Cardiac patients' concerns and desire for information: a case for unmet needs

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Abstract

Tailoring healthcare provision to fulfil patients' needs is a principal objective of health services. Data on needs are sparse, especially in patients with coronary heart disease, who tend to have a high mortality rate, who often require admission to hospital and have an impaired health-related quality of life. A novel questionnaire was administered concomitantly with generic and specific quality of life tools in a cross-sectional study of a random sample of patients ($n=242$) aged 31–93 years (median 71 years) admitted with suspected acute coronary syndromes.

Patients with confirmed infarction had fewer healthcare needs and reported less need for information on heart disease compared to those with other manifestations of coronary disease ($p<0.01$). Those recently seen by a general practitioner were better informed about their current treatment ($p<0.01$). Coronary disease patients with low quality of life scores were more likely to be anxious about cardiac problems ($p<0.001$). They were more likely to spend more time thinking about these concerns ($p<0.001$) and to seek help from, and to have increased expectations of, the family doctor or cardiologist ($p<0.001$), particularly in seeking greater commitment to their care. Reported deficiencies in service included difficulty accessing healthcare services, especially for men <65 years ($p=0.01$) and availability of repeat prescriptions for the over 75-year-olds ($p<0.05$).

Patients with coronary disease had unmet healthcare needs and worse health-related quality of life. Further investigation of healthcare needs among patients with coronary disease could lead to simply improved services and major health improvement. Assessment of quality of life appeared to be a surrogate for formal healthcare needs assessment.

Key words: coronary artery disease, informational needs, medical concerns, health-related quality of life.

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Introduction

Building healthcare services upon patients' genuine health needs is the ultimate purpose of modern healthcare systems.[1] A local population's health needs should be ascertained, and this may improve allocation of resources for the treatment of coronary artery disease (CAD).[2] Determining need is not straightforward: health needs assessment (HNA) tools exist in a few diseases but simple coronary disease-specific tools are warranted. Comprehensive evaluation of individual needs is demanding and time-consuming,[3] making assessment of a population a daunting prospect. Proposed proxies for healthcare needs include mortality rates, socio-economic status, service utilisation and prevalence but the relevance of these is at best indirect.[4,5]

Health needs embrace a variety of social care, accommodation, healthcare, finance, education, employment, leisure and transport (and other) issues.[6] Determining needs facilitates service improvement and equity of access and reduces variation. It is essential to consider a wide range of health needs as determined by epidemiological, comparative and corporate approaches[6] and to prioritise and satisfy these by tailoring services accordingly. We ascertained patients' healthcare needs and present here their informational needs, medical concerns and concerns about access to healthcare.

Method

This descriptive cross-sectional study appraised the healthcare needs of patients admitted to a coronary care unit with symptoms suggestive of myocardial infarction. This has been described in detail elsewhere,[7] but briefly a needs assessment questionnaire was developed and its psychometric properties established,[7] with Chronbach's alpha between 0.83–0.89 and all domains shown to have equivalent counterparts in health-related quality of life tools ($p<0.001$). The questionnaire comprised 46 questions in Likert 5-score format in five domains of 'physical needs', 'satisfaction', 'informational needs', 'social needs' and 'concerns'. A mean score in each domain was computed.

Table 1. General characteristics of the study population

Variable		N	%
Age group	≤ 65 years	76	32
	≥ 65 years	162	68
Gender	Female	99	41
	Male	143	59
Education level	Left school at age < 16 years	168	76
	A-level or higher	54	24
Occupation	Retired	194	81
	Unemployed	15	6
	Working	32	13
Diagnosis	Definite MI	27	11
	Possible MI	34	14
	IHD	152	64
	Chest pain	26	11
Social class	Non-manual	69	31
	Manual	154	69

Key: MI = myocardial infarction; IHD = ischaemic heart disease

Table 2. Variables related to healthcare services utilisation

		N	%
Major intervention	CABG/PTCA	94	41
	None	138	59
Co-morbidity	No co-morbidity	53	22
	Concurrent disease	183	78
First call in emergencies	GP	134	56
	999	81	34
	Others	24	10
Access to healthcare services	No difficulty	147	61
	Some difficulties	93	39
Repeat prescriptions	Regular	173	72
	Not regular (> 3 months)	69	28
Private services	Yes	18	8
	No	220	92
Appointments for check-up	Short intervals	84	36
	Long intervals	78	33
	Never/irregular	73	31
Under medical treatment	Yes	41	17
	No	193	83

Key: CABG = coronary artery bypass graft; PTCA = percutaneous transluminal coronary angioplasty

Patient population

All patients admitted to the coronary care units of Queen's Medical Centre, Nottingham, over a 12-month period were identified on admission. Each was approached and invited to take part in the study. Those who consented were asked to complete a battery of questionnaires covering demographic information, quality of life and health needs. The local ethical committee approved this survey.

Outcome measurement

Two health-related quality of life tools were selected as outcome measures: one cardiac-specific, the Seattle Angina Questionnaire (SAQ), and two generic tools, the Short Form-12 (an abridged form of the better-known Short Form 36 [SF-36][8] which is equally precise[9]) and the EuroQol-5D (EQ5-D). The SAQ has well-established psychometric properties and corresponds well with the Canadian Cardiovascular Society Classification.[10] The reliability and validity of EQ-5D have been established.[11]

Statistical analysis

SPSS version 11.0 was used for descriptive and correlation analysis, comparison of means, reliability and non-parametric (Mann-Whitney) tests where indicated, with $p<0.05$ considered significant. Contingency tables were formed to look for any correlation and the chi-squared test was used to measure the association between variables.

Results

We identified 1,322 patients who fulfilled entry criteria. Of these, 97 had a myocardial infarction confirmed either by a doubling of the normal upper limit of the cardiac enzyme creatine kinase, an elevation of troponin or the development of a 'Q' wave infarction. Some 1,108 patients had an acute coronary syndrome or unstable angina. There was no conclusive diagnosis in 117 patients. A random selection of this patient population (n=687) was recruited for this study, of whom 260 consented to participate and 242 (93%) returned the completed questionnaire. Information to encode social class, derived from the last occupation, was available for 223 patients.

Of the respondents, 59% were male. Ages ranged from 31–93 years (mean=69, 95% CI: 68–71). Details of the study population's demographic features are summarised in table 1.

Access to health services

Some 87 patients (37%) received treatment solely from their general practitioner and 108 (45%) were under review either by a hospital consultant or a general practitioner at the time of the study. More than one third reported some difficulty in accessing healthcare services, mostly because of transport (56%), need for a companion (32%), or some difficulty in making an appointment (12%). Patients over 75 years old and from lower socioeconomic groups were more likely to complain about access ($p<0.05$ and <0.01, respectively).

Patients frequently requested a regular check-up (36%) or repeat prescription (72%) (table 2). Non-infarct patients made more demands on health services compared with patients with a confirmed infarction (Pearson r=15, $p<0.01$).

Patients who were under regular review reported worse quality of life, especially on the visual analogue scale EQ-VAS ($p<0.01$). Fewer physical and social needs were reported by the 8% who accessed private healthcare ($p<0.05$).

Information needs

The information most frequently requested related to which daily

Table 3. Informational needs in different groups of patients (mean [SD])

Informational needs	Social class			Gender			Diagnosis		
	Non-manual	Manual	P	Female	Male	P	MI	IHD	P
Current treatment	4.38 (1.15)	4.04 (1.19)	<0.05	1.6 (0.5)	1.58 (0.5)	NS	4.42 (1)	4 (1.28)	<0.05
Long-term plan	4.23 (1.2)	3.85 (1.3)	<0.05	1.56 (0.5)	1.49 (0.5)	NS	4.16 (1.2)	3.83 (1.3)	NS
Rehabilitation	4.52 (0.98)	4.13 (1.23)	<0.05	1.6 (0.5)	1.66 (0.47)	NS	4.33 (1.1)	4.12 (1.3)	NS
Nutritional	4.33 (1.22)	3.95 (1.31)	<0.05	1.5 (0.5)	1.63 (0.48)	<0.05	4.27 (1.23)	3.91 (1.35)	0.05
Daily activities	4.22 (1.18)	3.73 (1.29)	<0.01	1.44 (0.5)	1.53 (0.5)	NS	4 (1.38)	3.8 (1.27)	NS

Key: MI = myocardial infarction; IHD = ischaemic heart disease; NS = not significant

Table 4. Patients' medical concerns

Variable	Frequency (%)*		Mean difference (z value) in Mann-Whitney test							
	Concerned	No. concern	Age (75 year cut-off)	Sex	IHD vs. MI	Co-morbidity	Social class	HNA-Sat	HNA-Info	HNA-Soc
Change lifestyle	50	23	0.85	0.26	0.55	1.57	0.66	2.15*	**4.93**	**4.01**
Have a worse QOL	56	23	0.4	2.3*	2.4*	**3.26**	**2.7**	0.8	**5.95**	**4.69**
Admission to hospital	63	19	1.3	0.19	**4**	2.16*	**2.95**	0.67	**5.05**	**4.1**
Any fear about your illness?	49	50	1.7	0.77	0.9	**2.8**	**3.37**	2.3*	**6.15**	**4.2**
Not sure how illness will change?	78	15	**2.78**	0.67	1.8*	1.6	**2.69**	1.9*	**5.55**	**3.29**
Not sure to get best treatment	36	49	1.34	0.09	1.5	2.5*	**2.87**	**4.23**	**5.12**	**1.7**
How often do you think about concerns?	64	34	0.23	0.09	0.67	**3.65**	**3.84**	2.01*	**6.57**	**5.04**
Seek help for your concerns?	73	24	0.43	0.6	1	1.2	2.1*	0.36	2.3*	2*

*Aggregated in two categories of concerned (including the first 3 scores in scaling) and no concern (the rest two scores)

P<0.05 is marked with an asterisk and <0.01 is bold face

Key: IHD = ischaemic heart disease; MI = myocardial infarction; HNA-Sat = Satisfaction domain in HNA questionnaire; HNA-Info = Informational needs domain in HNA questionnaire; HNA-Soc = Social needs domain in HNA questionnaire; QOL = quality of life

activities should be avoided or might be detrimental to their main illness (51% of all patients), followed by long-term plan of treatment (48%), advice about current treatment (41%), nutrition and diet (43%) and cardiac rehabilitation (36%).

Patients older than 75 years were particularly keen to receive information about current treatment (OR=1.9 CI:1–3.5), and expressed most concern about the long-term plan of treatment (p=0.01). Manual workers requested more information than non-manual workers (p<0.05; table 3). Non-infarct patients required more information about the long-term plan of treatment (table 3) than other patients (p<0.05), especially those who had not previously had a coronary revascularisation procedure (coronary bypass surgery or balloon angioplasty – n=114; p<0.01).

For 106 patients (44%), the general practitioner was the only source of medical information, and for 32 (13%) a principal source. Equivalent figures were 71 (30%) and 27 (11%) for consultants and 22 (9%) and 8 (3%) for nurses, respectively. Informational needs were significantly inversely related to the amount of time available for each consultation with the general practitioner. Those dissatisfied with the amount of general practitioner consultation time were more likely to want information about current treatment (p=0.01).

Results showed that 79 patients managed exclusively by the GP seemed better informed about their current treatment than those who had been referred to, and were managed by, a hospital consultant (p<0.01).

Medical concerns

These are summarised in table 4: 188 patients (78%) worried about future medical problems, especially the elderly (p<0.01) and non-infarct patients (p<0.05). Women were more likely to express concern about potential decline in quality of life as a result of their illness. Patients were most concerned about the likelihood of re-admission to hospital (p<0.01) or diminishing quality of life. Manual workers expressed more concerns than non-manual. Those who were satisfied with their healthcare and who trusted their medical and nursing advisers were less likely to be worried. Overall, the greater the concerns, the greater the demand for information.

Non-infarct patients with poor quality of life scores were

Key messages

- The aim of modern health services is to satisfy genuine needs yet health needs assessment is largely ignored
- Patients with ready access to the most trusted health professional, the general practitioner, considered themselves well informed
- Lack of information adversely affects satisfaction with health services
- Measuring health-related quality of life may play a great role in identifying deficits in informational needs and medical concerns

more likely to be anxious about cardiac problems (p<0.001), to spend more time thinking about these concerns (p<0.001); and to seek help from, and have increased expectations of, the family doctor or cardiologist (p<0.001), particularly in seeking greater commitment to their care.

Discussion

All patients have concerns about their diagnosis, treatment and prognosis, but because health-related needs may vary according to, inter alia, demographic features, co-morbid factors, socioeconomic variables and social support, the impact of ill health is likely to be different for each patient. Identifying these specific needs is the first step towards improving healthcare services. This study identified patients' desire for information about their current treatment and future treatment plans, which patients felt would improve their quality of life.

Coronary artery disease is a chronic process interrupted by intermittent acute symptoms, so patients frequently come into contact with health professionals to obtain consistent, appropriate and timely information. Patients with a myocardial infarction are generally given information during their hospital stay and are invited to attend a cardiac rehabilitation programme. Socially deprived patients are less likely to attend rehabilitation,[12] although we found they wanted more healthcare information.

The general practitioner is regarded as the most trusted health professional and continues to occupy an important position as a primary source of information for many patients. Patients who were able to access their family doctor easily considered themselves well informed, perhaps reflecting the amount of time for consultation.

Lack of information generated considerable dissatisfaction in nearly half of our patients, a point that health professionals should consider when reviewing patients, at least those admitted acutely to hospital. Patients may seek out alternative sources of information and for those with access to it, there are numerous sites on the World Wide Web relating to coronary disease and its treatment, though the content is of variable quality.[13] It does not take into account individual circumstances, and standard care in the US raises expectations of what is available to NHS patients.

It should not be assumed that information equates with knowledge. Nevertheless, information is the first step towards understanding illness, its likely impact on lifestyle and healthcare improvement. The results presented in this paper indicate that information needs may vary in different age groups and social classes. Cardiologists, general practitioners, practice and rehabilitation nurses need to:

- target specific interest groups more effectively, especially the elderly, who may have limited access to computers and who tend not to seek out information to the same extent as younger people
- develop different methods of imparting information
- focus on what patients need to know rather than on what clinicians believe they should know.

Conflict of interest

None declared.

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