposed. In order to understand what makes open heart surgery such an impactful event and to provide optimal support, insight in patients' experiences is needed. This qualitative study aims to clarify patients' experiences of the perioperative phase of their open heart surgery.

Methods. Six patients treated with coronary artery bypass surgery or heart valve replacement were in-depth interviewed. First of all, participants reflected on their experiences preceding surgery in relation to their health, physical complaints and daily functioning. Secondly, the period surrounding and following surgery was questioned. Participants were among other things asked about their recovery, their hospital period and complaints related to surgery and health. Interviews were audio-recorded, transcribed verbatim and analysed inductively.

Results. Four major themes (and 18 subthemes) were identified: (1) Somatic burdens, (2) Mental burdens, (3) Experiencing unpleasant emotions and (4) Experiencing a lack of professional support. Regarding to the somatic burdens, patients for example experienced intense pain, minimal endurance and complications following their surgery. When it comes to mental burdens, patients for example experienced a poorer memory and a loss of trust in their body. Patients experienced unpleasant emotions as fear, loneliness, depressive mood and patients became more emotional in general. Regarding professional support, patients experienced they have not been taken seriously, have not being fully informed and have underestimated the recovery of open heart surgery.

Conclusions. Patients seem to underestimate the duration and intensity of the recovery after open heart surgery and struggle with the acceptance of their new life situation and its consequences. Raising awareness of the seriousness of cardiac surgery and creating a sufficient social network can possibly contribute to better dealing with the before and aftermath of cardiac surgery. Making use of an intervention that is flexible in its approach of participation and is based on concepts stemming from positive psychology may be a valuable contribution in supporting cardiac patients during the perioperative phase of cardiac surgery.

Keywords: Patients experience, Cardiac disease, Cardiology, Open heart surgery, Cardiac surgery, Challenges, Qualitative, Interview

Samenvatting

Achtergrond. Ondanks het feit dat openhartoperaties meer en meer succesvol worden in het redden van levens worden deze ervaren als levensbedreigend en worden ze geassocieerd met angst en depressie. Terwijl onderzoek en behandeling gericht op het verbeteren van de mentale gezondheid onder hartpatiënten toeneemt, blijft onderzoek gericht op patiëntervaringen betreffende de gehele fase rondom de hartoperatie onderbelicht. Om te kunnen begrijpen wat maakt dat openhartoperaties als een dermate impactvolle gebeurtenis worden beschouwd en om patiënten optimale steun te bieden, is inzicht in patiënten hun ervaringen nodig. Huidig kwalitatief onderzoek tracht patiëntervaringen over de perioperatieve fase van hun openhartoperatie te verhelderen.

Methoden. Zes patiënten behandeld met een bypassoperatie (coronary artery bypass surgery) of aortaklep vervanging hebben een diepte-interview ondergaan. Ten eerste reflecteerden participanten op hun ervaringen voorafgaand aan de operatie gerelateerd aan hun gezondheid, fysieke klachten en dagelijks functioneren. Vervolgens is gevraagd naar de periode rondom en na de operatie. Er is participanten onder andere gevraagd naar hun herstel, klachten gerelateerd aan de operatie en gezondheid, en ziekenhuisopname. De interviews zijn audio opgenomen, schriftelijk getranscribeerd en inductief geanalyseerd.

Resultaten. Vier hoofdthema’s (en 18 subthema’s) zijn geïdentificeerd: (1) Somatische lasten, (2) Mentale lasten, (3) Ervaren onaangename emoties en (4) Ervaren gebrek aan professionele steun. Wat betreft somatische lasten ervoeren patiënten onder andere intense pijn, een minimaal uithoudingsvermogen en complicaties na hun operatie. Wat betreft mentale lasten ervoeren patiënten bijvoorbeeld een slecht geheugen en verloren het vertrouwen in hun lichaam. Patiënten ervoeren onaangename emoties als angst, eenzaamheid en depressiviteit en voelden zich in het algemeen emotioneler. Wat betreft professionele steun gaven patiënten aan zich niet serieus genomen gevoeld te hebben, niet volledig geïnformeerd te zijn en het herstelproces van de openhartoperatie te hebben onderschat.

Conclusies. Patiënten lijken de duur en intensiteit van het herstel na een openhartoperatie te onderschatten en worstelen met de acceptatie van hun nieuwe levenssituatie en de bijbehorende consequenties. Het vergroten van de bewustzijn van de ernst van hartoperaties en het creëren van een voldoende sociaal netwerk draagt mogelijk bij aan een betere omgang met de voor- en nasleep van hartoperaties. Het gebruik van een interventie die flexibel is in haar benadering van participatie en gebaseerd is op concepten die voortkomen uit de positieve psychologie, kan mogelijk een waardevolle bijdrage leveren aan de ondersteuning van hartpatiënten gedurende de perioperatieve fase van een hartoperatie.

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Introduction

Open heart surgeries are offered to more patients than ever before and become more and more successful in saving lives. To improve prognosis and patients’ chance of survival on one of the leading causes of death in almost all countries of the European Union (cardiac and vascular disease), almost 15.000 open heart surgeries are carried out in the Netherlands every year (Nederlandse hartstichting, 2018; Van Veghel, 2014). The most commonly performed procedure is the Coronary Artery Bypass Grafting (CABG), followed by the isolated Aortic Valve Replacement (AVR), which both have shown to have a mortality rate of only 3 percent (D’Agostino et al., 2018; Hoyer et al., 2008; Visser, 2012).

Having to undergo open heart surgery often has a big impact on patients’ life during the pre- and postoperative phase and is associated with fear and depression (Tully & baker, 2012). Cardiac surgery is experienced as a crisis or life-threatening event for most patients (Deyirmenjian, Karam, & Salameh, 2006). Between 30 to 40 percent of the CABG surgery patients experience depression and anxiety disorders at rates significantly higher than prevalent in the standard population, and mental health comorbidities are common in the course of open heart surgery (Pignay-Demaria, Lesperance, Demaria, Frasure-Smith, & Perrault, 2003; Tully & Baker, 2012). The states of anxiety and depression can persist until after the surgery and contribute to worsening the patient’s psychosocial functioning, quality of life and psychological well-being (Rymaszewska, Kiejna, & Hadryś, 2003). Furthermore, almost half of all patients experience difficulty in adjusting to life after heart surgery (Andrew, Baker, Kneebone, & Knight, 2000; Hoyer et al., 2008; Theobald & McMurray, 2004). According to research of Karlsson, Johansson, and Lidell (2005) patients knew that guarantees for permanent good health could never be given, and patients they had to live with this uncertainty for the rest of their lives. When it comes to patients’ experiences, it was found that during the waiting time for surgery the patients struggled against physical weakness, chest pain, anxiety and feelings of uncertainty. Lindsay, Smith, Hanlon, and Wheatley (2000) found that the patients generally realized the surgery had been a greater challenge than they had expected it to be and were prepared for.

To help patients cope with the challenging situation regarding cardiac surgery and to improve their psychological states, multiple studies and interventions have been developed. Psychological treatment often is a component of cardiac rehabilitation. These programs are largely similar, in that they use cognitive behavioural interventions to reduce distress and teach self-regulation skills (Linden, Phillips, & Leclerc, 2007). Preoperative education is used to improve patients’ experiences by providing relevant information about health care, coping skills and psychosocial support before surgery (Kruzik, 2009; Scott, 2004). Besides cognitive behavioural treatment, positive psychological treatment is getting more support in the recovery of cardiovascular illness. The relatively new field of positive psychology is a framework for how people achieve improved quality of life, which focuses on enhancing well-being and optimal functioning (Chakhssi, Kraiss, Sommers-Spijkerman, & Bohlmeijer, 2018; Seligman & Csikszentmihalyi, 2000). Increasing research supports the idea that positive psychological factors may play a critical role in cardiovascular health and recovery from illness (Boehm & Kubzansky, 2012; DuBois et al., 2012). ‘Positive psychological factors’ refer to strengths, capacities and personal resources as positive emotions [e.g., happiness] and cognitions [e.g., optimism, gratitude] (Chakhssi et al., 2018). Treatments aiming to boost positive psychological well-being seem to have the potential to improve outcomes in patients with cardiac disease (Huffman et al., 2011). Cardiac patients who followed a positive psychology intervention (that focused on optimizing positive psychological factors) experienced improved happiness and hope and had lower depression outcomes (Nikrahan et al., 2016).

While research and treatments focusing on improving mental states in cardiac patients are rising, patients’ perspective is often not taken into account. There seems to be a scarcity of research based on patients’ experiences focusing on the perioperative process of AVR and CABG open heart surgery. The few qualitative researches that did focus on patients’ experiences on undergoing cardiac surgery primarily focus on physical complications and discomforts during the immediate postoperative period (Doering, McGuire, & Rourke, 2002). It is valuable to gain knowledge on patients’ experiences in a broader time range which also focus on the mental impact of cardiac surgery. These patients’ experiences may explain negative postoperative outcomes, such as induced depression and anxiety. By gaining knowledge on patients’ experiences, it will hopefully become possible to optimize the match between the needs of the patients and given treatment during the perioperative phase of cardiac surgery. It is believed that when treatment is meaningful to the patient and fulfils its needs, the quality and efficiency of treatments and eventually health outcomes could improve (Coulter & Ellins, 2007; Van Gemert-Pijnen, Kelders, Kip, & Sanderman, 2018).

In order to understand what makes open heart surgery such an impactful event, insight in patients’ experiences is needed. The aim of this qualitative study was to clarify patients’ experiences regarding the perioperative phase of their open heart surgery. The following question is addressed: What are the challenges cardiac patients face during the perioperative phase of their open heart surgery? With the results of this study we will hopefully come a step closer to providing optimal support for patients, by developing treatment that takes patients' perspective into account and fully fits the needs of the users – cardiac patients during the perioperative phase of open heart surgery.

Methods

Study design and Ethical approval

A qualitative research design was chosen to gain insight into the challenges and experiences of cardiac patients regarding the perioperative phase of open heart surgery. Semi-structured interviews were conducted. This study was approved by the Ethical Committee of the University of Twente (no. BCE 15309).

Participants

Cardiac patients were recruited at the cardiology department of a Dutch hospital, in an area in the east of the Netherlands (Twente). Patients had to have undergone an AVR or CABG in the last 12 months and be at least 18 years of age. During one day, a nurse specialist asked her visiting cardiac patients that met the research criteria if they would be interested to be approached for research. Six patients were selected and received a letter informing them about the study and asking them to participate. The choice for this selection was made based on gender and age distribution, to assure the heterogeneity of the participant group. After a week the researcher contacted the six selected patients by telephone, suggesting a meeting for the face-to-face interview. All six approached patients indicated that they were willing to participate in the interview and were included in the research. Patients who were not selected, received a letter of thanks stating that their participation was no longer needed and were thanked for their willingness to be approached. In total, six interviews were conducted. The participant group included three women and three men, whose age varied from 63 to 79 and whose mean age was 69. Two of the patients have had an aortic valve replacement and four underwent an CABG. These and other personal characteristics are shown in Table 1.

Table 1.

Personal characteristics of the participants (n=6)

Participant no.	Gender	Age	Education level	Occupational status	Children	Type of surgery
1	Female	64	Low	Unemployed	Living away from home	AVR
2	Female	73	Middle	Retired	Living away from home	CABG
3	Female	65	Low	Retired	Living away from home	CABG

4	Male	76	High	Retired	Living away from home	CABG
5	Male	78	Low	Retired	Living away from home	AVR
6	Male	62	High	Retired	No	CABG

Data collection and procedure

Semi-structured interviews were conducted by one of the researchers in February and March 2016. All interviews were audio recorded. Initially the participants were invited to be interviewed alone. However, during two interviews the patients partner or daughter was also present because the participants wanted them to be there. At the start of the interview and prior to the audio recording, written informed consent was obtained from the participants. The interviews were conducted in Dutch. Quotes appearing in this article have been translated from Dutch into English.

A semi-structured interview scheme was used. The predetermined questions of the interview have been added in Dutch in Appendix A. Participants were firstly asked about their experiences preceding the surgery in relation to their health, physical complaints and daily functioning. Secondly, the period and experiences surrounding and following the surgery was questioned. Participants were, for instance, asked about their recovery, their hospital period and complaints related to surgery and health. Thirdly, patients were asked if they would be interested in an online intervention to help them prepare for the surgery and recover after the surgery. Current research used the entire interviews as output, including parts where the questions did not explicitly focus on the experiences of the patients.

The interviews lasted 45 to 80 minutes, with a mean duration of 65 minutes. Participants received a box of chocolates afterwards to thank them for their time and effort.

Data analysis

Thematic Analysis was used to analyse the data (Braun & Clarke, 2006). After recording the interviews, they were transcribed verbatim by the researchers (LH, TM, & KK) and made anonymous to ensure confidentiality. Following transcription, the interviews were read and re-read by the author (KK) to familiarize herself with the data.

For the coding and analysis process, Atlas.ti software (version 8) was used. The six interviews were open, axial and selective coded by KK. The researcher used an inductive approach, where relevant fragments were first selected and coded into subcategories that derived from the data. Subsequently, the subcategories were categorized into categories (based on grounded theory; Glaser & Strauss, 1967). A subcategory comprises one or more sentences fundamental for the purpose of the study. All six transcripts were coded and as a result of this process, a primary code book was generated, which was supplemented and adjusted during the entire iterative coding process. Some fragments were coded to multiple subcategories. Some subcategories were combined and/or integrated, resulting in a total of four categories and 18 subcategories. The names of the categories and subcategories were slightly adjusted until satisfaction was reached by the author that they fully represented the data.

Results

In the next sections, the challenges cardiac patients faced during the perioperative phase of their open heart surgery are described. The experiences can be divided into four categories: Somatic burdens, Mental burdens, Experiencing unpleasant emotions and the Lack of professional support. The categories and subcategories are shown in Table 2.

Table 2.
Codebook

Category	Subcategory	Total n	Subcategory total n	Example quote
Somatic burdens		6		
	Pain		4	*“They cut your body open and put it back together, but al those muscles that you have got there, everything hurts.”* (P1)
	Bad condition and minimal endurance		5	*“My condition still isn’t back to normal. When I walk the stairs, I just hear myself panting.”* (P2)
	Complications		4	*“I carried ten litres of fluid build-up with me.”* (P2)
	Lack of self-compliance		5	*“I couldn’t even walk to the mall. Terrible!”* (P3)
Mental burdens		5		
	Poor memory		4	*“Others tell me I forget things.”* (P3)
	Loss of trust in body		2	*“This morning I called my general practitioner. I felt something and I just wanted to know if it wasn’t something serious.”* (P2)

	Dealing with concerns of others		1	*“People think I can’t take rest. I can do that very well.”* (P2)
	Dealing with the accumulation of stressful events		1	-
	Family conflicts		2	*“The situation between me and my daughter have calmed down, but it is still my daughter so it still hurts.”* (P6)
	Hardly experiencing complaints but needing cardiac surgery		2	*“I was under control of the doctor, but I felt fine. So it was hard to hear that I needed surgery”* (P1)
Experiencing unpleasant emotions		6		
	Fear		6	*“It really scared me when I heard how much the situation had worsened in just three months.”* (P5)
	Loneliness		2	*“I have got no one to talk to. I just sit in my chair and watch some tv.”* (P1)
	Experiencing depressive feelings		2	*“Last year, I saw myself grumbling a lot and I thought well, I am really getting a little depressed.”* (P2)
	Becoming more emotional		4	*“I think the hormones made me more emotional after surgery. I feel more vulnerable.”* (P4)

Lack of professional support		5	
	Receiving too little postoperative care	4	*“When I got to leave the hospital, I was no longer under the responsibility of the hospital. From that moment I had to crawl from the stairs to my ride, so to speak.”* (P6)
	Not being taken seriously by professionals	2	*“I think the doctor has failed a little. I kept saying I was not able to walk anymore, but she didn’t do much with that information.”* (P1)
	Not being fully informed	4	*“I would have liked to now the consequences of the anaesthesia. I have been wondering if my poor memory is related to that.”* (P6)
	Underestimating the recovery	2	*“You have to take into account that it can take up to a year before you get to your senses again. More information could be provided about that.”* (P3)

Somatic burdens

The *somatic burdens* participants experienced during the perioperative process of their surgery can be divided into four themes: (1) Pain, (2) Bad condition and minimal endurance, (3) Complications and (4) Lack of self-compliance.

Four of the participants (n=4) experienced intense *pain* following their surgery. This pain could be related to the wound and its healing: *“After surgery, I had to stay at the hospital for a bit longer because the wound hadn’t fully closed yet. It is still really sensitive. If I wear* *the wrong clothes, it can really hurt."* (P3) Participants also experienced pain that was not directly related to the surgery. Patient no. 6, for example, had a tilted vertebra he was not aware of. After surgery, this pain got worse.

> *Because of my chest wound they could not treat my back. I could not handle the pain. After a while, I quit taking sleep medication. This medication would work for an hour and then I would wake up in pain again.* (P6)

Participants (n=5) got in a *bad condition* and had *minimal endurance* after surgery. Patient no. 5 mentioned: *"I can't do anything at all. I empty the dishwasher once and I am completely exhausted. That just isn't normal."* The bad condition and minimal endurance was experienced as unpleasant and frustrating, especially for participants who did not have these complaints before surgery: "*Before surgery, I could walk up and down the stairs ten times and feel nothing. I was never tired. Now I am always tired."* (P1)

Four participants (n=4) experienced *complications* following the surgery, such as wound bleedings and fluid build-up, and one participant needed to be defibrillated during surgery. He explains: "*It didn't go entirely according to plan. They had to take me back into the world with a defibrillator."* (P6) For participant no. 1 (urine in her kidneys) and participant no. 3 (lack of closure of the wound) the complication prolonged the duration of their hospital stay.

Due to their cardiac disease and surgery, participants (n=5) felt they *lacked self-compliance*. Participants lost some of the freedom they had before. They were not able to do all of the things they were used to and became dependent on others, due to physical impairments, cardiac malfunctioning or fear that held them back. The physical things participants were not able to do anymore were for example driving a car, walking and cycling. This made them unable to work, go to the mall and drink coffee with relatives and friends. *"I can't walk. When I walk down the street, I have to pause for three times!"* (P3), and *"Before surgery, I could go whenever and wherever I wanted. If I wanted to go, I could go. And now I cant. It is impossible. Because if I would drive a car, I would not be insured.*" (P1) In order to get things done, they had to ask others for help and let them help them, which was difficult for some participants to accept.

> *You have to ask others for everything. Do you want to help me with this? Can you do this for me? I don't recognize that part of myself, because I used to be able to do everything on my own.* (P1)

Mental burdens

The *mental burdens* participants experienced during the perioperative process of their surgery can be divided into 6 themes: (1) Poor memory, (2) Loss of trust in body, (3) Dealing with concerns of others, (4) Dealing with the accumulation of stressful events, (5) Family conflicts and (6) Hardly experiencing complaints but needing cardiac surgery.

First of all, participants (n=4) noticed they got a *poor memory* after surgery. One participant states: *"I should read some books, but I can't. I am really confused. When I have read a part, I can't remember the first part anymore."* (P1) Participant no. 6 noticed that the poorer memory influences the conversation he has, as he states: "*I already naturally have the talent to forget things, but I never before experienced that I wanted to say something and completely forget what I wanted to say."*

Two participants (n=2) *lost trust in their bodies*. The participants are more aware of the things that could be wrong with their health. One participant, for example, reports she is more alert of physical complaints: *"You get more insecure. Sometimes you feel something in your body and don't know what it is… Just like today, I felt something and called my general practitioner. You are more aware of it now, I guess."* (P2)

One participant (n=1) had to deal with the *concerns of others* about her and her situation. As a result she got scared. She went to cardiac-training and experienced that she was allowed to do more physical exercises than she was aware of, which has helped her to get rid of her insecurity.

> *Others think I am too active. Everybody has got an opinion about me. They think my yard is too big. And now, the yard is way too big, since I have a cardiac disease. Everybody is keeping an eye on me. They think I am too active*. (P2)

For one participant (n=1), the *accumulations of events* was what caused the whole perioperative process of the surgery to have so much impact on her. It was a challenge to handle multiple life changing events at once. She said: *"You are not yourself after surgery. First I lost my husband and now this [cardiac disease, surgery].*" (P1)

Two participants (n=2) have had long-standing *conflicts with family members*. These conflicts were already existing during the whole perioperative phase, but made it harder for the participants to cope with the whole process of the cardiac surgery. Participant no 4. had a fight with his daughter, which caused him extra stress during the postoperative period: *"When I turned 75 I gave all my children 100 euros. But my daughter refused to take it. This is just one of the multiple examples. Things like that play an underlying part.*" Another participant is convinced conflicts with family members have an influence on her health, as she states: *"All those fights, it is funnelling me."* (P1)

Two participants (n=2) felt no to hardly any complaints the moment they heard they needed to undergo cardiac surgery (*Hardly experiencing complaints but needing cardiac surgery*). They were regularly checked by the doctor, because of earlier disease and cardiac disease running in the family. Nevertheless, the lack of complaints made it difficult for them to accept the situation, because they felt better before undergoing surgery than after. Patient no. 5, for example, states: *"I was shocked. I hardly had complaints. I mean, I didn't feel anything. I was just dizzy*."

Experiencing unpleasant emotions

During the perioperative process of their surgery participants *experienced unpleasant emotions* that can be divided into four themes: (1) Fear, (2) Loneliness, (3) Experiencing depressive feelings and (4) Becoming more emotional.

Fear is an emotion all participants (n=6) describe during their interview. The fear participants experienced impacted and guided their daily life. Before surgery, participants were mostly afraid that they would not make it through the surgery and were wondering if the surgery would go as planned.

> *I once went back to my general practitioner and I told him I was afraid that I would not make it through the weekend, that I wouldn't survive. After a while, I didn't even dare to lay down anymore.* (P6)

However, the fear did not end when participants successfully underwent surgery. After surgery, participants were scared of their (future) health.

> *When I went home after surgery, the doctor gave me some papers with medical terms. I searched for those on the internet, but I should not have done that. The first thing I saw was that I would not grow old. I was shocked, of course.* (P6)

Patients also experienced more fear in situations non related to the surgery, for example when they had no control over a situation. *"When [name] picked me up and rode through the bend, I thought: Oh no! I got afraid. I had no control over the situation and was it very unpleasant*." (P4)

Two participants (n=2) described the *feeling of loneliness* experienced during their postoperative period. They became aware of the fact that they did not experience the support they needed, which led to feelings of disappointment. The loneliness was due to family conflicts, deaths, no longer watching the grandchildren because of them going to school and the nurses at the hospital having no time to talk with them. The loneliness started when they were still at the hospital, where they had no one to talk to, and it was also present when patients had come home from surgery. Participant no. 2 said: *"You know, at a certain point* *the physical therapist came by and I had a little conversation with him. After that I had not spoken to anyone else."* Participant no. 1 explained: '*Occasionally a nurse came by. But they don't have a lot of time for you. They are really busy. Now and then people came by to bring you some coffee, but they also had other things to do.*' About the period after leaving the hospital participant no. 1 said: *"I am always alone. Day and night I am on my own. My oldest son doesn't come by to visit me for weeks. My daughter in law doesn't come at all. I have had some troubles with her."*

Two participants (n=2) mentioned they were down and *experienced depressive feelings* in the postoperative period. The daughter of one participant (P1) states: *"If it will continue like this, I will call a doctor. I do not want to sit here and constantly hear 'I do not want to take this medication' or 'I'll hang myself in the shed'.*" The participant herself multiple times mentioned she is *'deep down*' and experiences mood swings. When asked what that concretely means to her, she responds: *"All emotions are shorter. They change faster. That all started after surgery."* (P1)

Four participants (n=4) felt they *became more emotional* since they had surgery (n=4). Old issues became emotional again and one participant became irritable. She says: *"I even argued with one of my sisters. I have never done that before!*" (P2) Participant no. 4 thought he was over the fight he had with his daughter. However, after the surgery, the emotions about this fight came up again: *"It acted up again when, at a certain moment, I awoke at night during the whole process after surgery thinking about it. I thought: 'oh no'."*

Lack of professional support

The *lack of professional support* participants experienced during the perioperative process of their surgery can be divided into 4 themes: (1) Receiving too little postoperative care, (2) Not being taken seriously by professionals, (3) Not being fully informed and (4) Underestimating the recovery of cardiac surgery.

Four participants (n=4) felt that they *received too little postoperative care*. Participants had the feeling they were thrown in at the deep end since the moment they were released from the hospital. This feeling was caused by the lack of support to arrange home care and the lack of contact with the cardiologist.

> *Nobody comes to look after you. I have to see my cardiologist tomorrow, for the first time again since the surgery! My children arranged home care for me. But what I lived alone? Then nobody would look after me*. (P3)

Patient no. 4 seems to share this opinion, as she said: *"The nurse is a nice woman, but what I really needed was to have contact with the cardiologist."*

Two participants (n=2) had the feeling that the *seriousness of their complaints was not taken seriously by the professionals*. Participants felt that there was not made enough rush to investigate their complaints, that the problem was downplayed or that the examination that was carried out seemed amateurish. Participant no. 6 described the following: *"I went to my general practitioner. He did not recognize my problem. In my opinion, too little rush was made from the general practitioner. There were days that I really felt I was on my own."*

Four participants (n=4) feel that they have *not been fully informed* about the surgery and the perioperative process. In retrospect, there are a number of points of information that they would have liked to know in advance. One participant would really like to have known about the side effects of the medication she was using.

> *I was in a constant state of dizziness. [name], who also went to cardiac-training, told me she went through the exact same thing when she was using that medication. I stopped taking this medication and within a week the dizziness was gone [unknown if this was with or without consulting the professionals]. I thought: Well, maybe I will survive after all. But it would have been really nice to have known this beforehand.* (P6)

Another participant thinks it would have been valuable if they had emphasized how long it takes to fully recover. She says: "*You have to take into account that it takes up to a year before you are fully recovered. More attention may be given to such things*." (P3)

Two participants (n=2) *underestimated the recovery of their cardiac surgery*. They confirm that information about the procedure and recovery was handed to them before surgery. Nevertheless, they expected it to be less invasive than it turned out to be. One participant reported the following about the intensity of the recovery:

> *I did not expect this. Before the surgery I received information, and they did say that it is possible you go to a dark place. I could imagine that. But that it would be this dark… I did not expect that. If I would have known this in advance, I would not have done it [surgery].* (P1)

Participant no. 3 underestimated the duration of the recovery process. She said: *"It disappointed me. It took too long. You have to come a long way before you'll be yourself again. That really disappointed me*." When the researcher asked this participant if she expected it to be over by now, she mentioned: "*I expected the shortness of breath to be gone by now, but it really isn't yet.*"

Discussion

Six cardiac patients described their experiences regarding the perioperative phase of undergoing open heart surgery. The aim of this study was to gain insight in the challenges cardiac patients face, which cause open heart surgeries to have so much impact on patients their lives. In general, patients had been affected not only by the open heart surgery itself, but also by a before- and aftermath. The patients mentioned the following challenges: somatic and mental burdens, the experience of unpleasant emotions and a lack of professional support.

All of the patients reported feeling fears. They feared to die before undergoing surgery and even when they successfully passed surgery, they found it difficult to let this fear go. For patients who did not have complaints before surgery it was hard to trust their body again after surgery, since they had not sensed that something was wrong before. Patients felt an inner turmoil, caused by the bodily betrayal they had experienced. In line with current research, the experience of fear has often been found to be the most dominant experienced emotion, leading to the highest payload surrounding cardiac surgery (Duits et al., 1998; Tully & baker, 2012). The fact that fear persisted even after successful cardiac surgery is in agreement with previous studies (Andrew et al., 2000; Hoyer et al., 2008).

Besides the fear, depressive moods were also reported by all patients. With rates of 30 to 40 percent of CABG patients coping with depression, research of Tully and Baker (2012) shows that depression plays a significant role in cardiac patients’ life post-surgery. In current research, some of the patients stated they felt worse after surgery than before. One patient even described having suicidal thoughts, even though the open heart surgery was executed months ago. The depressive state being present for the long-term has also been found in other research. Karlsson and colleagues (2008) found that more than half of the patients experienced a depressed mood during both recovery and three years after open heart surgery, which therefore has a long-term effect on patients their well-being.

In our research, we have seen that over 33 percent of the patients felt they were left in loneliness, which seems to be related to poor quality of family relationships and the need for more involvement of healthcare providers. The importance of the quality of family relationships is remarkable. Patients experiencing conflicts in family relationships originated before surgery, only came to the realization of the mental impact and consequences of these conflicts after surgery. In addition to family and friends, health professionals also seem to fulfill an important role in patients’ social support system. Social support can be defined as the perception or experience that one is loved and cared for by others, esteemed in their recovery process. and valued, and part of a social network of mutual assistance and obligations (Wills, 1991). The meta-analysis of Barth, Schneider, and Von Känel (2010) supports the perception of social support being important for coronary heart disease prognosis. It indicates monitoring of social support in cardiac patients and justifies interventions to increase the perception of social support (Barth et al., 2010). During the intake attention should be paid to the patients' support system and health professionals should estimate if patients are at risk of having a lack of social support. If this is the case, there should be focused on strengthening patients' social support network.

By striving to strengthen patients' social support network, we can focus on support received from family and friends and support received from health professionals. Multiple interventions attempting to enhance social support have been developed, such as family support interventions, practice in family-relationship skills and support groups, and have proved to be beneficial for mental and physical health (Chesla, 2010; Taylor, 2011). Evidence for specific intervention strategies is limited and it is recommended for future research to focus on developing evidence based intervention strategies to increase the perception of social support received from peers (Hogan, Linden, & Najarian, 2002; Barth et al., 2010). With regard to enhancing professional support, almost 70 percent of the patients wished to have received more postoperative care and especially more contact with the cardiologists than they could have. In the realisation to optimal access to care, among which physician contact, telemedicine could be helpful. Telemedicine is defined as the use of electronic information and communication technologies to provide and support health care when distance separates participants, and it has grown interest over the recent years (Field, 1996; Williams, Bhatti, Alam, & Nikolian, 2018). It has increased patients' satisfaction in postoperative care, for example with the use of telerounding (remote video conferencing) either as an additional visit or as a substituted bedside visit with hospitalized patients (Ellison et al., 2004). Telemedicine increases accessibility of health professionals as cardiologists and appears to facilitate physician communication with patients (Williams et al., 2018). Since patients indicated they were in need of more regular and satisfying contact cardiologists, it seems that patients can potentially greatly benefit from telemedicine such as video and phone calls.

Patients felt they have not been fully informed and have often underestimated their duration and intensiveness of the recovery. They did not expect the recovery to be as intense and hard as it turned out to be. Doering and colleagues (2002) have found that cardiac patients often underestimate the difficulty of their recovery, which may imply that they have not viewed surgical recovery as a process of work. It is important that patients know exactly what the surgery and surrounding process entails and that awareness for the challenging situations patients are going to be confronted with is created. It should be made clear for patients that recovery from open heart surgery is a long trajectory which requires a lot of effort from the patients themselves. How can we encourage patients to take the intense process that is waiting ahead of them after surgery serious? The use of peer support can link people living with a cardiac disease who share knowledge and experiences that others, including many health professionals, do not have (Solomon, 2004). Peers who have already undergone cardiac surgery can share their experience of the full process with other patients who are still at the beginning of the process. The World Health Organization (WHO) documents the promise of peer support as an effective approach to chronic disease management and health promotion (2007). However, research should provide more insight to the question if peer support can specifically increase the awareness of the severity of the recovery after open heart surgery.

When recovering of surgery, over 80 percent of all patients experienced a loss of freedom and felt they got dependent on others, which they found difficult to accept and found hard to get a grip on. This can be described as the lack of *environmental mastery*, which can be defined as how well an individual manages his/her life situations (Ryff & Singer, 1996). Shad and colleagues (2018) showed that cardiac patients experienced less environmental mastery (and overall psychological well-being) in comparison to healthy people. People who experience little environmental mastery often feel unable to change or improve surrounding contexts (Ryff & Singer, 1996). How can we ensure that people experience to remain in control over their lives? In older adults in residential care, mastery may be retained if this person is actively involved in choosing their place of residential care, instead of having it been ‘forced’ upon them (Knight, Davison, McCabe, & Mellor, 2011). It is thinkable that letting patients make decisions about their treatment, such as where or by whom to be treated, would increase their sense of empowerment. However, this is a hypothesis that first needs to be tested before any conclusions can be drawn.

In current research patients have acknowledged to experience difficulties accepting life with cardiac disease and its consequences. It could be beneficial for patients to strive for a more accepting mindset, since an accepting and progressive life course is favourable for getting through life threatening cardiac disease (Karlsson et al, 2005; Lukkarine, 1999). Our patients struggled with multiple unpleasant emotions before and after cardiac surgery and seemed to be carried away by it. Just as with patients struggling with chronic pain, it is often not realistic for cardiac patients to be completely free of symptoms and continue their life like they used to, even after successful treatment (Zambroski, Moser, Bhat, & Ziegler, 2005). Patients should learn how to manage a period of chronic distress and how to improve their resilience. Acceptance and commitment therapy (ACT) strives to create a rich and meaningful life, while accepting the pain that inevitably goes with it. People often tend to think that happiness is the same as experiencing no unpleasant emotions, causing them to avoid these unpleasant emotions. ACT states that unpleasant emotions are part of life, which can even be meaningful (Hayes, Strosahl, & Wilson, 2011). ACT has proved to be effective for multiple problems, such as chronic pain, depression and anxiety (Trompetter, 2014; Twohig & Levin, 2017). ACT can help to learn patients how to live with difficulties they face with regards to their cardiac disease and its belonging emotions, instead of resisting and fighting it.

Regarding to the development of a new intervention that fits patients' needs, current research showed a number of aspects that seem relevant to include. As far as the content of the intervention is concerned, it could be helpful for patients to provide a (online) social support group for patients that feel lonely and are in need of social support. Social activities and social support has proven to be important in helping patients to adjust to life with heart failure (Thornhill, Lyons, Nouwen, & Lip, 2008). Via social support groups patients can exchange valuable information and practical tips, encounter emotional support, find recognition and share experiences (Lockhart, Foreman, Mase, & Heisler, 2014). The intervention should work with a flexible approach in participation, where patients are able to engage in the type of contact with others that matches their wishes and lets patients be in control. Furthermore, the intervention should contain additional information about the rehabilitation process as well as peer support aiming to create more realistic expectations of the perioperative process of cardiac surgery. This peer support could entail written (anonymous) experiences and tips of other peers, or a web-based platform where patients can actively participate. Unfortunately, it is not likely for patients to be completely free of symptoms on a short term, and patients seem to struggle with that. It is therefore recommended to base the intervention on concepts stemming from positive psychology, such as acceptance and mindfulness, to make people more resilient and able to live at peace with their cardiac disease.

Limitations and strengths

Present study has some limitations and therefore its outcomes should be interpreted with caution. First of all, participants were recruited from one single hospital. The selected group of participants may not be representative for all cardiac patients who underwent open heart surgery. However, current study aimed to explore the experiences as heterogeneous as possible, and tried to succeed in this effort by selecting a wide range of participants in terms of gender, age and surgery type. Second, it should be noted that during this study no second encoder was used, so no inter-rater-reliability could be calculated. This absence could have led to a reduced transparency and trustworthiness of the study results, whereas the presence of a second encoder could have led to in depth discussion about the coding scheme during the analysis process. Third, it should be mentioned that during two interviews a third person (spouse, daughter) was present at the appointment. When the participant wanted the third person to be present this was agreed. However, it is possible that the presence of the third person has influenced the participants answers. Perhaps participants were more cautious talking about negative experiences in order to prevent insulting their spouse/daughter and to protect their feelings. To minimize extern influences, all interviews were held at the patients' home. This way, the accessibility for patients was taken into account. By ensuring patients were placed in a familiar environment and therefore feeling as comfortable as possible, patients could fully concentrate on the questions they were asked, which hopefully has led to complete and honest answers. During current research, data collection and data analysis has been performed by two independent researchers. This has been helpful for keeping the mind open and minimizing bias.

Conclusion

It can be concluded that cardiac patients often seem to underestimate the duration and intensity of their recovery after open heart surgery and seem to struggle with the acceptance of their new life situation and its consequences. Patients have perceived a lack of social support from family members and health professionals. It has become clear that for many open heart surgery patients, surgery is only one aspect of the entire process to long-term recovery. Patients are in need of support during the perioperative phase of cardiac surgery. By making use of telemedicine the accessibility of health professionals will be optimized. In order to develop a meaningful intervention for cardiac patients, a social support group that strengthens patients' social network should be established. The use of peer support could offer help in creating more realistic expectations regarding the recovery of cardiac surgery. It is recommended to base the intervention on concepts stemming from positive psychology and to work with a flexible approach in participation.

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Appendix

Appendix A.
Interview scheme participants in Dutch.

Interviewschema patiënten

1. Waar bent u aan geopereerd? Waar wordt u aan geopereerd?

Voor de operatie

2. Hoe was voor u de periode vóór de operatie? Wanneer was dat, bijv. wat voor weer, welk seizoen was het? Hoe zag uw leven er toen (in grote lijnen) uit?

3. Hoe voelde u zich in de periode voor de operatie?

4. Kunt u mij iets meer vertellen over uw klachten vóór de operatie?

5. Op wat voor manier hebben de klachten uw leven beïnvloed? Kon u alles nog doen wat u gewend was? Of is daar iets in veranderd t.o.v. vroeger (voor de klachten)?

6. Welke invloed heeft de ziekte op uw dagelijks functioneren gehad? (lichamelijk functioneren, sociaal functioneren, dagelijkse activiteiten, emotioneel functioneren, evt. gezinsleven, relationeel).

7. Zijn er nog andere dingen waar u tegen aanloopt/ of bent aangelopen (gedurende de ziekte)?

8. Wat heeft u al gedaan aan de klachten, vóór de operatie? Welke hulpverleners heeft u bijv. bezocht en wat heeft u zelf geprobeerd?

9. Wat werkte goed voor u? Wat werkte niet goed voor u? Waar zat voor u het verschil in?

Na de operatie

10. Hoe was de operatie voor u?

11. Hoelang heeft u na de operatie nog in het ziekenhuis gelegen?

12. Hoe voelde u zich (in de periode) na de operatie?

13. Hoe heeft u het herstel na de operatie ervaren?

14. Had u klachten ná de operatie?

15. Zo ja, wat heeft u gedaan aan de klachten, ná de operatie? Wat heeft u gedaan om uw herstel te bevorderen? Welke hulpverleners heeft u bijv. bezocht en wat heeft u zelf geprobeerd?

16. Wat werkte goed voor u? Wat werkte niet goed voor u? Waar zat voor u het verschil in?

Nieuwe interventie

17. Waar zou ik volgens u aan moeten denken (niet moeten vergeten), bij het ontwikkelen van een online programma voor mensen die geopereerd zijn?

18. Wat zou u geholpen hebben, voor – tijdens – en na de operatie? Hoe zou een programma hier op in kunnen spelen, of dit kunnen versterken?

19. Welke voorwaarden / eisen zijn nodig voor een nieuw programma?

20. Heeft u een idee van welke onderdelen het programma volgens u zou kunnen bevatten?

21. Wat zou u bijv. vinden van een functie als een forum, contact met andere patiënten, informatie over operatieprocedure en/of FAQ’s?

22. Zou u zelf gebruik maken van een online hulpprogramma voor patiënten die geopereerd worden?
☐ Waarom wel?
☐ Waarom niet?

Randvoorwaarden online hulpprogramma

Nu volgen nog enkele vragen over de randvoorwaarden van het online hulpprogramma voor patiënten die geopereerd worden.

eHealth

23. Bent u bereid om met een online programma (bijv. een website of een app) te werken, als dit uw herstel na de operatie zou kunnen bevorderen? Waarom wel / niet?

Tijdbesteding

24. Hoeveel tijd per week zou u kunnen/willen opbrengen voor een online hulpprogramma voor patiënten die geopereerd worden?
…………………uur per week

25. Ziet u voor uzelf hierin een verschil wat betreft voor, tijdens of na opname?
Ja, ……………….uur per week. Nee.

26. Hoeveel weken mag een online hulpprogramma maximaal duren?
…………………weken

27. Hoe zou u de weken verdelen, qua voor, tijdens of na opname?
…………………weken voor de operatie
…………………. tijdens de opname (1 week?)
…………………weken na de operatie

Oefeningen

28. Zou u bereid zijn om meerdere malen per week / dagelijks oefeningen te doen, als dit het herstel na de operatie kan bevorderen?

29. Zou u bereid zijn hier al een aantal weken vóór de operatie mee te beginnen?

30. Zou u bereid zijn oefeningen te blijven doen, tot een aantal weken na de operatie?

31. Zou u bereid zijn om oefeningen te doen om na te gaan wat u doet als u pijn heeft? En om dan na te gaan hoe dat voelt, of het helpt of niet?

32. Zou u bereid zijn om oefeningen te doen, die inzicht geven over uzelf? Oefeningen waarbij u kijkt naar uzelf?

33. Zou u bereid zijn om oefeningen te doen, waarbij u kijkt naar wat voor u belangrijk is in uw leven? Waarbij u kijkt naar wat u graag doet in uw leven?

34. Zou u bereid zijn om oefeningen te doen, waarbij u bewust uw aandacht moet richten? Waarbij u bijvoorbeeld uw aandacht moet richten op (delen van) uw lichaam? Bijvoorbeeld elke dag 10 minuten?

Vorm van de begeleiding

35. Stelt u volgt een dergelijk programma. Hoe wilt u dan begeleid worden?

36. Sommige mensen hoeven bijvoorbeeld niet standaard wekelijks contact, maar willen wel de mogelijkheid om hulp te vragen, mocht dat nodig zijn. Wat vindt u daarvan?

37. Sommige mensen willen bijv. bevestiging dat het goed gaat door een begeleider. Wat vindt u daarvan?

38. Sommige mensen willen bijv. aanmoediging om door te gaan, van een begeleider. Wat vindt u daarvan?

39. Zou u graag begeleid willen worden door een verpleegkundige bij het online hulpprogramma door bijvoorbeeld feedback te krijgen op gemaakte oefeningen?
☐ Ja
☐ Nee
Indien ja;
☐ Hoe vaak zou u graag contact willen hebben?
Indien nee;
☐ Waarom zou u liever niet begeleid willen worden?

40. Hoe zou de begeleiding eruit kunnen zien?
☐ Per email
☐ Per chat, video conferentie (bijvoorbeeld Skype)

41. Voorlopig wordt gedacht aan de volgende opzet:

Na een kennismaking gaan deelnemers zelfstandig aan de slag met het programma. Eenmaal per week is er een e-mailuitwisseling tussen de deelnemer en verpleegkundige. Tijdens de ziekenhuisopname stimuleert de verpleegkundige de deelnemer om de geleerde (mindfulness-)oefeningen toe te passen. De verpleegkundige is in staat om de oefeningen samen met de deelnemer uit te voeren indien dit nodig is. Na de operatie is er opnieuw e-mailcontact tussen deelnemer en verpleegkundige.
Wat vindt u van deze opzet? Wat spreekt u wel aan? Wat spreekt u niet aan?

Persoonlijke gegevens
Wat is uw geslacht?
☐ Man
☐ Vrouw

Wat is uw leeftijd?
…………

Bent u religieus?
☐ Ja
☐ Nee
☐ Niet bekend

Heeft u kinderen?
☐ Nee
☐ Ja, thuiswonende kinderen
☐ Ja, uitwonende kinderen

Wat is uw hoogst afgeronde opleiding?
☐ Geen opleiding
☐ Alleen basisonderwijs
☐ Lager beroepsonderwijs, MAVO, (M)ULO, 3-jarige HBS of VMBO
☐ Middelbaar beroepsonderwijs, 5-jarige HBS, HAVO, MMS, atheneum of gymnasium
☐ Hoger beroepsonderwijs (HBO) of Universiteit
☐ Anders, namelijk ……………………………………………………………………..

Wat is de beste omschrijving van uw huidige situatie?

☐ Ik verricht betaald werk voor 20 uur of méér per week

☐ Ik verricht betaald werk voor minder dan 20 uur per week

☐ Ik ben huisvrouw/ huisman

☐ Ik zit nog op school of volg een studie

☐ Ik ben werkzoekend

☐ Ik ben arbeidsongeschikt (WAO)

☐ Ik ben gepensioneerd (AOW of VUT)

☐ Anders, namelijk ……………………………………………………………………..

Heeft u thuis toegang tot een computer, tablet en/of smartphone?

☐ Ja

☐ Nee

Heeft u thuis toegang tot internet?

☐ Ja

☐ Nee

Hoe veel uur per week maakt u gebruik van het internet uit persoonlijke redenen?

Rond ……………….. uur

Afsluiting

Dan hebben we nu alle onderwerpen van het interview besproken.

☐ Heeft u verder nog vragen of opmerkingen?

☐ Zou u ook nog interesse hebben om aan vervolgonderzoeken deel te nemen?

Indien ja;

☐ Op welke manier mogen we weer contact met u opnemen (telefoon, mail, brief)……………………………………………………………………………