'It's like an explosion in your life…': lay perspectives on stress and myocardial infarction

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Summary

• Psychological difficulties are common after myocardial infarction (MI). These difficulties are most often represented to patients through cardiac rehabilitation services and the literature offered to patients after MI as being related to 'stress' and its management. However, no research has examined what MI patients understand by the term 'stress' or how congruent lay views of stress are with those evident in the professional literature.

• The aim of the study reported here was to examine post-MI patients' views of stress, its functioning and relationship to their MI.

• As patients' views of stress were sought, qualitative interviews were used. A philosophical approach was taken (critical realism) that recognizes the legitimacy of both professional and lay perspectives. Data were generated in 44 semistructured interviews with 14 MI patients who were interviewed 48 hours, 1 week, 1 month and 3 months after hospital admission.

• While participants described their experiences after MI as being difficult, to convey this they used everyday terms such as fear, fright and worry. Rather than viewing stress as being a consequence of their MI, they perceived it to be a common cause of heart problems.

• Many considered stress as having a more influential role than other risk factors, such as smoking and diet. They expressed a wide variety of sophisticated and diverse views of stress and its functioning. Each of these views placed different weighting on the roles of social, personal and situational factors in contributing to the stressful reaction. Parallels were apparent between these lay accounts and theories of stress developed in the professional literature.

Keywords: cardiac rehabilitation, cardiac, coronary, counselling, heart attack, psychology.

Introduction

Many patients have psychological difficulties after myocardial infarction (MI) (Keckeisen & Nyamathi, 1990; Shiell & Shiell, 1991; Bennett, 1992; Thompson *et al.*, 1995; Jones & West, 1996; Alonzo, 1999). These difficulties

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not only increase after hospital discharge but often remain over at least the first year after infarction (Billing *et al.*, 1980; Wiklund *et al.*, 1984; Thompson *et al.*, 1987; Jaarsma *et al.*, 1995; Crowe *et al.*, 1996; Bennett & Mayfield, 1998; Wiles, 1998; Dixon *et al.*, 2000; Stewart *et al.*, 2000). Beyond their intrinsic significance, psychological difficulties may be a risk factor for coronary heart disease (CHD) and an acute trigger for further CHD events (Friedman & Rosenman, 1974; Deanfield *et al.*, 1984; Hemingway & Marmot, 1999; British Heart Foundation, 2000; James *et al.*, 2000; Ketterer *et al.*, 2000).

After MI, psychological repercussions have been described in the professional literature using a wide range of terms including: psychiatric morbidity (Shiell & Shiell, 1991), post-traumatic stress disorder (PTSD) (Doerfler *et al.*, 1994; Kutz *et al.*, 1995; van Driel & Op den Velde, 1995; Lidell *et al.*, 1998; Alonzo, 1999; Bennett & Brooke, 1999), neurosis (Thompson & Lewin, 2000), threat (Wishnie *et al.*, 1979; Bennett, 1992), anxiety (Billing *et al.*, 1980; Thompson *et al.*, 1987; Elliot, 1992; Crowe *et al.*, 1996; Chiou *et al.*, 1997), stress (Rowe & Weinert, 1987; Beach *et al.*, 1988; Terry, 1992) and emotional reactions (Almeida & Wenger, 1982; Jaarsma *et al.*, 1995; Alonzo & Reynolds, 1998). However, psychological difficulties related to MI have come, in the main, to be represented to patients as linked to 'stress' and its management (Pritchard, 1998). The inclusion of stress management components in cardiac rehabilitation programmes has been supported widely by policy and clinical guidelines (NHS Centre for Reviews and Dissemination, 1998; Balady *et al.*, 2000; Department of Health, 2000). Stress is a common theme in the patient education literature given after MI (Pritchard, 1998), while forms of stress management are now present in approximately 90% of cardiac rehabilitation programmes provided in the UK (Thompson & Bowman, 1995; Bethell *et al.*, 2001).

JUXTAPOSITION OF LAY AND PROFESSIONAL PERSPECTIVES

People attempt to describe what they are experiencing but the labels they give to their diseases do not necessarily reflect how others would describe their underlying biological or psychological state. A distinction should then be drawn between psychological disturbances as they manifest themselves to the individual and how they are conceived and framed by other parties. This distinction raises the issue of how similar lay perspectives of the difficulties experienced after MI are to the perspectives held by professionals.

Differences between lay and professional groups occur frequently in health care. The disparities evident between professionals and patients are of such significance that an entire approach to health care based on bridging the gap between these groups has been developed (Royal Pharmaceutical Society of Great Britain, 1997). While public and professionals may increasingly share the same vocabulary (Giddens, 1991; Petersen & Lupton, 1996), they often appear to have different knowledge bases, systems of thought, preferences and values (Sayer, 1992). Differences between lay and professional perspectives have been identified in supposed fundamentals such as the body (Nettleton & Watson, 1998; Williams, 2000), causes and treatments of CHD (Davison *et al.*, 1992; Clark, 2001b; Reid & Clark, 2001) and CHD-prone behaviours (Farooqi *et al.*, 2000). While few studies have examined lay perspectives on psychological difficulties (Weber & Laux, 1990; Mulhall, 1996; Clark, 2001a), the meanings ascribed to psychological constructs appear to be highly contested. Masse (2000) identified, for instance, that members of the public associated 'stress' with approximately 2000 different terms and concepts.

In contrast to the voluminous professional literature on psychological difficulties after MI, relatively few published studies have explored patients' difficulties and, where this has been done, it is through examination of general experiences of or after infarction (Levy, 1981; Johnson & Morse, 1990; Fleury *et al.*, 1995; Thompson *et al.*, 1995; Wiles, 1998). While some studies specifically examining psychological disturbances do exist (Viswanathan & Vizner, 1984; Bennett, 1992; Scherck, 1992), these use predefined theoretical frameworks to structure data collection and interpret data. Consequently, the human experience of psychological disturbance after MI has come to be conceptualized almost exclusively in professional terms, approached using professionally derived theories, and evaluated using professionally designed and validated measurement tools.

While there have been few empirical attempts to explore patients' perspectives on psychological difficulties after MI, professionals' understandings of patients appear to be poor. Other MI patients, or those close to them, have been shown to have more accurate insight than health professionals into MI patients' needs and emotional conditions (Johnston, 1982; Tilley *et al.*, 1987; Turton, 1998). While studies into psychological difficulties after MI have attempted to incorporate lay perspectives by identifying what individuals find stressful after MI (Rowe & Weinert, 1987; Toth, 1987; Miller *et al.*, 1990), this approach assumes that professionals and lay members share similar views of what stress is and how it is

manifested. However, evidence suggests that difficulties experienced after MI are strongly affected by personal dimensions (Bennett, 1992; Scherck, 1992). The study reported here therefore aimed to examine lay perspectives of stress after MI and relate these perspectives to existing professional discourse in the area.

Research design and method

APPROACH

A focus on participants' views of stress was central to this study. An approach was sought that could allow examination of participants' experiences of disturbance after MI but could also relate these perspectives to the discourse in the professional literature on stress. Critical realism was identified as a philosophically sound approach that was able to recognize the legitimacy of both lay and professional perspectives (Sayer, 1992; Wainwright, 1997; Murphy *et al.*, 1998; Proctor, 1998).

Briefly, critical realism is a philosophy of scientific inquiry that has grown out of the weaknesses of positivism and relativism (Phillips, 1990; Schumacher & Gortner, 1992; Clark, 1998; Lincoln & Guba, 2000). It acknowledges that the world exists independently of our knowledge of it (Schwandt, 1997) and can be known, albeit fallibly (Sayer, 1992; Lincoln & Guba, 2000). Importantly, whilst seeking truth, critical realism recognizes that different representations of truth can exist and it can embrace knowledge developed from a wide range of approaches, including qualitative and quantitative research methods (Dzurec & Abraham, 1993). This plurality is especially relevant for nursing because it uses the findings of biological, social and psychological sciences (Kikuchi & Simmons, 1996). In the same manner, from a critical realist perspective, both professional and lay perspectives on phenomena are seen as valid, although different, accounts of phenomena (Sayer, 1992; Proctor, 1998). The approach does not attribute absolute priority to lay beliefs and constructs but views them, along with other discourses (including professional ones), as being part of a range of possible representations (Sayer, 1992; Wainwright, 1997; Proctor, 1998).

METHODS

Qualitative methods were chosen as they could explore the nature and complexities of lay accounts of psychological disturbances after MI. Semi-structured interviewing was used as this allowed unanticipated or previously unexplored findings to be investigated in the participants' own terms.

'Stress' is a term, like many, that is common to professional and lay discourses (Giddens, 1991). To preserve the nature and integrity of the lay perspectives during the interviews, I did not introduce any professional concepts or terms related to psychological disturbance. Instead, I talked with the participants about their experiences more generally, taking a lead after this from the terms and constructs that they used to describe any reported disturbance.

SAMPLING STRATEGY

Data were collected with patients from a single hospital in Glasgow, Scotland. Individuals were interviewed if possible 48 hours, 1 week, 1 month and 3 months after their admission to hospital. The recruitment strategy targeted a more heterogeneous sample in terms of sex, age and socio-economic group than would have occurred if a consecutive sample of patients had been used. This increased the rigour of the study by countering idiosyncratic patterns in the incidence of MI in Glasgow (Schofield, 1993), where individuals with MI tend to be younger and from lower socio-economic groups than elsewhere in the UK (Smith *et al.*, 1990; Carstairs & Morris, 1991). Sampling across socio-economic groups was based on census-generated data (Carstairs & Morris, 1991).

To ensure that participating in the study did not endanger individuals who were vulnerable physiologically, a number of exclusion criteria were used. Only those with a confirmed diagnosis of first-time MI were approached. For practical and safety reasons they had to be conscious and not intubated, have stable vital signs, have been pain free and not to have had an invasive procedure for the previous 8 hours (other than blood sampling). Finally, senior medical or nursing staff had to have judged the patient as being medically stable and unlikely to experience further MI-related complications. The hospital and community ethics committees gave ethical approval for the study.

Fourteen participants (eight men and six women) agreed to take part over the 7 months of data collection (see Table 1). At this point, saturation had been reached as no new substantial themes were emerging from the data (Sandelowski, 1995). Two patients refused to take part, citing the adverse impact that talking about their experiences would have on their well-being. To preserve confidentiality, each participant was given a pseudonym and code. All interviews were audio tape-recorded with participants' permission and lasted between 35 and 90 minutes.

Table 1 Description of study sample

	$n = 14$ (eight males, six females)
Mean age	56
Median age	56
Standard deviation of ages	12.7
Range of ages	48 (min 36, max 86)
Mean dep cat	4.14
Standard deviation of dep cat	2.17
Range of dep cats	6 (min 1, max 7)

Dep cat: deprivation category.

To assist with analysis and increase familiarity with the transcripts, I transcribed the taped interviews. Field notes were also made after each interview. These data were analysed with a specific focus on the language used by participants. After the interviews and this preliminary analysis were complete, common themes were identified between participants and in individuals over time. The rigour of the study was maintained through the use of extensive field and analytical notes that allowed a third party to understand the interpretive processes linking the data to the analytical themes generated (Rodgers & Cowles, 1993; Cresswell, 1997).

Findings

STRESS AS PART OF DAY-TO-DAY LIFE

Participants associated the term 'stress' with everyday living, rather than seeing it as a consequence of MI. This was apparent in the language they used to describe their experiences after infarction and in their specific commentaries on stress. They did not, however, see their MI as being straightforward; indeed, they acknowledged and reflected throughout their accounts their feelings and responses to the taxing nature of their experiences. These involved sensations of 'panic', 'worry', 'fright', 'sweats' and 'anger':

> …It's like an explosion in your life. Everything changes, everything. 'Will I see my kids again? Will I see my house again? Will I get better again? Will I be out of this place (Coronary Care Unit) with all these wires? What are all these things for, all these things that was on me?' I was wondering what they were. I've never ever been as ill as that in my life.

When the data were examined for instances in which the term 'stress' was used, participants' conceptions were mostly psychological and focused on everyday stress and its contributing role in the MI.

STRESS AS A CAUSE OF MI

Most pervasively, participants voiced that stress had played a formative part in causing their MI. This stress was perceived to have been chronic and related to various demands such as leading a busy or demanding life, work-related difficulties, harrowing events or relationship problems. This association left the majority feeling vulnerable to the perceived future adverse effects of stress, including having another MI:

> All of a sudden I could be sitting watching TV and then I think 'Oh God, I better not stress out about that.' (or) 'I better not worry how much money I spent' or 'I better not stress.' Or if I waken up during the night and I'm worried about something, I think 'Oh no, don't worry, don't worry, don't…Go through your relaxation technique.' Because that is one thing they cannot tell you, if you are stressed out or not – if it IS doing you harm…I think it probably is a big factor….

STRESS AS SOCIETAL NORM

The everyday stress in participants' lives was seen as coming from wider society. Members of the general population were seen as typifying stressful behaviour, with their hectic and rushed approach to life. A man who had fought during the Second World War felt that stress was a term that was used incorrectly by many people to describe the pressures of contemporary life. Throughout the accounts of his MI, he was reluctant to use any language that might imply that life after infarction was difficult:

> I think 'stress' is a word that's abused…I think it's abused because, there was never…During the War years, when you had bombs dropping all over the place, there was a damn sight more stress, and that was real stress. Nowadays 'stress' is used when a small bit of strain is all that it is. Something you get that's a little bit exceptional and it's: 'STRESS, STRESS, STRESS!'. and I think it's the most abused word in the English language at the moment. I know conditions are changing all the time but I don't think they're any worse than they have been in other times throughout my life.

This account reflects a relative conception of stress that associates it only with highly threatening situations and demonstrates how language, personal beliefs, experience and society can inform understanding.

STRESS AS A PERSONAL TRAIT

Other participants saw stress as being part of daily life that was grounded principally in their predisposed reactions to situations. One man identified with this person-centred view of stress in relation to his job as a taxi driver:

> You're thinking about the future…I probably didn't realize it at the time, but I think I am quite a stressful person and worrier…It is my nature, my nature is, I just like to make sure of everything, a place for everything and everything in its place…That's the way I am. Having a heart attack is a thing to tell you to 'slow down', and change your lifestyle a wee bit. I don't know if I could change that side of it, because, it's just in my nature to make sure, to want to make sure, if it's not paid…Obviously if I'm not working, I'm not earning money. So you start thinking: 'What am I going to do?

He saw his recovery after MI as conflicting with the way he normally dealt with stress – the event itself compounded his stress by reducing his capacity to earn. Not only believing that all attempts to deal with his stress must come from himself, but also feeling unable to change how he deals with his concerns, he felt helpless to influence his stress. Similarly, one woman saw stress as being an inherent part of her normal existence:

> I always was sort of uptight…I always was a sort of stressed up person, I never was as laid back as my husband, and I'm really trying. I'm really trying to take a page out of his book…I was always sort of busying myself about, while he (husband) is always sitting about.

STRESS AS A RESPONSE TO MAJOR LIFE EVENTS

Stress was also seen as a predominantly personal response to a range of diverse demanding situations. Unlike person-centred conceptions of stress, this view did not imply a predisposition to act in specific ways. Rather, stress was identified with particular situations. As one participant expressed, thoughts about his divorce and child remained strong in him despite many years elapsing since his problems began. He saw his stress as being a consequence of his experience of and care over what had happened:

> Sometimes I can be getting on all right with my life and then somebody will say 'Oh I saw your daughter the other day.' Now my daughter's 18, and I've not seen her since she was eight. So when I get home, I start thinking about that…Then I cannot sleep at night…It causes me stress. People say: 'Why should you still bother about it?' But it does, and then you

cannot sleep and you're thinking: 'Oh Christ. How could she not come along and just visit me?' All the things you go through, obviously that doesn't help you either, well they say that stress is one of the…it's not the main cause but…I would say over the last blooming 10 or 15 years…Because I never really got over my divorce to be honest with you.

Similarly, other participants associated emotionally demanding events with chronic personal stress and the development of MI. One man referred to the death of a family friend from cancer and his wife's more recent diagnosis of terminal cancer, while a woman saw providing long-term care for her ageing mother as causing her MI.

STRESS AS A RESPONSE TO EVERYDAY EVENTS

Participants also associated stress with events that occurred daily in their lives. In these instances, stress was seen to recur mainly with problematic family relationships, such as with spouses, general family or in one case with teenaged daughters:

> I've just noticed about my mood swings…It's a bit of a mixture because I think it's my age as well. I think between the heart attack and the stage my girls (daughters) are at as well. I think it's all been interrelated. I couldn't specify and say 'Oh it's my teenage daughters, it's this or that'. I think it's just a combination…And I think with me being at home as well…It's just a mixture of everything, just a mixture of everything and sometimes it just gets to you.

This presents a complex view of stress, seeing it not only in terms of events but as encompassing also a personal element. In this way, stress was seen as coming from an interaction between situations and the self. Unlike the previous conceptions of stress described, this woman acknowledged her own role in influencing the stress she experienced.

A male interviewee saw stress as being inherent in common situations and believed that after his MI he could only reduce this by avoiding stressful situations:

> Any area that I find that's stressful now, I just sidetrack. I just delegate it…Deliberately avoiding anything. I think I've always been used to stress…all my life. Although I was taking responsibility, I've never went away from any responsibility. I've always been a leader, I've always you know, but now I feel that: 'No, I'll just take a back seat, let the other people do it.

Another man, who also associated stress with certain situations, exercised similar avoidance strategies. In his case, these related to social activities and responsibility in

his local dominoes league. Feeling vulnerable after his MI, he suggested avoiding league meetings to avoid the stress he believed would inevitably result:

> I've not really been doing anything to put myself into a stressful situation or anything like that. And I try not to get steamed up about anything. I get involved…But I don't think I'll be attending it. I think I'll miss it.

Seeing stress as being inherent within situations, rather than changing the way in which situations are perceived he saw that he must avoid situations entirely in order to minimize stress for himself.

Discussion

Similarities and differences exist between lay and professional discourses on CHD (Johnston, 1982; Casey *et al.*, 1984; Karlik & Yarcheski, 1987; Tilley *et al.*, 1987; Murray, 1989; Davison *et al.*, 1991; McSweeney, 1993; Turton, 1998; Emslie *et al.*, 2001). Likewise, although this was a small study carried out in a single site, the participants expressed a wide range of different conceptions of stress that were both different and similar to professional discourse.

As is common in members of the general population and those with CHD, participants perceived stress as being a primary cause of CHD (Bar-On, 1986; Affleck *et al.*, 1987; Davison *et al.*, 1991; Low *et al.*, 1993; McSweeney, 1993; Petrie & Weinman, 1997; Farooqi *et al.*, 2000; King, 2002). In accordance with this view, stress was seen as something that should be avoided as to

experience stress was to place oneself at greater risk of another MI.

Amongst a small minority of participants, stress was considered to be a term that should be applied to only the most extreme of circumstances. Others provided a range of commentaries on how stress arose in their life. It was a state of existence that was seen as being consequential of a personal predisposition, a demanding single life event or as a combination of personal reactions to a range of events and circumstances. Participants' accounts therefore not only placed different weight on the roles that environment, situation and personal factors had in determining stress but also provided a commentary on how these factors interacted. These accounts of stress reflected many professional approaches previously taken to stress in the academic literature (see Table 2), including questioning the validity of the term altogether (Kasl, 1995). In this way, professional and lay accounts, although equally diverse, referred to similar factors when accounting for stress.

Yet despite this similarity, participants seldom used the term 'stress' when talking about the psychological difficulties they experienced after infarction. This is at odds with how psychological care after infarction is often described to patients. While the literature uses terms such as stress, anxiety and PTSD, participants talked in less medicalized terms about fright, vulnerability and feeling bored or isolated. As cardiac rehabilitation moves to menu-based provision (Department of Health, 2000), there should be greater scope for those with psychological difficulties to discuss their beliefs about these difficulties with health

Table 2 Professional vs. lay views of 'stress'

Commentary on stress	Professional	Lay
Risk factor for CHD	Stress as a minor risk factor for CHD	Stress as a major risk factor for CHD
Misplaced term	Stress as an ambiguous term of psychological disruption that lacks parsimony (Kasl, 1995; Mulhall, 1996)	Stress as an inappropriate label
Personal trait	Stress as personality variable (Nunes *et al.*, 1987; Ben-Porath & Tellegen, 1990)	Stress as a predisposed reaction
Response to major life events	Stress as cumulative in response to major life events of the recent past (Holmes & Rahe, 1967; Turner & Wheatson, 1995)	Stress as a result of major events of long-term and recent past
Response to minor everyday events	Stress as a consequence of daily hassles (De Longis *et al.*, 1988; Lazarus & Folkman, 1989)	Stress as part of everyday demands

CHD: coronary heart disease.

professionals. The disparities highlighted between lay and professional language suggest that it is important for nurses to be attuned to the language patients use to describe their difficulties and that there may be benefit in using lay terms in services and therapeutic interactions. Even in instances where patients and health professionals refer ostensibly to the same phenomenon, it should not be assumed that meanings and assumptions are shared. Assumptions behind professional representations often differ from the beliefs held by the lay population (Summerfield, 1999; Walsh & Shaw, 2000). This in part results from the different aspirations and interests of professionals and disciplinary groups (Engelhardt, 1992; Davies, 1993, 1997; Lupton, 1995; Petersen & Lupton, 1996; Summerfield, 1999; Moynihan et al., 2002). Inadequate knowledge of the factors, meanings and values that inform patients' perspectives and decisions about CHD can limit the effectiveness of interventions (Alonzo & Reynolds, 1997; Clark et al., 1998; Ruston et al., 1998; Horne & Weinman, 1999). For example, if individuals believe that stress is inherent in their reactions and/or beyond their control, interventions to reduce stress that focus on improving personal adaptation may not be seen by them as viable. It is therefore also important to understand patients' own views of stress because these may influence the outcomes of psycho-educational interventions (Walsh & Shaw, 2000).

While there is considerable debate in the academic literature about the nature and functioning of stress, the role of stress in causing CHD is discussed frequently in the information booklets that patients receive when in hospital or during cardiac rehabilitation (Pritchard, 1998). By emphasizing this causative role, this literature may reinforce existing beliefs that stress, above other risk factors, is *the* or a major cause of CHD. While acknowledging that stress may be considered a risk factor for CHD, based on current evidence (Wood et al., 1998), it is inappropriate to emphasize this so heavily in comparison with other influential factors such as smoking, exercise and diet (Thompson & Lewin, 2000). To avoid reinforcing such beliefs, patient literature on stress should give more consistent and comprehensive views of the range of risk factors associated with CHD. In instances where patients attribute their cardiac event predominantly or wholly to the effects of stress, health professionals should challenge this belief.

Acknowledgements

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