



Fathers' reactions over their partner's diagnosis of peripartum cardiomyopathy: A qualitative interview study

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ABSTRACT

Background: Fathers' experience of childbirth has been described as both distressing and wonderful, but little has been described in the literature about fathers' reactions when their partners get life threatening diagnoses such as peripartum cardiomyopathy (PPCM) during the peripartum period.

Aim: To learn more about fathers' reactions over their partner's diagnosis of peripartum cardiomyopathy.

Methods: Fourteen fathers, whose partner was diagnosed with PPCM before or after giving birth, were interviewed. Data were analysed using inductive content analysis technique.

Results: The first reaction in fathers was shock when they heard their partner had PPCM, which was sudden, terrible and overwhelming news. Their reactions to trauma are described in the main category: *The appalling diagnosis gave a new perspective on life* with emotional sub-categories: *overwhelmed by fear, distressing uncertainty in the situation and for the future, feeling helpless but have to be strong, disappointment and frustration, and relief and acceptance*. Although terrified, fathers expressed gratitude towards health care professionals for the diagnosis that made it possible to initiate adequate treatment.

Conclusion: Exploring father's reactions will help peripartum and cardiology healthcare professionals to understand that emotional support for fathers is equally important as the support required for mothers during the peripartum period. Specifically they will help professionals to focus on future efforts in understanding and meeting the supportive care needs of fathers when their partner suffers from a life-threatening diagnosis like PPCM.

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Introduction

Fathers' experience of childbirth has been described as both distressing and wonderful (Dellmann, 2004), but when a mother is diagnosed with a life-altering illness, e.g. peripartum cardiomyopathy (PPCM), both partners are likely to experience a range of emotions (Hanson et al., 2009). Peripartum cardiomyopathy (PPCM) is an idiopathic form of cardiomyopathy presenting with heart failure secondary to left ventricular (LV) dysfunction towards the end of pregnancy or in the months following the birth, where no other cause of heart failure is identified (Sliwa et al., 2010). Data from the ongoing EURObservational Research Registry on PPCM have shown that this condition occurs globally with varying prognoses (Sliwa et al., 2018). The baseline characteristics are similar

(Sliwa et al., 2017) in spite of the differing incidence rate of PPCM between countries (Sliwa et al., 2017) ranging from 1:300 in Haiti (Fett et al., 2005) to 1:20 000 live births in Japan (Kamiya et al., 2011). The prevalence is 1:5719 births in Sweden (Barasa et al., 2017).

Frequently expressed concerns in fathers during childbirth, even in healthy partners, are: fear of observing their partner in pain, feelings of helplessness, and lack of knowledge about the process (Dellmann, 2004; Gage and Kirk, 2002). Serious diagnosis like PPCM in the partner can be a traumatic life event. Life events are defined as discrete experiences that disrupt an individual's usual activities, causing a substantial change and readjustment (Schwarzer and Schulz, 2003). Partners of women with complicated childbirth have explained how sad, fearful and disappointed they feel, that pregnancy and childbirth has not proceeded as expected (Elmir and Schmied, 2016; Hanson et al., 2009; Lindberg and Engström, 2013; Steen et al., 2012). During the perinatal period fathers experience stress and face unique stressors that can impact

Abbreviations: PPCM, peripartum cardiomyopathy.

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negatively on their health and social relationships (Philpott et al., 2017).

Sweden has a reputation for gender equality, and its child health services seek to support both parents. (Swedish Social Insurance Agency, 2009) However, a meta-ethnographic analysis from 62 studies found that despite the policy change nearly 50 years ago to include both parents, fathers were still not fully accepted and supported. (Wells, 2016).

Qualitative studies from different continents about men's attendance at routine childbirth has identified their feelings of uncertainty and helplessness and their inability to support their partner in pain during labour (Kaye et al., 2014; Lwanga et al., 2017; Sapkota et al., 2012), but ultimately joy at the birth of a healthy child (Kunjappy-Clifton, 2008; Premberg et al., 2011). However, there is little research on the reactions of fathers who receive news of serious illness in their partner along with joyous news of a birth. Given that fathers' reactions influence those of their partners (Iles et al., 2011), understanding their reactions is important. The paucity of the literature on fathers who found themselves experiencing the trauma related to PPCM diagnosis indicates a need to explore their reactions in this context.

The aim of this study was to learn more about fathers' reactions over their partner's diagnosis of peripartum cardiomyopathy.

Methods

Design

A qualitative design with interview approach was used to explore fathers' reactions over their partners' diagnosis of PPCM. This method was chosen to answer the study aim and explore the phenomenon freely, while keeping close to the data and generating findings with an open mind and constructive standpoint (Elo and Kyngäs, 2008).

Data collection

Nineteen women with PPCM, were asked during their participation in an interview study reported earlier (Patel et al., 2016a, 2016b), to obtain consent to provide their partners' contact details. Seventeen women provided their partners' cellphone number, with their verbal consent. Two women were separated and had no contact with their children's father. The lead researcher (HP) contacted the fathers via telephone. Fourteen agreed to participate, two declined because of lack of time and one did not want to be involved. Prior to researcher's call, their partners already told the fathers about the study, and written information was posted to participating fathers. Time and place for the interviews either was decided, for face-to-face or telephone interview, and consent was obtained by mail in the case of the seven telephone interviews. Those seven agreeing to face-to-face interviews were interviewed in the research clinic, and gave their written consent prior to the interview. Fathers were asked to confirm that they had understood the participant information, were reminded of their right to withdraw and asked to confirm that they wished to continue with the study. They were also given an opportunity to ask any questions. Interviews then proceeded following the open-ended question: "Will you describe your reactions when you heard about your partner's PPCM diagnosis?". The fathers were encouraged to talk freely and clarifying questions, or probes, were used. Interviews were conducted by the first author (HP) in the native Swedish language, were audiotaped and lasted between 20 and 73 minutes. Time for interviews varied from 3 months to 7 years after the birth. Interviews were transcribed verbatim and non-verbal reactions were noted (Begley, 1996). Although some of the fathers were sad while describing their stories, they left with the positive

feeling that their contribution had made to improving the care for other parents in a similar situation. They also expressed their gratitude for the opportunity to voice their needs and concerns and to be heard and appreciated. They were informed about the opportunity to contact the interviewer if they wanted to talk further about these issues.

Data analysis

Inductive content analysis inspired by Elo and Kyngäs (2008) was chosen to identify fathers' reactions to their partners' diagnosis of PPCM. The analysis started with reading the transcriptions several times to make sense of the data, by HP. In the next step, data were reread and unit of analyses were selected for open coding. HP read and coded the transcripts. HP, CB and ÅP discussed the coding comprehensively to provide sound interpretation of data (Burla et al., 2008), and discussed any divergent opinions concerning the coding related to its content and categorisation. The discrepancies were resolved by discussion and consensus (HP, ÅP & CB). The categories were revised throughout the process by either deleting or collapsing under a new heading as the analysis progressed until the final categories were abstracted in consensus. Once the main and sub-categories had emerged, and suitable quotations to illustrate them had been identified, the excerpts were translated into English by HP, and checked by ÅP and CB.

Results

Fourteen fathers, aged between 26 and 44 years old (mean = 34.5; SD 5.7), participated in the study. All were married or cohabiting; 12 were employed and two had their own business. Four had high school, seven had college, and three had university education of more than 3 years.

PPCM diagnosis was perceived as an uncontrollable force that dramatically changed the lives of fathers in a blink of an eye. When fathers heard about the diagnosis, they felt traumatised by the sudden and terrible news of their partners suffering from PPCM. Their reactions to the trauma resulted in, *the appalling diagnosis gave a new perspective on life as the main category*, which was illustrated by five emotional sub-categories; *overwhelmed by fear, distressing uncertainty in the situation and for the future, feeling helpless but have to be strong, disappointment and frustration, relief and acceptance*. The translated quotations from transcribed text are provided to confirm and illustrate the findings and richness of data.

Overwhelmed by fear

Their partner's life-threatening diagnosis triggered feelings of fear and grief in the fathers, who were shaken and shattered to discover women's suffering from PPCM. The fear emerged in two forms: partly as fear of the unknown and secondly, fear of losing their partner. An overwhelming experience of being in a chaotic situation during childbirth existed when suddenly a happy event in the family turned to a life threatening condition. The rapid change from looking forward to welcoming a baby with the joy of impending fatherhood, to being informed of the appalling diagnosis was hard to comprehend. Fathers never thought that childbirth could be a danger for a woman's life, especially in terms of heart failure, which was thought to be an illness of old age. Expressions in the following quotes describe fathers' tumultuous experiences:

"We had no idea that such a thing can happen after child birth...how come this change appears when everything was supposed to be normal? ..." (P4).

“She was not feeling well. It was scary... we were looking forward to growth in the family...we had just received our son and it was uncertain whether she would survive or not...it was not fun at all having a new born baby to cope with and the news about my wife’s heart failure” (P7).

“I was with her and did not dare to close my eyes, because I needed to monitor her breathing and that she was alive” (P2).

The fathers feared for the worst, mirroring the women’s distress. One of the fathers recalled that “he nearly passed out”, when he heard that his wife might be listed for a heart transplant if she did not recover following drug therapy. Fathers described their desperation and uneasiness as:

“It was traumatic to see that she was about to die” (P5).

“It took a long time to realise and reflect on what could have happened and the severity of the diagnosis of heart failure” (P6).

For some fathers the news was very confusing and they simply could not absorb it because of the unexpectedness of PPCM. Experiences of being blocked or isolated were described and it took several days, weeks or months for them to be able to think and understand how to deal with the intrusion that had occurred in their lives. They described a need to understand and to get a hold of the situation. Fathers immediately sought information on the web and were horrified, as they found that heart failure is common in the elderly and carries a poor prognosis. One of the fathers believed he had developed hypertension related to the stress reaction and was on medication for hypertension at the time of interview. Another two were feeling depressed and went for counselling once a week. They told a common story of being left alone with little clue of what was happening, while fearing for the lives of the mother and baby.

Distressing uncertainty in the situation and for the future

The uncertainty in fathers encompassed many issues such as not knowing the timescale and trajectory of the PPCM, and experiencing lack of control over making plans for the future, employment and finances. Some fathers believed that not having a formal diagnosis earlier resulted in difficulties in receiving adequate timely treatment that might have prevented worsening of PPCM. Their descriptions showed the vividness of their memories around women’s constant struggle to be taken seriously (Patel et al., 2016a); the trauma experienced around childbirth and then, finally, receiving the life threatening diagnosis of PPCM. All these caused intensive distress related to uncertainty because of professionals’ initial explanations that the symptoms were those of a normal pregnancy. Uncertainty was also generated due to insufficient knowledge about prognosis, and about how to take care of a newborn child and siblings at home. One of the fathers expressed his uncertainty in the diagnosis:

“I still don’t understand how can she get heart failure? She has always been healthy” (P12).

Most couples were together when they found out about the diagnosis. Five fathers (P4, P8, P11, P13, P14) were informed by the partner, which was perceived as secondary information from a person who was ill and hardly in a fit condition to explain what was going on. The professionals were criticised for this action, for not involving fathers while giving a heart failure diagnosis to the women. The fathers stressed the importance of understanding the partner’s behavior and for that reason it was essential to get a clear picture of the whole situation both from the medical and psychological perspective. Two of the fathers explained:

“I received information from my wife when this happened. Had no idea what to ask for...I was numb...when you’re in a bubble, it is a difficult situation, and then you need to talk with an expert. ...” (P8)

“...because when the wife says, it is not certain that all was told. One has a lot to think over, needing a correct explanation” (P14).

Some fathers did not remember how and when the information was received as the situation itself was chaotic, with the woman in the intensive care unit, the baby in the neonatal ward and not knowing what was going on. The fathers were confronted with ethical dilemmas; they were torn between worrying about a partner with an uncertain medical outcome and caring for a newborn baby and, possibly, older children at home. It was a terrible feeling of not being able to support both the woman and the baby. Fathers expressed deep uncertainty, due to a lack of information about their partner’s future prognosis and long-term health.

The fathers’ reaction of uncertainty had been felt before the diagnosis was made, due to the woman’s pain and need of recurrent investigation or hospitalisation for pre-eclampsia. For example, one of the fathers stated:

“The uncertainty was elevated after the childbirth, as she (his wife) was discharged in spite of ongoing symptoms. I was afraid...had no idea why? What? ...doctors said it was embolus. I was horrified and sad” (P9).

However, the majority of fathers expressed that uncertainty could have been reduced by more support from professionals and reassurance that they were doing the right thing in the situation.

The fathers used existing networks and support from their family, where available, but noted the paucity of individualised care for them.

Feeling helpless but have to be strong

For many fathers, not knowing what the future held was a significant source of stress in them. Some fathers initially were shocked and felt detached. They had difficulty believing in what had happened and were confused. In spite of the fathers’ reported use of their usual coping strategies, they experienced a feeling of powerlessness. Sad thoughts and helplessness overflowed their mind over the PPCM diagnosis. The first questions they vocalised as emerging in their minds were:

“Will she die? Be disabled? How long will she be in the hospital? Will I be visiting her twice a week? What have I done to deserve this? Could I have done something to prevent it?” It was not easy when you had built up a picture how it will be and the reality turned out to be totally different” (P1).

“I was concerned about what will happen with the baby and it was the first thought. Man is powerless; you cannot do anything” (P12).

“I was stunned when I heard about it, and could not stop crying” (P6).

First-time fathers lacked a normal reference. One of the young first-time fathers said:

“I am used to having everything under control in my life and believe that every problem has a solution, but this situation let me down” (P1).

The helplessness of these fathers is evident in these comments:

“She has been through a traumatic event and I could only stand by her, I couldn’t do much for her.” (P5).

"All of the sudden she deteriorated and she was moved to the intensive care unit and on the respirator and I was standing by her side. It was a shock and it was painful. She was sinking... had water in the lungs and I felt powerless, could not help her" (P5).

"I'm used to being independent and with strong self-efficacy, but this was beyond my control" (P10).

Fathers felt resentful, they could not protect the women from PPCM. Some of the fathers had not had time to prepare for the arrival of the new baby in the family; they felt very lonely, especially if they were a first-time father and experienced a double shock of the baby being delivered too early by unplanned emergency cesarean section, and the diagnosis of their partner's PPCM. The narratives also revealed the burden of dealing with health care professionals while their partners and child/children needed their support. For example, fathers heard partners' complaints and had to argue or beg for the right and emergent care, while health care professionals wanted to wait and see.

At the same time as they were dealing with the life-threatening issues and trying to comprehend their wife's illness, the fathers had to show a strong and secure façade to support their wife, which was described as demanding. Fathers were sad but tried to be tough, holding back their fears to avoid burdening their partners. They were unable to talk about their feelings but felt they had to focus on taking care of the woman and new born: *"She did not need any further stress."* (P8). Their own feelings and needs were set on hold, to be there for their family. For example, one of the fathers was sent home with the newborn, while the wife/mother of the child was still in intensive care. The responsibility for the family and caring for the siblings of the newborn could be tough. They struggled with thoughts about how to balance their life between the woman in the hospital, other children at home and a job. Alternating between the supporting their wife at the hospital, dealing with the work situation and coping with family life was an act of balance. Furthermore, the fathers believed that, being a male, they were expected to handle family matters on their own.

"The same day I found out that she had heart failure, they (health professionals) forced me to take care of the child " (P13).

"I have been adversely affected emotionally because of this... not happy or positive anymore ... so she (physician) gave me the medicine... there's nothing more I can do ... just suck it up until the children grow up and you can take some time yourself" (P8).

Disappointment and frustration

In most fathers, hearing about the diagnosis changed their life drastically. Not only daily living activities were altered but also they were affected emotionally and psychologically. Besides, in-depth understanding of their partner's condition was very important to fathers, in that it would better help them to care. Initially when the diagnosis was made not all fathers understood about what heart failure was. Some of them merely realised that something was wrong but never imagined that PPCM could be so dangerous. One of the fathers said:

"I was busy taking care of another child at home, beside I never understood what heart failure was so I did not take it seriously. It was like a viral infection...and will go away" (P7).

Another father, who was informed by his wife said:

"When she called and told me about this (heart failure)...she hung up and I searched for more information online, and I realised that it was very serious.... I was completely destroyed. I was convinced that she will die. I was really stressed; our twins were in the post-

natal care ward. I have my own business and couldn't handle everything by myself and they said I had to take home the babies as they were healthy. It was really overwhelming shock and unfair to me. (P13)".

This father, affected himself by chronic hypertension, said he was *"not done yet with the mourning process after 6 years"* (P13). The majority of the fathers looking for explanations, had guilt feelings but no idea about how to react and felt that the world was not fair. One father expressed his thoughts in the following quotation:

"There were lot of questions but no answers...a disappointment and lost expectations. I had a different picture of what it would be after the childbirth. The picture became different, I had to stay at home and do everything" (P1).

The condition as a relative could be frustrating. Even though fathers did not question that the care of the woman was the crucial duty for the health care providers, it was frustrating when their questions and thoughts as a relative sometimes were unmet. To be in the secondary role as relatives also meant that they could be dismissed from the treatment room without explanation and ignored by professionals.

Some fathers blamed and questioned the health care professional's competence. The birth was remembered as a baffling situation with anger and irritation:

"She received acupuncture for relaxation, and after that started chaos...a doctor running in and out, panic, lot of blood tests, oxygen and ...[she] became unconscious. It was like a circus...pulmonary edema ...acute caesarean section...extremely fast ... I wonder if they really knew, why? They did not really have an eye on her" (P2).

Fathers also expressed their anger and frustration over the handling of breastfeeding, which was viewed as an additional amount of suffering for women caused by professionals. One of the fathers criticises the midwives' focus on breastfeeding in spite of the woman's illness:

"How can they think about breastfeeding, when ... she just survived a death threatening condition at the ICU." (P11).

The frustration in the horrendous situation was exacerbated by the fathers' lack of someone to talk with about their experiences of being an excluded relative. Paradoxically, those who were offered counselling had to turn down the proposal as they were too occupied with taking care of the family and the timing was not suitable.

Relief and acceptance

Some of the fathers did not understand the seriousness of the diagnosis. Although for some, heart failure was a term with no meaning of severity or prognostic significance, they trusted the professionals, who asserted security by maintaining, *"everything is under control"* at all meetings. Such communication reassured the couple but also they felt it was redundant to talk with a counsellor or psychologist. The bright ray of hope was kindled when they heard from the cardiologists that *"she will recover"*. The cardiologists' compassionate and explanatory approach was successful for some fathers to become calm regardless of their understanding, *"...the doctor explained it well, but that it was heart failure, I did not understand until much later"* (P2). One of the first-time naive fathers did not understand the seriousness of heart failure, stating:

"I have not seen her suffering or depressed except that she was not able to lift heavy things... I focus on the children rather than

on wife's heart failure. The length of hospitalisation decides seriousness and she was in the hospital only for days, not months, so it was easy to understand that her heart failure was not serious" (P4).

Fathers believed that the wisest thing for them was just to forget the painful event of PPCM and appreciate the positive things that had been brought by the awful diagnosis, i.e. reality of life. One of the fathers described his feelings:

"I was sad but can't say that it was huge trauma because we got our daughter, and my wife is getting well too. We are appreciating life with a different perspective now. Hence I don't want to dwell on the negative things" (P3).

Although a devastating situation, fathers had developed a sense of courage and hope inspired by the challenges arisen by their partner's illness and unexpected circumstances around the childbirth.

The appalling diagnosis gave a new perspective on life

The main category appalling diagnosis gave a new perspective on life is the result of the above described sub-categories. The fathers recalled how they had supplanted everything else and looked forward to a child. Although the woman's anxiety and symptoms raised strong suspicion that something was wrong, they believed in midwives' explanations that these were the normal symptoms of pregnancy, as there was no other option. The general belief gained was that all the symptoms will disappear after childbirth, but the reality did not turn out like that. The process of childbirth was not smooth, as expected. The fathers were looking forward to the pregnancy and childbirth as a pleasant and enjoyable time with their partner. The vision of happy family life with the newborn changed drastically with their partner's PPCM diagnosis. The broken-heart experience was obvious as they mourned the loss of what they expected after childbirth. At the same time they acknowledged that there was no time to mourn because of increased responsibilities. Most of the fathers were on an emotional roller-coaster, happy at having a baby but sad for their partner's diagnosis of PPCM.

Initially, when fathers described hearing about PPCM, they recalled a feeling of numbness, and being devastated and shocked. The feelings of fear, uncertainty, helplessness, disappointment, frustration and anger appeared associated with the lack of knowledge and attendant belief that heart failure affects the elderly and carries a poor prognosis. The father's reaction depended on many factors; their expectations, knowledge, attitude, and the way the diagnosis was provided; the information given and understood, personal beliefs, and support available to the fathers. The father's need of emotional support reflected in ensuring good prognosis in the communication with health care professionals.

Although the excitement was replaced with fear, disappointment, uncertain future and powerlessness, fathers expressed enormous relief over recognition of the woman's problem by diagnosis and initiation of treatment that resulted in rapid symptom retraction. Having a diagnosis also meant that "now she will receive the best medical care" and a light of hope was seen in the darkness. The majority of fathers also described the way they coped with and re-evaluated their values and redefined the meaning in their life, with increased bonding with family and changed priorities.

Discussion

This study is, to the best of our knowledge, the first study to explore fathers' reactions whose partner received a PPCM diagnosis. Fathers found childbirth wonderful but distressing, related to the upheaval and unexpected diagnosis of PPCM in the

woman. The main overarching category 'The appalling diagnosis gave a new perspective on life' was identified from the sub-categories overwhelmed by fear; distressing uncertainty in the situation and for the future; feeling helpless but have to be strong; disappointment and frustration; and relief and acceptance. The fathers struggled to understand the content and meaning in the diagnosis of PPCM.

Previous studies have found that childbirth can be a traumatic time for fathers, during which they feel vulnerable, fearful for their partner and infant, and are in a transitional period that leaves them powerless, conflicted, and in limbo as a spectator without a traditional male role (Hanson et al., 2009; Hunter et al., 2011). Even if masculinity is under change and men today take more responsibility for their children and family hegemonic masculinity (Connell, 2002) still is interwoven in fatherhood.

It is well known that men under normal conditions are at increased risk of mental health problems (Wong et al., 2016) and anxiety disorders are common during the perinatal period (Leach et al., 2016). Furthermore, fathers experience partner's pregnancy and childbirth to be the most demanding period in terms of psychological reorganisation of the self (Genesoni and Tallandini, 2009). A difference for the fathers in this study appears to be that, the most fearful catastrophe really happened in terms of woman's PPCM, which they had to face by serving as both parent and family breadwinner, often without any support. However, an unexpected stressful diagnosis like PPCM led to a number of predominantly negative reactions. Fathers in our study described undesired reactions and feelings, which they hid under a strong façade that hindered them in getting professional timely support. Health care professionals need to have an eye on fathers' reactions, and offer counselling support as necessary, as the stress on them influences the whole family.

Cullberg (2010) described how crisis reactions occur after unexpected and dramatic events and can lead to lifelong consequences if the victim does not receive help in time. One of the fathers in our study developed hypertension and some others were feeling depressed in relation to the stressful situation. There are aspects that can further pinpoint the crisis situation, which means that it can have different meanings for different people (Cullberg, 2010). This is how the triggering situation looks, what inner and personal significance the event has for the individual, what meaning an event has for the victim and the individual's social conditions. The fathers in our study varied but clearly displayed the reactions of crisis like shock, fear, uncertainty in the outcome, disappointment and so on. Since PPCM is uncommon in pregnancy, follow-up care can be inconsistent and there may be unmet needs of clarification. It is of utmost importance that professionals create a practical and emotional order in the chaos the father is feeling. Hence, clear and honest communication with health professionals is highly valued and can facilitate fathers to cope with the crisis process.

The knowledge, empathy and self-knowledge of professionals dealing with such situations are important qualities for achieving a professional attitude, something that Cullberg (2010) calls therapeutic posture. However, Cullberg considers that people do not need psychotherapeutic education to respond to others in crisis, but that professionals should be trained in appropriate support provided immediately after the event, to prevent morbidity.

Consistent with previous studies (Etheridge and Slade, 2017), we found that fathers experienced "a rollercoaster of emotion" because of the unexpectedness of the PPCM, coming at what should be a time of joy. Shilling et al. (2017) described the uncertainty in carers of cancer patients about broad impact on their lives and their ability to move forward. Fathers in our study described a similar dilemma and the need to have control over the situation. Having control meant having information about PPCM prognosis and

long-term health of their partner. Often health care professionals spend all their time taking care of mothers and infants, but they need to think about fathers as well (Patel et al., 2018). The problem seems to be that when the woman had left the maternity ward, the father could not get any more support from midwives, and at the intensive care and cardiac care unit, there was only room for the patient, and little support for families and relatives was available. Inglis (Inglis et al., 2016) interviewed fathers following a traumatic childbirth and found, in accordance with our study findings, a lack of communication between professionals, and fathers' experience of marginalisation. These factors may have contributed to the crisis reactions in the fathers.

The starting point for good care must be to prevent the emergence of fear and other reactions related to the crisis experience. Professionals can enhance fathers' feelings of involvement by attentiveness, through interaction, giving information, and good communication skills (Johansson et al., 2015), and considering fathers as an important person contributing to the woman's wellbeing.

Fathers in our study described the need to hide or control their emotions and fear from their partner. However, the number one rated fear for fathers in many studies across countries has been described as the fear of a partner possibly dying during a normal childbirth (Eriksson et al., 2006; Hanson et al., 2009; Vehviläinen-Julkunen and Liukkonen, 1998; White, 2007). Some fathers fear the loss of both their wife and their unborn child. They reported coping the best they could without revealing their fears to their partner (White, 2007), similar to the findings of this study.

Fathers may be in need of support but reluctant to receive it in the belief that to do so would detract from their partner's needs. Lindberg (Lindberg and Engström, 2013) reported that new fathers of prematurely born babies prioritised the needs of the mother and child, while putting their own feelings and needs second. Earlier studies (Courtenay, 2000; Etheridge and Slade, 2017) have described that men often view admission of fear as a sign of weakness, and a reluctance to acknowledge fear may be an acculturated Westernised male gender response. It is indeed important during childbirth to be strong and secure to encourage the woman, especially when the couple is under extraordinary pressure. Johansson (Johansson et al., 2011) explored men's experiences of infertility and found that fathers tend to keep up appearances, conceal their feelings and be chivalrous. It might be a gender relic from old times, but it seems still to be apparent in these fathers.

Strengths and limitations

The analysis depends on data, which depends on the fathers' capability to express themselves in words. We found during interviews that many of the fathers had difficulty articulating their feelings. However, we ensured that analysis and interpretation of findings remained data-near and is representative of the views and experiences of the fathers. The strength in the analysis is that data have been analysed from diverse perspectives, i.e. cardiac nurse (HP), midwives (ÅP, CB) and finally a cardiologist (MS) reviewed the manuscript. However, the quotes illustrate fathers' self-disclosure, and that increases reliability in the analysis. The retrospective approach is vulnerable to biasing effects such as selective memory and over-reporting (Haley, 2002). In general, people tend to report fewer events for a more distant period. So, our results where the interviews took place up to 7 years after the onset of PPCM will be more likely to have underestimated the problem.

Conclusion

The dominating core of the fathers' reactions of their partners' diagnosis of PPCM was overwhelming fear, uncertainty and helplessness. The crisis reaction culminated in fathers' numbness, feel-

ings of isolation, and outbursts of anger and frustration over the situation. Sometimes the strategy of keeping up a strong façade had a negative impact, in that the needed support in the distressing situation was not provided. These results will help peripartum care and cardiology health professionals to understand that emotional support for fathers is equally important as the support required for mothers during the peripartum period. Specifically they will help professionals to focus future efforts in understanding and meeting the supportive care needs of fathers when their partner suffers from a life threatening diagnosis like PPCM.

Clinical implications

Health care professionals need to be aware that an appalling diagnosis like PPCM in the woman is an extra demanding situation for the partners. Planned strategies and guidelines to support fathers are crucial in helping them to understand the woman's situation, undertake their own role in supporting the woman, and appreciate the importance of caring for themselves as well. There is a place for societal and childcare support in the early postnatal period for not only the elder children at home but also the care of the newborn.

Conflict of interest

None.

Ethical approval

Ethical approval for the current study was approved from the research ethics committee of the University of Gothenburg (DNR 589-11).

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