Cardiac care experience of younger persons and their next of kin one year following myocardial infarction: An interview study

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Abstract

Background/Aims Coronary heart diseases, including myocardial infarction, remain a major health problem worldwide. Little is known about the cardiac care experiences post myocardial infarction of younger people and their next of kin. This study aimed to describe the cardiac care experiences of post-myocardial infarction younger people (<55 years old) and their next of kin.

Method This study employed an exploratory inductive qualitative design involving individual interviews with younger people ($n=17$) and their next of kin ($n=13$).

Results Three categories were identified and patients were deemed to be in need of: tailored information, recognition and a post-discharge rehabilitation plan

Conclusions Findings demonstrated the importance of using the experiences of younger people and their next of kin as the starting point when planning care and cardiac rehabilitation. Health professionals must systematically and purposefully provide person-centred care, both in hospital and post-discharge settings. Next of kin must be regarded as an important resource in post-myocardial infarction care for younger people, as they tend to be engaged in providing their relatives with support, which is valuable for the recovery of young people post myocardial infarction. Further research is warranted to investigate what makes person-centred interventions directed towards post-myocardial infarction younger people and their next of kin effective.

Experience of care; Myocardial infarction; Next of kin; Person-centred care; Younger patient

Key points

- Post-MI YPs are in need of a systematically provided person-centred care which must be operationalized in a rehabilitation plan that is implemented both in the hospital and post-discharge settings.
- NoKs should be regarded as a valuable resource and must be involved in the care of post-MI YPs.
- The narrations of YPs and NoKs should be used as a starting point when planning for post-MI care and cardiac rehabilitation.

1. INTRODUCTION

Coronary heart diseases (CHD), including myocardial infarction (MI), are a major health problem and are the leading causes of disability; however, CHD-related mortality has markedly decreased in the past decades (Townsend et al, 2016), and there has been improvements in diagnostics and interventional therapies (Piepoli et al, 2014). Nevertheless, concerns have been raised because younger persons (YPs) aged ≤ 55 years seem to have less benefited from this promising trend (Shah et al, 2016). The onset of MI at a younger age can be devastating due to its impact on patients' psychology and ability to work and due to the socioeconomic burden it entails. YPs are at the peak of their productivity at work, and the aftermath of MI can affect their dependents (Shah et al, 2016). Research (cf. Izadnegahdar et al, 2014; Arora et al, 2019) has found an increase in MI-related hospitalization rates among YPs, especially in women, as well as an increase in drop-out rates from cardiac rehabilitation (Mikkelsen et al, 2014). A reduction of health-related quality of life has also been observed in YPs post-MI (Shah et al, 2016). Moreover, the long-term mortality prediction is poor wherein the death rate is 15% within 7 years post-MI and may reach up to 25%–29% within 15 years post-MI. Despite these trends, YPs have been inadequately studied in cardiovascular research as highlighted in an editorial (cf. Vaccarino, 2019). Thus, it is high time to devote special attention to this patient group.

Although it is already known that the onset of MI at a young age is likely to add distress to one's everyday life, only a few studies have investigated the post-MI experiences of YPs and their next of kin (NoK). (Flagging for author completion: citation) has shown that post-MI YPs experienced physical, emotional and existential struggles as well as faced demands from the healthcare system, employers and authorities, and these experiences negatively impacted their daily lives. By contrast, McAnirn et al (2015) have shown that post-MI YPs were highly motivated to live healthier lives and were determined to learn and change their lifestyle. In fact, the YPs considered their NoKs as an important source of motivation for them to make necessary lifestyle changes. Research (Flagging for author completion: citation) has also shown that NoKs were willing to provide encouragement and support to post-MI YPs as the latter make healthier life choices, and these NoKs felt that they bear a great deal of responsibility for the well-being of their recovering relatives.

Secondary prevention following an MI plays a crucial role in reducing the risk and in preventing the occurrence of a new cardiac event (Piepoli et al, 2016a). In this context, introducing secondary prevention services prior to patients' discharge from a hospital and involving their NoKs in the patients' treatment are important aspects to consider. There is a paucity of qualitative investigation on the post-MI cardiac care experiences from the dual perspective of the YPs and their NoKs; thus, further research is warranted (cf. McAnirn et al, 2015). A better understanding of the post-MI care experiences of YPs and their NoKs is essential in developing and providing care and cardiac rehabilitation because the potential resources of the patients and their NoKs are identified. In the literature, the age of post-MI patients who are considered to be 'younger' varies from ≤ 40 years old to ≤ 55 years old (Journiac et al, 2020; Shah et al, 2016). In this paper, the term 'younger' refers to persons younger than 55 years. MI is an age-related

illness, and MI patients aged under 55 years are still fairly young from the medical and social points of view. This study aimed to describe the cardiac care experiences of post-MI YPs (<55 years old) and their NoKs.

2. METHODS

This study employed an exploratory inductive qualitative design involving individual interviews with the YPs and their NoKs. The emphasis of the qualitative design is on understanding a person's experiences as lived, usually by collecting and analysing narrative qualitative data (Polit and Beck, 2012).

2.1. Setting

The YPs were initially cared for due to MI in a coronary care unit (CCU) of any of the three county hospitals in south-east Sweden. These hospitals are located in three separate towns, where the population ranged from 128,000 to 234,000 only. The CCUs consist of an emergency care unit (6–7 single rooms) and a step-down/rehabilitation unit (6–11 rooms with 16–24 beds) equipped with telemetry facilities. The first of the three CCUs had access to round-the-clock invasive diagnostic, interventional therapy and cardiac surgery services. The second CCU had access to round-the-clock invasive diagnostic and interventional therapy services. The third CCU had no access to the aforementioned services and thus patients in this CCU were brought by an ambulance to the first CCU in the event they needed diagnostic and/or interventional therapy services.

2.2. Recruitment and participants

The YPs were selected based on the following inclusion criteria: (a) aged ≤ 55 years, with (b) an initial MI diagnosis within 12 months, (c) diagnosed to have an MI based on symptoms and electrocardiographic changes and/or the diagnosis was confirmed by abnormally elevated cardiac enzyme levels, and (d) physically and mentally able to participate.

Moreover, the YPs were selected by using the purposive sampling strategy (Polit and Beck, 2012) wherein age, sex, education and time since MI onset were considered. A contact registered nurse (RN) was recruited from each CCU. These RNs assumed the responsibility of sending the invitation letter to the prospective participants. Those who were interested to participate were requested to send in their contact details by using the enclosed reply-paid envelope. The prospective participants were contacted by telephone to set the time and venue for their interview; also, information about the research was provided to them once again, and they were given the opportunity to ask questions they might have regarding the research. Nineteen YPs agreed to participate, but two of them could not be located at the time of the interview, leaving the final sample to consist of 17 YPs.

The NoKs were recruited by using the convenience sampling technique (Polit and Beck, 2012). A NoK was broadly defined as the YPs' significant others, family, partner, relatives or individuals with whom they share close emotional relationships. The only inclusion criterion was that the NoK should be younger than 55 years. The invitation letter sent to the YPs included a question asking whether they have a NoK who could take part in an interview study. If the answer was in the affirmative, then they should provide the NoK's contact details. A total of 17 prospective NoKs were invited but only 16 agreed to participate. However, 3 of them were over 55 years old, leaving the final sample to consist of 13 participants. The characteristics of the study population are presented in Table 1.

2.3. Data collection

In this study, data were obtained from the unpublished independent data of two previous studies published in 2013 (Flagging for author completion: citations); these studies were included in a research project on post-MI experiences of YPs and their NoKs. The individual interviews with the YPs (n=17) began with an overarching question "Please tell me about your experience of

care and support following MI”, whereas the interviews with the NoKs (n=13) began with the question “Please tell me about your experience of care and support following your relative’s MI”. Probing questions such as “Can you tell me more?”, “What do you mean?” and “Can you exemplify?” were used to encourage narration and to check for understanding. To test the suitability of the research questions, we conducted pilot interviews involving both YPs and their NoKs (not included in this study). Most of the interviews took place in the participants’ homes and only two interviews were conducted elsewhere (i.e. workplace and private hospital room). The interviews, which lasted around 30 min, were audio recorded and transcribed verbatim.

--Insert Table 1 here --

2.4. Data analysis

Data were analysed using manifest content analysis as described by Graneheim and Lundman (2004). A content analysis is a systematic, detailed examination and interpretation of various forms of human communication, such as a transcribed interview, to obtain a broad, condensed description of the investigated phenomenon. In this study, manifest content analysis refers to the examination of the visible and obvious components of the interview texts.

The transcribed interviews were read and re-read numerous times to achieve an overall understanding. The interviews were read again to identify the meaning units, that is, phrases or sentences that are related to this study’s aim. These meaning units were extracted from the text, condensed and coded, that is, the text was reduced and each meaning unit was labelled based on its content. The codes were subsequently compared with one another in relation to their differences and similarities and then sorted. Finally, three categories which constitute the manifest content of this study were identified. The analysis process, characterised by moving back and forth between the parts of the text and the whole text, was led by the first author (x) in close collaboration with the co-authors (x and x). All authors read and discussed the results until consensus was reached.

2.5. Ethics

This study was performed in compliance with the principles outlined in the Declaration of Helsinki and was approved by the Regional Ethical Review Board of Lund (H15 2010/101). Verbal and written informed consents were obtained, and all participants were informed about confidentiality as well as their right to withdraw at any time without the need to give a reason for doing so.

3. FINDINGS

In the analysis, three categories emerged, as follows: i) in need of tailored information, ii) in need of recognition, and iii) in need of a post-discharge rehabilitation plan.

3.1. In need of tailored information

According to the YPs, the information and education they received from the healthcare professionals were important, but the information they acquired were not based on their individual needs for daily living. They received pieces of general information that are neither suited to their age nor to their life situation. The YPs were invited to watch an educational video at the hospital ward and were given a booklet about MI. However, these educational materials were prepared primarily for elderly patients and thus the YPs had a difficulty identifying pieces of information that address their individual needs. This issue was further made complicated by the lack of dialogue between the YPs and the “busy healthcare professionals”.

This lack of information prompted the YPs to search for information on the Internet, which is an accessible source of information but at the same time experienced as difficult to value and trust. The YPs lacked a dialogue with the healthcare professionals who could help them learn how to live with their illness and its consequences to their future life and career. They also lacked information on the medications and their side effects, on stress reactions and their consequences, and on ways to prevent the onset of another MI. According to them, they needed to know why they experienced MI at a young age so they could prevent its recurrence.

Furthermore, they described that after returning home from the hospital, they still had questions regarding their situation, but they had no one to consult. One YP said, *“I asked the doctor why, why I got it (MI). “Oh, it was just bad luck that it was you,” he said basically, because I don’t smoke or take snuff or have any family history of it, so to say. (p) So he really didn’t have any explanation why me.” (YP C9)*

As for the NoKs, they lacked information about the status of their relative who was admitted. Receiving information was of paramount importance to the NoKs because they carry a great deal of responsibility for their relative’s well-being. They needed to receive tailored information addressed to their entire family unit, but such a valuable piece of information was apparently unavailable. Those who had children at home had many questions regarding their family situation considering the difficulties involved in knowing what was best for their children under their current circumstance; for instance, should they talk about MI with their children and should the children accompany the adults to the hospital or should they just stay at home. Moreover, they had a lot of questions that remained unanswered even if they searched for information on the Internet; they found it challenging to find relevant information. As one NoK said, *“It would have been worth everything to be able to gather the family and tell them what had happened and why you react in different ways and that you really talk based on our situation and don’t suppress it... To also let the kids and family know what has happened and how you should act.” (NoK A9-9)*

3.2. In need of recognition

The YPs described that they needed to discuss with RN about their personal illness experience and about what happened to them. They needed someone who would devote time to attentively listen, to show interest in their story, and to offer a tailored care. Having confidence in an RN in this unpredictable situation was important. They wanted RNs to spare time to listen and to

engage in conversations with them so that these RNs would see the complete picture of their situation; more importantly, the YPs would want to feel that they are truly cared for. They described, however, that the RNs they encountered solely focused on observing visible signs (i.e. measurable parameters) and on performing tasks or procedures but not on recognising symptoms (i.e. subjective experience of illness). Furthermore, knowing whom to contact if they felt unwell is very important. Similarly, trust in an RN's ability to keep a commitment is valuable. For instance, if the YPs phoned an RN to ask for an advice and the RN had no time to answer, this experience seen as "rejection" and a "terrible experience". Such a scenario would result in loss of confidence not only toward that RN but also toward the entire healthcare system. As one participant said, *"I think that the healthcare professionals should see more, to the extent that it is possible to individualize, so that they work more person-centred, according to my needs and how I do after this (MI). What status am I in, when I come back from the illness? What do I need?"* (A16)

The NoKs described that they did not receive any recognition when their relative suffered from MI. They stressed the need for healthcare professionals to take the situation of the NoKs and of the entire family into account, for instance, by actively asking about their perspective of the situation. To have someone to turn to was described as vital, especially because the NoKs are concerned about their relative and about their family as a whole. The NoKs needed someone who would show interest to them, who had the courage to listen to their story about their experiences, and who would give them recognition. Several of the NoKs felt that instead of being considered, they felt neglected and overlooked. As one participant said, *"She (the nurse) was very nonchalant and sort of didn't care at all... they (the nurses) barely say hello to [an] NoK those nurses. They sit up there on a, behind a desk and check up on the rooms and you kind of don't get any information on what is going on."* (B7-7) The NoKs nonetheless tried to

justify such a lack of recognition, saying that the healthcare professionals lacked experience working with YPs suffering from MI, along with their NoKs.

3.3. In need of a post-discharge rehabilitation plan

The YPs described that the healthcare professionals were not prepared to meet the rehabilitation needs of the post-MI YPs. The YPs were invited to attend a post-discharge patient education program called “Heart School” (HS) organised by the cardiac rehabilitation team (CRT), but those meetings were held at daytime when the YPs were expected to be at work. Not all YPs could participate because of their work commitments. Moreover, the HS meetings were held long after discharge, and the YPs suggested that HS meetings should be conducted sooner after discharge. Additionally, those who attended the HS meetings described that the perspective of the YPs was not tackled given that most of the attendees were of retirement age with whom the YPs do not share much commonality. According to the YPs, no one from the CRT inquired what their perspective was as regards their post-MI situation, what they needed, and what was most important to them in their daily life; in other words, an individualized post-discharge rehabilitation plan was needed. The YPs inquired whether they could participate in training classes that are tailored to their personal goals, capacity and age group and whether they could attend HS sessions in the evenings, along with their NoKs. As one described.

... for the ones of us who are younger, there must be some individual opportunities e.g. in the evening, because it's so important this heart school and gymnastics and all of that, to also have some opportunities in the evenings for those of us who can't go during the day. We have such individual prerequisites and goals. Because it's really stressful having to take time off from work. I mean, it's not always appropriate to do that once a week and the gymnastics is two times a week, like the last one that is two times a week. (C6)

The YPs requested that their experience be taken into consideration by the CRT and that their life situation should serve as the starting point when preparing a care and cardiac rehabilitation plan. They described that attending to their full time work, HS sessions, training classes and several follow up visits, which are all scheduled at daytime, was quite stressful. The YPs already felt the need to attend stress management classes, but such services were not offered. The YPs requested to be given access to a social worker who had an experience working with a post-MI YP both in the hospital and post-discharge settings. Those who had phone access to an RN from the CRT or those who were part of a nurse-led telephone follow up soon after discharge found it to be a good source of support.

For the NoKs, their participation in cardiac rehabilitation was important because they were willing to help their relatives with their daily self-care post discharge and thus they need to learn about MI. Only a few NoKs were invited to participate in all HS meetings, and those who participated mentioned that the perspective of the YPs and of their families as well as the sensibility to the NoKs' needs in daily life were not tackled. They were expecting that the RNs would consider their needs and would show support to them, but the RNs missed to provide the attention they were seeking. The NoKs suggested that it would be of great value to be invited to participate in a rehabilitation meeting or during the presentation of the rehabilitation plan upon discharge because they wanted to know the goals, the rules and the health plan so they could further provide support to their relatives. Moreover, they needed to talk to a social worker at times of difficulties. According to one participant:

Well, I am completely cut off. No, I haven't really been involved in anything. Neither this nor that... I'm only a name in the case book as the next-of kin to (name of the YP), except for that I don't exist... I should have needed to talk to a physician or registered nurse to get to know how (name) prognosis is looking for the future, what you can expect, how he is going to be able to manage his work, maybe what I should be observant of. I think that would have been very

helpful for me to get tailored plan but also for (name of YP). So maybe I could have tackled things completely differently when it comes to his wellbeing than I'm doing now. Because I'm just as lost as he is when it comes to this. (C10-10)

4. DISCUSSION

The study findings indicated that the YPs and their NoKs have had unmet care needs, particularly the need for tailored information, for recognition and for a post-discharge rehabilitation plan. These unmet needs affect the YPs ability to deal with the consequences of their illness and to self-manage their condition, both of which are a central aspect of post-MI care and rehabilitation. This issue is important because, as a study by Andersson and Vasan (2018) has shown that YPs with a cardiovascular disease tend to display an increasingly unhealthy cardiovascular risk profile which must be addressed in post-MI cardiac care and cardiac rehabilitation. The provision of interactive, person-centred information and education to both the YPs and their NoKs is a central component of secondary prevention post-MI as recommended by the European Guidelines on Cardiovascular Disease Prevention (Piepoli et al, 2016b). The provision of information and education is of great importance because patients who poorly understand their illness may lack interest in secondary prevention and rehabilitation (Perk et al, 2015; Piepoli et al, 2016a). However, a recent study (Ögmundsdottir Michelsen et al, 2020) conducted in Sweden has shown that only two cardiac rehabilitation centres out of 78 offer interactive group education that is suited to individual patients' needs, such as age. Given that RNs are members of CRTs in many countries, including UK, Sweden, USA, Australia and Canada (Doherty et al, 2017; Jackson et al, 2018; Kaminsky et al, 2013; Turk-Adawi et al, 2015), they are in a position to conduct early assessment of individual's needs and to assume the responsibility of providing tailored pieces of information that are suited to the needs and life situation of YPs and their NoKs.

Although secondary prevention after an MI is vital in reducing the risk of future cardiac events and in reducing illness progression (Piepoli et al, 2016a), the attendance to cardiac rehabilitation remains low (Kotseva et al, 2018) and there is a higher drop-out rate from cardiac rehabilitation among YPs (Mikkelsen et al, 2014). In a systematic review and meta-analysis (Wanyonyi et al, 2011), it was concluded that interventions involving tailored face-to-face education exert a positive effect on participants' lifestyle and health behaviours. Telerehabilitation is a potential complement to traditional cardiac rehabilitation in order to monitor and deliver content and support; in fact, telerehabilitation has improved the uptake, adherence and completion of rehabilitation in younger patients (mean age: 55.5 ± 9.6 years) (Turk-Adawi & Grace, 2014). Systematic implementation of person-centred care through the care chain should be evident in cardiac care because according to a research (Fors et al, 2015) it contributes to the improvement of self-efficacy, which in turn increases the patients' opportunity to explore and to participate in self-care. RNs and other healthcare professionals involved in cardiac care must recognize a patient as a person with his/her own unique subjective experience of an illness, and they must endeavour to use such experiences when planning a tailored care, that is, to work in a partnership that, according to Ekman et al (2011), includes sharing of information, deliberation and shared decision making. With the use of a person-centred approach, the requirements and standards for cardiovascular prevention can potentially be met (Doherty et al, 2017) and the YPs will be provided with assistance to help them achieve their personal goals.

Our findings showed that the YPs and their NoKs are in need an individualized post-MI rehabilitation plan in order to manage their illness and implement the necessary lifestyle changes post MI. Svavarsdóttir et al (2016) stated that cardiac patients have various educational needs, and they desire for person-centeredness when receiving general information, that is, education must be tailored according to each person's needs, resources and situation. The NoKs

in the present study desired to know the rehabilitation plan for their relatives as they wanted to support them after discharge. It is important to acknowledge that NoKs are a valuable resource in cardiac care and cardiac rehabilitation; research has shown (Di Castelnuovo et al, 2008) that NoKs exert a positive influence on their relative's lifestyle changes. Moreover, Wolf et al (2019) reported that a person-centred care following a cardiac illness leads to a patient's enhanced care experience partly because their NoKs are more involved and active in care provision. It is of course important to follow the national and international guidelines in providing post-MI care, but the starting point must be to listen to the patients' narrative (Ekman et al, 2011) with a focus on their capabilities and resources and not only on the knowledge of the disease. Healthcare professionals in cardiac care must work in partnership with their patient and together co-create a personal rehabilitation plan which is documented and accessible to professionals at all care levels and to the patients themselves. A recent study (Pirhonen et al, 2019) has shown that person-centred care for younger patients (under 65 years old) with acute coronary syndrome was found to be more effective and less costly compared with ordinary care. Thus, a person-centred care must be an important component of sustainable modern cardiac care both from the personal and societal perspectives.

4.1. Methodological consideration

One methodological strength of this study is the inclusion of a large number of individual interviews (n=30) with YPs and their NoKs; this large number of interviews will reveal the varied experiences as regards the investigated phenomenon. The sampling strategies employed in this study aimed to achieve variation in order to describe the investigated phenomenon from as many perspectives as possible. In recruiting the YPs, purposeful sampling (Polit and Beck, 2017) was used, wherein age, gender, educational level and time since the onset of MI were considered. The NoKs were recruited using the convenience sampling strategy. A convenience sampling strategy can increase the risk of sampling bias (Polit and Beck, 2017); this study

included a broad spectrum of NoKs who were chosen by the YPs; the NoKs included were the husband/wife, cohabiting/non-cohabiting partner, or daughters/sons of the YPs. X, who had a work experience as an RN in coronary care, conducted all of the interviews with an open mind and sensitivity to the participant's narrations. Familiarity with the care context was important so that the interviewer could pose relevant probing questions based on his/her immediate understanding of what the participants were trying to express. Data analysis was led by (x) who collaborated through a series of discussions with the co-authors (x and x, both of whom have an experience in qualitative data analysis), who also participated in data analysis. Throughout the process of the data analysis, critical reflections were made and regular discussions took place to ensure trustworthiness (Graneheim et al, 2017). Quotations from the interviews were used to validate whether the resulting categories were supported by the interview data, thus enhancing transparency.

The interviews were carried out several years ago, which can be considered as a limitation. Since that time, local (Perk et al, 2015) and foreign (Kotseva et al, 2018) researchers have called for new models for secondary prevention. In Sweden, a new hospital-based model for cardiac rehabilitation has been implemented (Perk et al, 2016), but to our knowledge this model has not yet been evaluated. We still consider the knowledge obtained in this study as valuable both to the academia and to clinical practice.

5. Conclusion

The study findings demonstrated the importance of using the perspectives and experiences of the YPs and their NoKs as the starting point when creating a post-MI care and cardiac rehabilitation plan. Thus, health care professionals must systematically and purposefully provide a person-centred care (both in the hospital and post discharge settings) that is documented and continuously updated in a personal rehabilitation plan. NoKs should be

regarded as a valuable resource in providing post-MI care to YPs, and they should be considered as key persons providing both support and coaching to their relatives. Further research is warranted to investigate how the person-centred interventions directed towards the post-MI YPs and towards their NoK can be used and operationalized in coronary care and cardiac rehabilitation, as well as to determine how effective such interventions are for the YPs' recovery.

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