

Health and Illness Perceptions of Patients suffering their First Acute Myocardial Infarction and Undergoing Primary Percutaneous Coronary Intervention in Queensland: A Qualitative Study

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Abstract

As a result of advances in technology and treatment techniques, interventional cardiology has led to significant changes in the treatment of patients suffering a heart attack (or Acute Myocardial Infarction - AMI). The current treatment often involves primary (emergency) Percutaneous Coronary Intervention (angiogram and angioplasty) followed by a rapid recovery. Patients often do not experience significant pain during recovery, have markedly reduced hospital stay and return to work sooner than in the past. Therefore it is plausible that they may dismiss the significance of their cardiac illness and its long-term implications. Therefore the meaning that these patients assign to their experience of having a heart attack and emergency treatment in the form of PCI plays a pivotal role in their subsequent health behaviour, including cardiac rehabilitation attendance, medication adherence and functional status.

This qualitative study used hermeneutic phenomenology to explore participants' experiences and gain an understanding of their perceptions of the event and beliefs about their subsequent health and illness. Semi-structured, in-depth interviews were conducted three to six months following discharge with thirteen participants (ten males and three females). Four key themes emerged from the data, illustrating the physiological, emotional and social adjustment experienced by the participants. These included confusion about the expected and experienced symptoms of AMI, a realization of their vulnerability to sudden death, amazement at the speed of intervention and physical recovery and a gradual understanding of the need to modify risk factors and revalue priorities in life. It is anticipated that the findings will contribute to the provision of effective and streamlined cardiac education that are tailored to the needs of this group of patients.

Introduction

Cardiovascular disease (CVD) continues to be the leading cause of death in Australia. It is estimated that more than 200,000 potential years of life are lost annually up to the 75-year-old age group as a result of CVD (AIHW 2006:61; Bunker et al. 1999:34-38). The term CVD refers to all diseases of the heart and blood vessels. It includes coronary heart disease (CHD), stroke, other vascular diseases and heart failure. The two major forms of CHD are Acute Myocardial Infarction (AMI, commonly known as a heart attack) and angina pectoris (AIHW 2002:1; AIHW 2005:2).

Advances in the treatment and management of CVD have substantially contributed to major reductions in mortality and ongoing morbidity over the past few decades (AIHW 2004:4). Until 1977, drug therapy and Coronary Artery Bypass Grafting (CABG) were the only treatment modalities available for patients with coronary heart disease. Since then percutaneous coronary intervention (PCI) has evolved as an alternative therapeutic option (Brezynskie 1998:8). The procedure requires the use of a fine catheter with a balloon at its tip which reaches the heart's vessels via an artery in the

wrist or groin under local anesthesia. The balloon is inflated to dilate the narrowed vessel and a stent (a tubular metal structure) can be placed at the narrowed vessel to keep it patent (AIHW 2003:3). Elective PCI refers to patients undergoing a booked procedure whereas primary PCI is an emergency procedure.

The management of AMI is moving increasingly towards PCI and intracoronary stenting at admission, or alternatively, within the first twenty-four hours of admission (DeGeare et al 2001:15; Smith, Rothman & Timmis 2004:502). Consequently hospital discharge periods have shortened over the years: from fifteen days in the 1970s to the current American and European recommendations that patients with uncomplicated AMI may be considered for discharge within four days of admission (Kaul et al. 2004:511; Smith, Rothman & Timmis 2004:502). However, these gains in managing the acute phase of the illness contrast with the slow and limited progress that has been achieved in managing the rehabilitation phase of the illness (Petrie et al. 1996:1191).

Cardiac rehabilitation (CR) programs have been designed to limit the effects of cardiac illness, modify risk factors and encourage change in lifestyle to stabilise or reverse the atherosclerotic process and enhance the psychosocial status of selected patients (Stiller & Holt 2004:20; Thompson et al. 1996:89). Such comprehensive programs have proved to be effective in helping patients to improve their exercise capacity and lipid levels, and hence their psychosocial well-being, as well as helping them to reduce their cigarette smoking, stress and hence their risk of further coronary events (Morris, Black & Reid 2000:115; Ratchford et al. 2004:150). A Victorian study found post-discharge, 53% of the CABG patients were attending CR programs compared to 27% of AMI patients and only 10% percent of PCI patients (Bunker et al. 1999:334). Because patients who have undergone PCI do not experience much physical pain during recovery, have reduced hospital stay and return to work earlier, they may not initiate lifestyle changes as diligently as patients who have had CABG. These patients also tend to be younger in age and return to work more quickly (Bunker et al. 1999:335).

Patient's beliefs or perceptions about their illness plays a pivotal role in health behaviour including CR attendance, medication adherence, functional status, return to work and physical functioning following AMI (Cooper et al. 1999:234; Petrie et al. 1996:1191). In a more recent study Eastwood (2001:131-137) reports on the attitudes of patients towards CVD following elective PCI. Some patients viewed this procedure as having 'fixed' their problem and there was a detectable reluctance or a perceived 'no need' to attend CR.

No research was found on the health and illness perceptions of AMI patients undergoing primary PCI. Therefore it is not known whether this group of patients dismisses the seriousness of their illness, in ways similar to elective PCI patients.. The aim of this paper is to provide some information on the experiences and perceptions of health and illness in patients suffering their first AMI and undergoing primary PCI. To better locate the findings of the present research it is important to discuss how health and illness is conceptualized.

Conceptual Framework

A conceptual framework of health and illness cognition was chosen to guide this research, the Common Sense Model (CSM). Literature suggests that peoples' responses to health care threats are guided by a cognitive representation about a particular illness, and the way they perceive their illness influences how they seek professional help and/or their willingness to continue treatment (Bishop & Converse 1986:96; Zerwich et al 1997:92-98). Thus, illness cognition has important health consequences (Lau, Bernard & Hartman 1989:196). Bishop and Converse (1986:96)

advocate that people process information about physical symptoms according to preconceived notions they may have about how symptoms fit together. These notions serve as standards against which to match and evaluate symptoms being experienced.

The CSM was developed by Leventhal and Nerenz (1985:518-519) who believed that people are active problem solvers and their behaviour is guided by how they perceive and interpret health threats. The health threat is assessed through the perception of symptoms which lead to the development of illness cognitions, and it involves changes to the emotional state of the individual (MacInnes 2005:107). The model consists of the following stages (Lau and Hartmann 1983 cited in Leventhal & Nerenz 1985:521; Leventhal & Nerenz 1985:520; Weinman et al. 1996; Zerwic et al. 1997):

Identity: Illnesses are identified abstractly by their label, e.g. AMI and cancer and concretely by their symptoms, e.g. pain and nausea.

Consequence: The perceived physical, social and economic consequences of the disease and the emotional consequences experienced, e.g. shame or despair.

Causes: The perceived causes of the disease, e.g. genetic factors, environmental pathogens, such as virus or the individual's behaviour, such as smoking and stress.

Time line: The perceived timeframe for the development and duration of the illness threat, whether the disease is acute, cyclic or chronic.

Cure and / or Control: The extent to which people believe their condition is amendable to cure or control.

Research Design and Methodology

A qualitative research design was chosen for this study to allow in-depth exploration of the experiences of individuals who suffered their first AMI and underwent primary PCI. As hermeneutic phenomenology is considered both a way of 'being in the world' and a way of understanding (Maggs-Rapport 2001:377) this approach was chosen as a guiding philosophy and methodology for the present study. The methodology allows the researcher to describe the lived experiences of a particular phenomenon and to identify, describe, understand and interpret these experiences in relation to their day-to-day lives (Crotty 1996:12-19; Koch 1999:28; Walters 1994:140).

Purposive sampling was used to select potential participants for the study. Participants were recruited from a private hospital offering primary PCI to its private and public patients in South-eastern Queensland. This area was chosen as it allowed for both privately and uninsured participants to be included. People with cognitive impairment, such as dementia, and chronic or serious illnesses, such as diabetes or cancer were excluded, as were participants from non-English speaking background. The exclusion of the latter group was for logistical reasons as it would not have been possible to arrange for interpreters. The interviews were conducted between four and seven months following discharge after a first ever episode of AMI and primary PCI. Thirteen participants were recruited, eight of whom were treated in a private hospital and the remaining in a public hospital. The participants ranged in age from 43-63 years. There were ten males and three females in the sample. Nine participants lived in a metropolitan area and four in rural areas. Nine were employed, two were retired and two ticked the box 'other'.

Semi-structured in-depth interviews were chosen as a data collection technique as the participant is free to describe their experiences in their own words and it allows the researcher to use an interview schedule related to issues that are essential to the study (Draper 1996:48; Minichiello et al 1995:65). The questions were based on a critical

review of the existing literature on patients undergoing elective PCI and also guided by the conceptual framework of this study. A cardiologist who also had personal experience of a first AMI and primary PCI reviewed the interview guide. A conversational style of questioning was adapted in order to collect 'detailed and richly textured person-centred information' (Minichiello et al 1999:396). The interview questions were thematically related to the research topic and the questions were adapted to suit the dynamics of the interpersonal relationship that evolved in the interview. Interviews lasted from 45-140 minutes, average 85 minutes. Permission was sought to audio tape the interviews. The researcher, who is the first author of this paper, kept detailed post-interview notes in a journal, which included additional information on the participant and her reflection of the dynamics of the interview and the setting in which it took place.

Data Analysis

All interviews were transcribed verbatim and themes were identified using thematic analysis bringing together similar and recurrent ideas, experiences and behaviour of the participants (Koch 1995:835; 1996:181). The transcripts were then read and re-read to identify and analyse the ideas, concepts and opinions of the participants which were then clustered into categories that represented important aspects of the participants' experiences. These categories were then analysed and condensed further using the approach of thematic analysis to provide an insight into the meanings of these experiences. The findings are presented as themes which are consistent with the phenomenological-hermeneutical inquiry chosen for this study. The themes were aimed at capturing and describing a consistent, re-occurring aspect of the structure of an experience, thereby allowing the reader to have some understanding of what it is like to experience the phenomenon under study (DeSantis & Ugarriza 2000:356).

Results

Four key themes emerging from the data are presented below and sequenced as stages of a journey from the initial symptoms of the AMI through the recovery to the development of a new outlook on life. This journey is described as a metaphor for the personal adjustment and development that took place following the participants' experiences of their first AMI and primary PCI. The key themes include: 1) 'I didn't know that it was a heart attack' – expectations and actual experiences of a heart attack. 2) 'I wonder what number I am' – facing one's own mortality. 3) The 'operation' that fixed the blockage – a surreal experience. 4) Adapting to 'The New Me' – living through the process of adjustment. Although within each of these themes there were several sub-themes, space constraints only allow a discussion of the over-arching key themes in this paper.

Theme 1: 'I didn't know that it was a heart attack' – expectations and actual experiences of a heart attack

All the participants described being confused about their symptoms. They related these symptoms to past illnesses and they attempted to control these by applying different strategies. The early symptoms were interpreted as indigestion, a pulled muscle, exhaustion, lack of fitness, stress, asthma and anxiety:

I thought it was anxiety, because I have had anxiety in the past and it was sort of like a lump in the throat (Carla)

As the symptoms got worse and they felt they were losing control, most of the participants sought medical help. This was their first stage of their journey. For many participants the early symptoms differed considerably from their expectations of an AMI, being a sudden and dramatic event as often portrayed on television, rather than an evolving event:

Because it wasn't right where you would think like what you see on TV, I was really surprised when I was having a heart attack (Alana)

Theme 2: 'I wonder what number I am' – facing one's own mortality

This was the second stage of the participant's journey. Suffering an AMI caused the participants to experience emotions such as fear and anxiety being faced with their own mortality and for some balancing on the edge between life and death. At the same time they were challenged practically with admission procedures and preparations for the angiogram. For some of the participants this was followed by emotions of reliefs and gratefulness for having survived:

I had a rough idea that this was going to be it. I have a picture of as if I was in a tunnel I saw death and I could see both my brother and my mum or dad but I could see life as well I could see my grandkids and I took the life side, makes me feel that I am a lucky man. I got a second chance of life (Ernst)

The fear of dying during the acute stage of the AMI made participants aware of their mortality and affected the way they envisaged their future. Feeling grateful for having survived, an ongoing fear of dying and a need for re-evaluating and improving one's life were emotions experienced by the majority of the participants.

Theme 3: The 'operation' that 'fixed' the blockage...a surreal experience

All the participants referred to the PCI procedure as the 'operation'. They all had some interesting experiences undergoing this procedure, feeling 'gob smacked', 'somewhere else', 'cloudy', 'inert', 'sketchy' and 'drugged out'. For some of the participants their experiences may have been aided by the administration of morphine that they were given as a pain relief:

I thought the technology to be able to do that it stunned me it changes the treatment of heart attacks quite a lot. I can see in the next ten twenty years heart attacks will be like migraines you know people just have them and get over them and keep on living (Ian)

All the participants indicated their amazement about the nature of their treatment and how quickly it had made them feel well. Some were struggling to comprehend that such a serious event could happen in such a short period of time which did not match up with how good they felt and what they believed a recovery would be like following an AMI. Others just felt that they wanted to 'get on with it' and not dwell too much on what had happened. For everyone it led them to a new belief of what the 'modern' treatment of an AMI is like in today's health care system. It appeared that the participants believed that the procedure had 'fixed' their blockage. However most of them also believed that they now suffer from an illness that requires long-term treatment, which was revealed in their responses to a question on the timeframe needing to take medications. Therefore it seems that the participants did not believe

that the cause behind their blockage has been 'fixed' otherwise their response to this question may have been different.

Theme 4: Adapting to the 'new me'- Living through the process of adjustment

Having survived the initial and acute stages of the journey and being discharged led the participants to a different stage, moving through an unknown terrain. It became a journey through a discovery of and adaptation to the 'New Me', testing out and regaining control of their body, its limitations and opportunities. Some were feeling lost or depressed, for shorter or longer periods along this journey, realising that doors had been closed to old habits and lifestyles and they were no longer able to control and read their body. Experiencing loss, resistance and uncertainty was all part of the journey when they had to let go of the past and adapt to other and new paths in life. It became a physically, emotionally, mentally, socially and spiritually challenging stage of the journey having to adjust to 'The New Me':

Now I have got this heart disease label for the rest of my life and I have to be on these tablets, people who have heart disease they are a burden to the medical system and usually it is through neglect in their eating or their behaviour and I didn't want to be guilty of being a burden on the society by being labelled so it is very humiliating (Fred)

All participants were challenged by their new lifestyle, the nature and label of their illness and the physical, psychological and social changes it involved. Some of them felt that their AMI had caused a physical impairment or loss, whereas others believed that they were fitter in many ways.

However, all of the participants attained a level of self-actualisation where they had adjusted to their new lifestyle by being able to reflect on their entire journey from a different perspective. The discovery of new paths, and loss of others, provided new insights that allowed the participants to question the meaning of life while trying to find a new purpose in life. The experience encouraged participants to reflect on their attitudes towards life, and to actively improve their quality of life and lifestyle by prioritising 'everyday' values such as family, friends, health and wellness. It encouraged them to make and act upon decisions, and work to change directions. For many it was a journey towards better health not only physically but also mentally. Despite having had a physical injury and illness, health was perceived as better and as a state of being balanced mentally, socially and spiritually, achieved by eating differently, exercising more and prioritising things differently in life:

What has changed is probably my attitude to life live for today because you just never know it has given me more energy to want to do things mentally you might as well go through life and run through the fire and do everything you want to so maybe hindsight has given me that open door to go forward (Belinda)

A divergent insight and outlook on life was revealed by four of the participants. Those participants took a broader perspective on AMI and discussed their views of treatment in the light of today's health care system. In a comparison between the real and the ideal world', these participants identified and suggested areas of improvement to the health care system to prevent others from developing an AMI. For these participants it was important to deliver a message to 'people out there' from someone who had been close to 'the other side' and wanted to prevent others from taking the same path that they had taken prior to their AMI. These participants suggested more education to

teenagers, more healthy food alternatives, publicity on the diverse symptoms of an AMI, informal places where people can monitor their health, and a holistic view and approach to the treatment of AMI:

I would have liked to have seen more alternatives rather than being put on this regime of pills. I believe that there is another alternative that is not being offered in the normal hospital or rehab. I guess they are just fixed into this is the way they do things and I guess a lot is based on pharmaceutical companies unfortunately (Dennis)

It is important to note that despite the themes having been presented as stages of a journey, representing the continuous personal adjustment and development of the participants, it does not necessarily mean that this development is truly linear, as some of the participants' initial experiences reappeared at later stages of their journey but from a different perspective. The fear of dying was one example of an experience that appeared as an initial reaction to the AMI when the participants were faced with their own mortality. At later stages of their journey, distanced from the acute stage with its uncertainty of survival, the participants' experienced these emotions of anxiety and fear again when resuming ordinary daily activities, such as driving a car and exercising. Therefore certain emotions were experienced in a cyclic manner and the reactions and adjustment that followed depended on where the participants were in their phase of recovery both emotionally and mentally.

Discussion

Alonzo (2000:1475-1484) asserts that it is appropriate to explore the meaning of patient's disease from within their illness schemata. The present study found that the five major domains belonging to the CSM (Leventhal and Nerenz 1985:520), identity, consequences, causes, timeline and cure/control was useful in exploring how the participants created meaning out of their experiences. The model can also assist health professionals to understand how illness threats and symptoms serve as targets for interpretation and self-regulative procedures that may result in delay of seeking help, adherence to treatment, or non-adherence and poor treatment outcomes (Leventhal, Diefenbach & Leventhal (1992:150).

It is a well-known that delays in seeking medical attention for cardiac symptoms contributes to mortality and reduction in preserved cardiac function in both men and women who survive (Martin & Suls 2003:222). Barbagelata et al (2007:260) state that the delay from onset of symptoms to seeking medical attention represents almost two thirds of delay in treatment period and depends on the patient factors, such as insufficient knowledge, poor coping mechanism, misperception of symptoms to a less serious condition and embarrassment about being wrong. The results of the present study show that many of the issues outlined by Barbagelata et al. apply to the Australian setting.

Despite AMI being one of the leading causes of illness and death in Australia, and the considerable amount of time and money expended on health promotion messages in the media. The present study found that people's perception of onset of an AMI are influenced by its portrayal as a sudden and dramatic event on television and in films rather than government-sponsored health promotion messages which include a range of symptoms. Van Gaal et al (2007:468) claim that public education campaigns to help people recognize the symptoms of AMI and promptly call an ambulance have not had much success. An Australian study claimed that despite continuing education over the past 30 years, there has been little progress in reducing delay times (Holliday, Lowe & Outram 2000:307-316). The present study found that delay in seeking hospital care is

common. For health education messages to be better targeted, there is a need to better understand individuals' perceptions of illness cognition and reorientation of health messages accordingly.

This study provides valuable insights into the experiences of Australians, in South-eastern Queensland, who suffered their first AMI and underwent an emergency and invasive procedure. The findings provide some useful information for both practitioners and policy makers. However, as this was a qualitative study the findings cannot be generalized. It is important that additional research is conducted with a larger sample size in order to achieve a broader and more comprehensive understanding of patients' perceptions of health and illness.

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