# Identifying the health and mental health information needs of people with coronary heart disease, with and without depression

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## ABSTRACT

**Objective:** To identify the health and mental health information needs of people with coronary heart disease (CHD), with and without comorbid depression.

**Design and setting:** A qualitative study conducted in Melbourne in 2006, using thematic analysis of semi-structured interviews on the types of health information that patients with CHD considered useful to assist with the management of their illness. Structured clinical interviews were used to assess current and prior depressive episodes in these patients.

**Participants:** 14 general practice patients (eight with current or prior history of major depression) who had experienced myocardial infarction, coronary artery bypass graft surgery, angioplasty or angina (confirmed via testing).

**Results:** Four themes relating to information on how patients could manage their cardiovascular health and improve their psychosocial wellbeing emerged: psychosocial; physical activity; medical; and information for family. The most prominent information needs included identification and management of risk-related physical symptoms, and psychosocial information, most notably to enhance patients' social support. Patients considered this information important for alleviating health anxiety and negative affect.

**Conclusion:** This small patient sample endorsed the need for health and mental health information on a range of psychosocial and physical health topics. Participants desired specific types of information to assist with the self-management of their health and to assuage their health concerns.

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Heart and vascular diseases remain a leading cause of death and disability in Australia, contributing to about 38% of all deaths in 2002.[1] In people with established coronary heart disease (CHD), the absolute risk of subsequent adverse cardiovascular events is exceptionally high. There is a continuous relationship between risk factor levels and risk of further illness,[2] indicating that reducing modifiable risk factors through secondary prevention is imperative.

While CHD on its own causes significant impairment, comorbid depression seriously impedes prognosis and increases the risk of death.[3,4] Clinical depression and non-clinical depressive symptoms are also strongly associated with reduced quality of life and increased physical limitation and symptom burden.[5,6] The prevalence of depression in patients with established CHD is disproportionately high.[6] One study found 45% of patients had major depression within 10 days after myocardial infarction, with no remission 4 months later for 33%.[7]

Secondary prevention of CHD is largely managed by general practitioners and may involve medication use and behavioural counselling to encourage modification of high-risk behaviour.[2] Behavioural counselling typically involves providing advice, motivational interviewing, and establishing and assessing goals. A key component is health education to increase awareness of the contribution of the patient's social and physical environment and behaviour on his or her health. Effective health education also promotes self-efficacy, which is essential for self-directed behaviour change.[8]

"Health literacy" is the capacity to access, comprehend and use information in ways that promote and maintain good health.[9] By extension, "mental health literacy" refers to an individual's ability to recognise mental disorders, knowledge of risk factors and causes, and understanding of how to seek mental health information and services.[10] Physical and mental health is diminished among those with inadequate health literacy, which is related to relatively poor use of preventive health services,[11-13] delayed diagnoses,[14] decreased knowledge of medical conditions,[15,16] reduced adherence to medical advice[17] and poor self-management.[18]

We conducted exploratory qualitative research to identify the types of health information that patients with CHD endorse as beneficial in assisting them to manage their physiological and psychosocial health. Due to the high prevalence of depression in people with established CHD, people both with and without depression were included.

## METHODS

### Participants

The study was conducted in 2006, and was promoted directly to GPs in metropolitan Melbourne through presentations conducted by one of us (CP) at several mental health training programs for GPs provided by the Victorian Divisions of General Practice, and by advertisements in print media such as newsletters of the Royal Australian College of General Practitioners. GPs who indicated an interest in participating were mailed written materials about the study and were contacted by telephone or in person to discuss referral of patients to the study.

Two GPs searched their patient databases to identify potentially eligible patients who met one or more of the study's criteria for CHD: myocardial infarction, coronary artery bypass graft surgery, angioplasty or angina (confirmed through testing). The GPs posted letters to the identified participants informing them of the study and asking them to contact the research officer if they wished to participate. Of these patients, 20 consented to participate. Four later withdrew (reasons not provided), leaving a total of 16 participants (14 men and two women). However, as prominent themes emerged from interviews with the first 14 participants, the remaining two men were advised that their participation was no longer required.

### Measures

#### *MINI Plus*

The Mini International Neuropsychiatric Interview (MINI) Plus is a brief, structured clinical interview to assess 16 Axis 1 disorders from the *Diagnostic and statistical manual of mental disorders*, fourth edition (DSM-IV) and the International classification of diseases, 10th revision (ICD-10), and one personality disorder. It includes questions to differentiate disorders of organic origin or those due to alcohol or drug use.[19] The MINI has high validity and reliability and can be administered within 20 minutes.

### *Interviews*

Interviews designed to obtain qualitative data were conducted in a private room and took about 40 minutes to complete. The interviews were semi-structured, in that the interviewers were guided by a series of open-ended questions supplemented by spontaneous probes. Information was requested about patients' current access to health information and the type of information they would find useful to help them manage their heart health, including their physiological and psychological wellbeing. The interviewers encouraged participants to talk freely about the subject matter but redirected participants who deviated from the purpose of the interviews.

## Procedure and analysis

The study was approved by the Monash University Human Research and Ethics Committee. Participants completed the clinical diagnostic interview (MINI) by telephone after giving informed consent. On a separate day, each patient met with two investigators (CP and JLF) to complete individual semi-structured interviews.

All semi-structured interviews were performed in a standardised manner, audiotaped, transcribed verbatim after removal of identifying information, and analysed by an independent investigator (KAS) using the thematic approach. Subsequent examination of the analysis by CP and JLF verified concurrence of the key themes identified.

## RESULTS

Complete data were collected for 12 men (mean age, 67 years) and two women (mean age, 81 years) with CHD. Demographic and health characteristics of the participants are shown in the Box. Eight participants had a current diagnosis or prior history of major depression, as assessed by the MINI.[19]

All participants endorsed the view that further provision of health information would be useful in helping them manage their CHD or psychosocial wellbeing. Four common themes of information topics emerged from the data, categorised as: psychosocial; physical activity; medical; and information for family.

**Characteristics of the 14 participants**

| Characteristic | No. of patients |
|---|---|
| Age range (years) | |
| 50–64 | 4 |
| 65–79 | 8 |
| ⩾ 80 | 2 |
| Highest education level | |
| Primary school | 2 |
| High school | 6 |
| Tertiary | 6 |
| Major depressive episode | |
| Current | 5 |
| Prior history | 3 |
| None | 6 |
| Diabetes | |
| Type 1 | 1 |
| Type 2 | 1 |
| None | 12 |

## Psychosocial

### *Depression*

Six participants indicated that information on depression would be useful for themselves or others with CHD, particularly information about how to recognise and manage depressive symptoms and about the relationship between depressive symptoms and physical health.

> I've suspected for quite a number of years that I've probably suffered depression, sort of apprehension, if you like, in a way subsequent to that event [heart attack].

Patients also suggested provision of information about particular strategies for managing depression, such as positive self-statements and a logbook to record activities to stay motivated. Information on where to seek help for depression was also considered important, although most patients indicated that they had not sought such information.

> [Interviewer] Have you ever sought any other information about the depression?
>
> [Patient] No, not really. I've often wondered where one could gain some further direction from it… I wouldn't know where to go, to be quite honest.

### *Social isolation*

Five patients expressed the view that social connectedness is important, either in helping them to manage depressive symptoms or to gain support and understanding about their medical condition from other people with CHD. Several patients in this group indicated the need for information on how to establish social networks and access appropriate social and support groups.

> I suppose you gotta learn to get out and do things and be faced with other people … So those sort of things, it might be handy if that was sort of indicated … [that] social support might be sort of remedial treatment in depression …

### *Anger*

Four patients reported feelings of anger or irritability either soon after their first cardiac event, or later, in relation to the burden of managing their illness medically. They suggested that information about how to identify precipitating symptoms of anger and anger management would be useful.

## Physical activity

Four participants reported a need for information on physical activity, such as how much postoperative exercise is too much. Patients reported a need for information on how to reduce their activity without stopping altogether, and how to safely reintroduce physical activity and exercise options after a cardiac event. They stated that this information needed to be relevant to individual variations in disease severity.

## Medical

Nine patients reported a need for medical information, particularly to assist in alleviating anxiety levels. The suggested information could be grouped into the two areas of symptoms and prognosis, and surgery.

### *Symptoms and prognosis*

Patients wanted information about symptoms that might occur, rather than only those that will occur. They also endorsed the need for information about how to determine when particular symptoms indicate the need for medical assistance, such as contacting their GP or presenting to a hospital emergency department. Interviewees also expressed a need for information about what to expect regarding disease progression and prognosis, and prevention of further adverse cardiac events. Several also wanted statistical information, such as survival rates.

The most common experience regarding anxiety, reported by eight patients, pertained to uncertainty about how to interpret physical symptoms. Patients indicated that information about whether certain physical symptoms are normal or a sign of an impending cardiac event would help alleviate their anxiety. For this reason, they also requested more information about medical procedures. As expressed by one patient:

> The other thing, I suppose, that sort of causes anxiety is, how often can they do this sort of thing? How many stents can you actually have? … I think that sort of information would be helpful to know, to at least sort of negate the anxiety …

The need for medical information relating to anxiety and depression was more frequently endorsed by participants who had experienced multiple cardiac events, compared with those who had experienced one.

#### *Surgery*

Four patients reported a need for more information before and after surgical intervention. They wanted procedural information to inform them of exactly what would happen during the operation and what to expect when waking from anaesthesia, particularly regarding the use of medical equipment such as respirators.

### Information for family

Nine patients reported that information for family members and spouses would be useful. In particular, patients wanted information pertaining to the psychological aspects of the illness, such as how the patient might react emotionally to an adverse cardiac event or medical procedure. Information about how family members and spouses could manage their own anxiety about their loved one's illness was also suggested.

## DISCUSSION

This small sample of primary care patients with CHD in metropolitan Melbourne endorsed the need for health and mental health information to help them self-manage their physical and psychosocial health.

It is notable that most patients expressed the view that information about how to manage risk-related physical symptoms would alleviate their health anxiety. This finding suggests that improvements in subjective psychosocial wellbeing may result if this information is readily available to patients. The provision of such information may enhance patients' perceived control over their medical condition.

Secondary prevention of CHD, including behavioural counselling, is primarily managed by GPs. However, time limitations and other constraints on GPs often preclude systematic provision of secondary prevention.[20] This, combined with relatively low rates of attendance at cardiac rehabilitation programs,[2] limits the opportunity for people with CHD to gain access to health and mental health information resources.

GPs need to be assisted to improve the health and mental health literacy of patients with CHD, which may in turn enhance patients' self-management of their chronic illness. For example, affording GPs direct access to a range of health and mental health resources for patients may be useful. Such resources may provide patients with guidance on the self-management of various health concerns. The provision of health information tailored to the specific needs of individual patients is likely to be the most effective strategy. Therefore, innovative approaches, such as the use of technology for information delivery, may be required.

## COMPETING INTERESTS

None identified.

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