CARDIOVASCULAR MEDICINE

Ethnic differences in patient perceptions of heart failure and treatment: the West Birmingham heart failure project

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Objective: To investigate further the hypothesis that ethnic groups would have different levels of knowledge and perceptions of congestive heart failure (CHF) and treatments for this condition, a cross sectional survey was conducted of patients who were attending the heart failure clinics in two teaching hospitals of Birmingham, UK, that serve a multiethnic population.

Methods: 103 patients with CHF (66 men, 37 women) were surveyed by standard questionnaire: 42 were white, 34 Indo-Asian, 22 Afro-Caribbean, and 5 Oriental.

Results: When asked about their beliefs about control of one's health, 22 (64.7%) of Indo-Asians felt that God/fate controlled their health. The majority of white patients tended to believe that the greatest factor influencing their health was the doctor (15 (35.7%)). Of the total study cohort, only 68 (66%) of patients were aware of their primary diagnosis of heart failure; the majority of Indo-Asians (21 (61.8%)) were not aware of their diagnosis. Half of Indo-Asians (17 (50%)) felt that heart failure was not severe, in contrast to 40.9% (n = 9) of Afro-Caribbeans and only 19.1% (n = 8) of white patients. Of the study cohort, 38 (36.9%) were taking their drugs because their doctor told them to, a response most common among the Indo-Asians. The majority of Indo-Asians (22 (64.7%)) and Afro-Caribbeans (14 (63.6%)) stated that they did not have, or did not know whether they had enough, information about their drug. The corresponding figure for white patients was 21.4% (n = 9). When asked whether they took their medication regularly as prescribed, 7 (31.8%) of Afro-Caribbeans reported that they did not take their drugs regularly.

Conclusions: Our study has highlighted deficiencies in the knowledge of CHF among patients from ethnic minority groups, as well as deficiencies in the information being given to these patients. There is a clear need to invest more in patient education for CHF, with special emphasis on certain high risk subgroups.

Congestive heart failure (CHF) is a major public health problem in the western world. Aetiological factors involved in its development include hypertension, diabetes, and ischaemic heart disease—all of which differ in prevalence, and possibly mechanisms, between patients of differing ethnic groups. Unfortunately, epidemiological and therapeutic trials have involved almost exclusively white populations and evidence from these trials cannot necessarily be assumed to be fully generalisable to populations with high proportions of patients with other ethnic origins.[1]

In England and Wales, the largest non-white ethnic group is the Indo-Asian (4.2%), followed by African Caribbean (2.3%) (Office for National Statistics, data from 2001/2), and there is great regional variation. In a study of 348 admissions for acute CHF to a Birmingham city centre hospital serving a multiethnic population, 76% were white, 16% Indo-Asian, and 8% Afro-Caribbean.[2] The non-white patients in that study were significantly younger than the white patients, suggesting an earlier onset of the syndrome of CHF. A re-analysis of this study taking into account population data has suggested that the relative risk of CHF among patients aged 60–79 years was 3.1 (95% confidence interval (CI) 1.9 to 4.9) for Afro-Caribbeans and 5.2 (95% CI 3.7 to 7.4) for Indo-Asians, suggesting the CHF may be a major problem among non-white populations in the UK.[3] There are also data from North America that black patients, compared with white patients, have a similar mortality but greater functional decline after hospitalisation for CHF, which is not explained by clinical, socioeconomic, access to care, or quality of care differences.[4] A greater understanding of knowledge and disease perceptions among non-white populations may improve our approach to management of CHF in these ethnic groups.

Certainly, compliance with medical treatment is likely to be improved if patients have a better knowledge and understanding of the drug, its benefits, and its side effects.[5] The views of family and friends, societal pressures, and a patient's own cultural or ethnic background also influence compliance. Indeed, ethnic group is an important factor especially if language difficulties are involved.[6 7] Patients with chronic cardiac disease conditions, such as atrial fibrillation, often have very limited knowledge of the disease process, as well as its consequences and the need for long term treatment.[8] In particular, our study highlighted significant differences between ethnic groups in terms of their knowledge of the risks, actions, and benefits of warfarin, as well as of the cardiac condition itself.

To extend our previous observations in atrial fibrillation,[8] we hypothesised that ethnic groups with CHF would have different levels of knowledge and perceptions of their disease state and treatments. To investigate this further, we conducted a pilot cross sectional survey of a multiethnic patient population attending heart failure clinics in two teaching hospitals in Birmingham, UK.

PATIENTS AND METHODS

Consecutive patients attending the heart failure clinics at two large Birmingham teaching hospitals (City Hospital and Selly Oak Hospital) were recruited over a period of three months, from January to March 2003. These hospitals serve a patient catchment area of about 500 000, with the ethnic mix being approximately 25% Indo-Asian, 11% Afro-Caribbean, and 64% white European. The majority (90%) of Indo-Asians are of Punjabi origin and their population is fairly homogeneous. The Afro-Caribbean and white groups are also fairly homogeneous and, indeed, the clinic ethnic population would be typical for West Birmingham.

Heart failure was defined on the basis of clinical symptoms and signs, with evidence of heart disease, in keeping with published diagnostic criteria of the European Society of Cardiology.[9] To keep the background aetiology and severity of CHF fairly homogeneous, enrolled patients had left ventricular systolic impairment secondary to coronary artery disease and a documented ejection fraction of $< 35\%$ as determined by echocardiography, cardiac catheterisation, or radionuclide ventriculography. All patients attending the heart failure clinic are given a ''package of care'' containing the clinical assessment, optimisation of medical treatment, and input from specialist heart failure nurses with education and recommendations for lifestyle changes. Therefore, all patients entered into this survey were taking angiotensin converting enzyme inhibitors (or angiotensin receptor blockers), diuretics, and, if tolerated, β blockers—only patients whose medication was optimised and whose condition was stable with heart failure drug regimens were recruited into this study. Thus, patients who were having their dose of β blocker, for example, up-titrated by specialist nurses were not entered into the study.

A standardised questionnaire was devised that asked questions on disease perception and understanding about their treatment for heart failure. The level of education of these patients was also determined, as this would influence the level of understanding of the disease and the treatment. The last part of the questionnaire asked whom they got their information from and whether they were satisfied with the information that was given to them by the doctor. The questionnaire was initially piloted and each patient was interviewed in a similar manner by three interviewers who were fluent in English, Punjabi, Hindi, and Urdu. Ethical committee approval was obtained and all patients gave informed consent to their participation.

Data are reported as mean (SD), or number and percentage, as appropriate. Continuous data were analysed by one way analysis of variance or Kruskal-Wallis test. Categorical data were analysed by the χ^2 test for comparison between the three main ethnic groups (white, Afro-Caribbean, and Indo-Asian). A probability value of $p < 0.05$ was considered significant.

RESULTS

We surveyed 103 patients with CHF (66 men, 37 women) by standard questionnaire: 42 were white European, 34 Indo-Asian, 22 Afro-Caribbean, and 5 Oriental. In view of the small numbers of the Oriental ethnic group, the ethnic analysis details the data from white patients, Indo-Asians, and Afro-Caribbeans (n = 98).

The vast majority of patients (84.5%) left formal education before the age of 16 years, and this was reflected across all the ethnic groups. When asked about their beliefs about control of one's health, 64.7% of Indo Asians felt that God/fate controlled their health compared with 22.7% of Afro-Caribbeans and 33.3% of white patients (χ^2 test, $p = 0.003$) (table 1).

In comparison, 63.6% of Afro-Caribbeans felt that control lay with them, whereas only 20.6% of Indo-Asians and 26.2% of white patients felt this way. The majority of white patients tended to believe that the greatest factor influencing their health was the doctor (35.7%).

Patients' perceptions of heart failure

Of the total study cohort, only 66.0% of patients were aware of their primary diagnosis of heart failure (table 2). The majority of Indo-Asians (61.8%) were not aware of their diagnosis; in contrast, 85.7% of white patients were aware of their primary diagnosis (χ^2 test, $p<0.001$).

When questioned about their perceived severity of their illness, 51.5% of the study cohort felt that their condition was severe, whereas only 12.6% felt that heart failure was a very severe condition. The majority of Indo-Asians (50.0%) felt that heart failure was not severe, in contrast to 40.9% of Afro-Caribbeans and only 19.1% of white patients (χ^2 test, $p = 0.007$). Moreover, 71.4% of white patients felt that heart failure was severe compared with only 29.4% of Indo-Asians.

Of the total study cohort, 71.8% felt that heart failure was not curable; this view was broadly similar across all three ethnic groups. In terms of treatment, 80.6% of the study cohort felt that heart failure was a treatable condition, which was reflected across all the ethnic groups.

Of the study cohort, 52.4% felt that their health status was unchanged and only 11.6% felt that their health was worsening. The majority among all ethnic groups felt that their health status was unchanged.

Patients' perceptions of heart failure treatment

Of the study cohort, 51.5% of patients reported that they were taking pharmacological treatment to relieve their symptoms (we did not extend this questionnaire to a specific definition of these symptoms) but 36.9% were taking their drug because their doctor told them to (table 3). The majority of white patients (64.3%) were taking a drug to relieve symptoms. However, more Indo-Asians (50.0%) were taking their drug because their doctor told them to.

When asked about the perceived level of risk associated with taking drugs for heart failure, 64.1% of the study cohort felt that it was associated with low risk, which was reflected across all three ethnic groups.

Of the study cohort, 68.9% of patients felt that they had enough information about their heart condition and 54.4%

Table 1 Demographic distribution of the patients

	Total cohort (n = 103)	Indo-Asian (n = 34)	Afro-Caribbean (n = 22)	White (n = 42)
Age (years)	71	66	70	75
Male:female	66:37	23:11	15:7	25:17
Age on leaving formal education				
<16 years	87 (84.5%)	29 (85.3%)	20 (90.9%)	33 (78.6%)
>16 years	16 (15.5%)	5 (14.7%)	2 (9.1%)	9 (21.4%)
Patient's beliefs about control of own health				
Patient him- or herself	32 (31.1%)	7 (20.6%)	14 (63.6%)	11 (26.2%)
Doctor	25 (24.3%)	5 (14.7%)	3 (13.6%)	15 (35.7%)
God/fate	44 (42.7%)	22 (64.7%)	5 (22.7%)	14 (33.3%)
Family	2 (1.9%)	0	0	2 (4.8%)

Table 2 Patient perceptions of heart failure

	Total cohort (n = 103)	Indo-Asian (n = 34)	Afro-Caribbean (n = 22)	White (n = 42)
Patient's awareness of the primary diagnosis of heart failure				
Aware	68 (66.0%)	13 (38.2%)	15 (68.2%)	36 (85.7%)
Not aware	35 (34.0%)	21 (61.8%)	7 (31.8%)	6 (14.3%)
Perception of the severity of heart failure				
Not severe	37 (35.9%)	17 (50.0%)	9 (40.9%)	8 (19.1%)
Severe	53 (51.5)	10 (29.4%)	11 (50.0%)	30 (71.4%)
Very severe	13 (12.6%)	7 (20.6%)	2 (9.1%)	4 (9.5%)
Perception whether heart failure is curable				
Curable	29 (28.2%)	10 (29.4%)	5 (22.7%)	14 (33.3%)
Not curable	74 (71.8%)	24 (70.6%)	17 (77.3%)	28 (66.7%)
Perception whether heart failure is treatable				
Treatable	83 (80.6%)	30 (88.2%)	17 (77.3%)	33 (78.6%)
Not treatable	20 (19.4%)	4 (11.8%)	5 (22.7%)	9 (21.4%)
Perception whether patient health is:				
Improving	37 (35.9%)	15 (44.1%)	8 (36.4%)	13 (31.0%)
Worsening	12 (11.6%)	2 (5.9%)	3 (13.6%)	5 (11.9%)
Unchanged	54 (52.4%)	17 (50.0%)	11 (50.0%)	24 (57.1%)

felt they had enough information about their treatment. With particular reference to information about treatment, 78.6% of white patients felt that they had enough information compared with only 35.3% of Indo-Asians and 36.4% of Afro-Caribbeans (χ^2 test, $p<0.001$). Of the total cohort, 17.5% felt they did not have enough information and 28.2% felt that they did not know whether they had enough information. Thus, the majority of Indo-Asians (64.7%) and Afro-Caribbeans (63.6%) did not have, or did not know whether they had, enough information about their drug. The corresponding figure for white patients was 21.4%.

When asked whether they took their medication regularly as prescribed, 87.4% of the total cohort said that they did take their medication regularly. However, 31.8% of Afro-Caribbeans reported that they did not take their drugs regularly (χ^2 test, $p = 0.014$).

DISCUSSION

This study is limited by its cross sectional aspect and its reliance on questionnaire based interviews. One potential bias is that the questionnaire may have been presented differently to English speaking (or reading) patients and non-English speaking and reading patients. Furthermore, the interviews were conducted in the heart failure clinic and it can be argued that a selection bias was inherent, as only the patients with some insight and enough knowledge would come regularly to the clinic in the first place. Indeed, most of the patients in the study had a fairly good idea of what their treatment entailed.

We are unaware of other similar studies of CHF patients from a multiethnic population in the UK, but our findings are consistent with data from North America and elsewhere. For example, Artinian and colleagues[10] reported that knowledge

Table 3 Patient perceptions of heart failure treatment

	Total cohort (n = 103)	Indo-Asian (n = 34)	Afro-Caribbean (n = 22)	White (n = 42)
Reason for taking drugs				
Relieves symptoms	53 (51.5%)	11 (32.4%)	11 (50.0%)	27 (64.3%)
Relieves pain	12 (11.6%)	6 (17.6%)	2 (9.1%)	4 (9.5%)
Doctor told me to	38 (36.9%)	17 (50.0%)	9 (40.9%)	11 (26.2%)
Perception of level of risk associated with drugs				
High risk	6 (5.8%)	3 (8.8%)	1 (4.6%)	2 (4.8%)
Moderate risk	31 (30.1%)	9 (26.5%)	8 (36.4%)	13 (31.0%)
Low risk	66 (64.1%)	22 (64.7%)	13 (59.1%)	27 (64.3%)
General feelings about heart failure and its treatment				
''I have enough information about my heart condition''				
Yes	71 (68.9%)	23 (67.6%)	13 (59.1%)	33 (78.6%
No	22 (21.4%)	8 (23.5%)	4 (18.2%)	9 (21.4%)
Don't know	9 (8.7%)	3 (8.8%)	5 (22.7%)	0
''I have enough information about my treatment''				
Yes	56 (54.4%)	12 (35.3%)	8 (36.4%)	33 (78.6%)
No	18 (17.5%)	7 (20.6%)	3 (13.6%)	6 (14.3%)
Don't know	29 (28.2%)	15 (44.1%)	11 (50.0%)	3 (7.1%)
''I take my treatment regularly as prescribed''				
Yes	90 (87.4%)	31 (91.2%)	15 (68.2%)	39 (92.9%)
No	13 (12.6%)	3 (8.8%)	7 (31.8%)	3 (7.1%)

on self care was deficient in a diverse sample of CHF patients, especially in relation to heart failure medications, weight monitoring, and the correct definition of heart failure. They also found that heart failure knowledge scores were uniformly low across sex and racial groups. A recent Spanish study[11] also reported that CHF patients had poor information about dietary and medical treatment.

In the Indo-Asian communities, the elderly and women are more likely to leave their treatment in the hands of others, rather than to take responsibility for themselves.[12,13] In our recent report on ethnic differences in perception of atrial fibrillation,[8] nearly half of the patients from all ethnic groups said that they took warfarin because their doctor told them to and were unaware of what the actual benefits were. This observation was broadly confirmed in the present study. Indeed, Indo-Asians tended to leave a lot of the control of their health to ''God/faith''[4,13] and this belief would influence their compliance and willingness to find out more about their illness and the medication that they take.

A lack of awareness among the patients concerning the disease process and drug side effects may in part reflect the poor amount of counselling and information given to patients by health care professionals. Our heart failure clinics were run by a multidisciplinary team of clinicians, specialist nurses, etc, who have all been trained in accordance with local and national guidelines.[14,15] Certainly, we cannot account for the degree or intensity of individual communication or education between the doctor and patient in every case, although this aspect has been shown to be important in chronic medical conditions. Patients who reported that their physician counselled them regarding adherence to treatment were more able to recall and adhere to their recommendations.[16,17]

In conclusion, this study has highlighted deficiencies in the knowledge of CHF among patients from ethnic minority groups, as well as deficiencies in the information being given to these patients. There is the need to invest more in patient education for CHF, with special emphasis on certain high risk subgroups, including ethnic minorities.

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REFERENCES

1 **Sosin M**, Bhatia G, Davis RC, *et al.* Heart failure—the importance of ethnicity. *Eur J Heart Failure* (in press).
2 **Lip GYH**, Zarifis J, Beevers DG. Acute admissions with heart failure to a district general hospital serving a multiracial population. *Int J Clin Pract* 1997;**51**:223–7.
3 **Chaturvedi N**. Ethnic differences in cardiovascular disease. *Heart* 2003;**89**:681–6.
4 **Vaccarino V**, Gahbauer E, Kasl SV, *et al.* Differences between African Americans and whites in the outcome of heart failure: evidence for a greater functional decline in African Americans. *Am Heart J* 2002;**143**:1058–67.
5 **McCormack PM**, Lawlor R, Donegan C, *et al.* Knowledge and attitudes to prescribed drugs in young and elderly patients. *Irish Med J* 1997;**90**:29–30.
6 **Ziguras S**, Lambert TJ, McKenzie DP, *et al.* The influence of client's ethnicity on psychotropic medication management in community mental health services. *Aust NZ J Psychiatry* 1999;**33**:882–8.
7 **Hellman S**, Baker L, Flores D, *et al.* Effect of ethnicity on adherence to diabetic regimen. *Ethn Dis* 1997;**7**:221–8.
8 **Lip GYH**, Kamath S, Jafri M, *et al.* Ethnic differences in patient perceptions of atrial fibrillation and anticoagulation therapy. *Stroke* 2002;**33**:238–44.
9 **Remme WJ**, Swedberg K. Guidelines for the treatment and diagnosis of heart failure. The task force on heart failure of the European Society of Cardiology. *Eur Heart J* 2001;**22**:1527–60.
10 **Artinian NT**, Magnan M, Christian W, *et al.* What do patients know about their heart failure? *Appl Nurs Res* 2002;**15**:200–8.
11 **Garcia Gomez P**, Montoto Otero C, Reyes Perera N, *et al.* [What information do elderly patients with heart failure have about their treatment?] *An Med Interna* 2003;**20**:59–62 [In Spanish].
12 **Aslam M**, Davis SS, Fletcher R. Compliance in medication by Asian immigrants. *Nurs Times* 1979;**75**:931–2.
13 **Nadar S**, Begum N, Kaur B, *et al.* Patients' understanding of anticoagulant therapy in a multiethnic population. *J R Soc Med* 2003;**96**:175–9.
14 **Gibbs CR**, Davis MK, Lip GYH, eds. *ABC of heart failure.* London: BMJ Books, 2000.
15 **National Institute for Clinical Excellence**. *Clinical guideline 5. Chronic heart failure: management of chronic heart failure in adults in primary and secondary care.* National Collaborating Centre for Chronic Conditions. National Institute for Clinical Excellence. 2003. www.nice.org.uk/pdf/CG5NICEguideline.pdf (accessed 18 February 2004).
16 **Kravitz RL**, Hays RD, Sherbourne CD, *et al.* Recall of recommendations with adherence to advice among patients with chronic medical conditions. *Arch Intern Med* 1993;**153**:1869–78.
17 **Arnsten JH**, Gelfand JM, Singer DE. Determinants of compliance with anticoagulation: a case control study. *Am J Med* 1997;**103**:11–7.

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(*Heart* 2004;**90**:e54) www.heartjnl.com/cgi/content/full/90/9/e54

Prolonged profound abciximab associated immune thrombocytopenia complicated by transient multispecific platelet antibodies

J A G Lown, A S Hughes, P Cannell

Patients receiving abciximab occasionally develop transient severe thrombocytopenia within a few hours of receiving the drug. Thrombocytopenia has been reported to resolve within 10 days of abciximab administration, but in this case profound thrombocytopenia lasted 21 days before a slow spontaneous recovery. Management was complicated by the presence of HLA antibodies and the transient production of antibodies directed at major platelet glycoproteins IIb/IIIa, Ib/IX, and Ia/IIa. The patient remained refractory to platelet transfusion and two courses of intravenous gammaglobulin for the duration of her admission.

(*Heart* 2004;**90**:e55) www.heartjnl.com/cgi/content/full/90/9/e55