

'I'm only here because of my family.' A study of lay referral networks

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SUMMARY

Background. *Illness, although partially the result of disease, is determined by social and cultural factors. Ways in which illness is constructed through conversations with others were investigated in a study of lay referral networks for patients consulting general practitioners (GPs) with new symptoms.*

Aim. *To describe these conversations, describe the importance or otherwise of the conversations in the decision to consult, compare the relative importance of conversations with partners to conversations with non-partners in deciding to consult, and investigate whether patients with a worse perceived health status are less likely to use lay referral networks than patients with a better perceived health status.*

Method. *A total of 101 patients who had consulted with new symptoms were interviewed. The measure of perceived health status used was the SF-36.*

Results. *About 70% of the patients reported conversations that were either very important or of some importance in the decision to consult. The people most likely to influence the potential patient in the decision to consult were their partners. There was no evidence of an extended referral network. Discussions about symptoms usually occurred in conversations taking place for reasons other than discussing illness. Men talked to equal numbers of women and men, but women talked to more women than men. There were only minor differences in these discussions between patients who varied according to age, social class, and perceived health status.*

Conclusions. *The importance of lay conversations in decision-making about illness is confirmed. The results describe how illness is socially constituted through these conversations.*

Keywords: *lay referral network; illness behaviour; consulting behaviour.*

Introduction

ONLY small numbers of people with symptoms decide to consult GPs.¹ People discuss symptoms with others before they discuss them with a doctor.^{2,3} Since symptoms of consulting patients may not appreciably differ medically from those of non-consulting patients,⁴ such conversations could be important in the decision to consult.

However, much of the work on these conversations is now dated. For instance, Friedson's⁵ description of lay referral networks is 40 years old. He argued that, typically, a patient experiencing symptoms would receive advice from a close relative

before being referred to progressively more remote and expert people. The process was likely to be more extended for ambiguous symptoms and for patients from cultures differing greatly from medical cultures. However, extensive lay referral networks have not been confirmed by other work.⁶⁻⁸ Friedson saw lay referral networks as means of providing advice and treatment, but conversations with others may also provide support, assurance that consultation is necessary, active persuasion, and material help.^{4,9,10}

Various studies have attempted to use lay referral networks as a basis for explaining different patient behaviours, although there are difficulties in defining and comparing 'networks'.¹¹ Patients with differing types of networks (contacts with different groups of people) have been shown to make differing uses of the following services: general practice,¹² psychiatry,¹³ antenatal,¹⁴ abortionists,¹⁵ and psychotherapy.¹⁶

The aim of this study was to take a fresh look at lay referral networks for patients consulting GPs with new symptoms. The importance of lay conversations in deciding to consult was described, and the importance of advice given by partners was compared with advice given from non-partners. It seemed plausible that patients would have less need to discuss symptoms with others before deciding to consult, the more unwell they understood themselves to be. We therefore wished to establish whether patients with a poorer perceived health status would make less use of lay referral networks (i.e. would have fewer lay conversations and fewer important conversations). We wished to study whether patients, varying in age, sex, social class, or with type of symptom, used lay referral networks differently.

Method

We intended identifying 100 patients consulting GPs with selected groups of new symptoms (selected because of their frequent occurrence) and then interviewing them about conversations held before consultation. A pilot study in different practices had been used to improve the questionnaires.

The main study took place in three urban practices in Middlesbrough. All 14 doctors in the practices contributed to the study, which continued from January to December of the same year. Suitable patients were first identified from two, varying surgeries a week. After seeing a receptionist (and before the consultation) each patient was given a questionnaire identifying those consulting because of a new symptom. The questionnaire classified the symptom (respiratory, gastrointestinal, musculoskeletal, emotional, or other). The surgeries included booked and urgent appointments but excluded visits and specialized clinics. Two (or more) patients booked as one appointment were considered individual appointments. We included patients younger than 16 years of age by giving the questionnaire to the accompanying adult. Patients who had completed the questionnaire previously were excluded unless consulting for a different symptom. After each surgery the appropriate doctor checked the questionnaires of patients indicating they were consulting with a new symptom.

One of the authors (HMC) arranged by telephone or letter to interview those patients indicating on the questionnaire, and confirmed subsequently by the GP, that were consulting with new respiratory, gastrointestinal, musculoskeletal, or emotional symp-

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toms. One reminder was sent if necessary. Patients were defined as adults consulting either because of their own symptoms or on behalf of their children.

During the interviews, information was obtained about who the patients talked to before consultation. Telephone conversations were included. Conversations with receptionists were excluded if the only purpose was to book an appointment. Conversations with pharmacists were similarly excluded if limited solely to buying medication without discussing symptoms. Information was obtained about the context in which the conversations occurred, patient expectations before the conversation, and the actual advice received. The importance of the conversation in deciding to consult was defined as 'very important' (the patient would not otherwise have consulted), 'of some importance' (the patient consulted with more confidence, consulted earlier or later, asked for a more urgent consultation, or the decision to consult was a joint decision), or of 'no importance'. The Anglicized version of the SF-36 was completed by each patient except those consulting because of children. The SF-36 produces eight scales of health status, with lower scores indicating poorer health status perceptions.

The EPI-INFO software package was used for data entry and analysis of categorical data. The *P*-values quoted are based on chi-squared values or the Mann-Whitney U test. Yates' correction, recommended for small sample sizes, was used. Fisher's exact test was used where appropriate. Significance testing was at the 95% level; i.e. *P*<0.05 was considered to be significant.

Results

The questionnaire was given to 1221 patients arriving for consultation, and 1190 were returned correctly completed. Those consulting with new symptoms totalled 439 (37%), of whom 201 had either new respiratory, gastrointestinal, musculoskeletal, or emotional symptoms. The GPs confirmed that 161 (80%) of the 201 patients had new problems. Of the 161, three were excluded because of language problems or because they had moved out of the area. We interviewed 101 of the remaining 158 (response rate

64%). Table 1 compares responders and non-responders.

Patients decided to consult, on average, 9.5 days after the start of the illness. They were interviewed, on average, 11 days after their consultation (range = 1–62 days).

Who did the subjects talk to?

The patients talked to a total of 365 people, an average of 3.6 with a range of 0 (for one patient only) to 16. The conversations occurred, on average, 2.9 days after the start of symptoms (range 0–42 days). Nevertheless, many conversations (104 from the 365 total) occurred within 24 hours from the start of symptoms.

Of the total conversations, 126 (34.5%) were with relatives other than partners, 68 (18.6%) with partners, 66 (18.1%) with workmates, 59 (16.2%) with friends, 12 (3.3%) with neighbours, 18 (4.9%) with nurses, 9 (2.5%) with pharmacists, and 7 (1.9%) with others.

Context of conversations

Some conversations were considered to take place in more than one context. The most common context was a conversation in passing; occurring, for instance, during a conversation about something else. Another frequent situation was when the person was aware of the problem anyway, when a 'conversation' was, so to speak, unnecessary. Relatively rarely had patients contacted lay people thought to have expertise (Table 2).

Patient expectations before the conversations

Patients expected nothing from 140 (38.4%) conversations that included meetings occurring for reasons unrelated to discussing symptoms. Patients had a total of 301 expectations from the remaining conversations. Advice was expected in 100 (33.2%) of the conversations held, reassurance in 78 (25.9%), and assurance that a GP consultation was necessary in 60 (19.9%). Material help (child minding and transport) was expected from 26 (8.6%) conversations. Other expectations numbered 37 (12.3%).

Advice received

No advice was given in 96 (26%) conversations. The patients received a total of 362 'items' of advice from the remaining 269 conversations. Advice to see the doctor occurred most frequently in 210 (58%), 109 of which were considered of no importance in the decision to consult. Advice to take a medicine (almost always common proprietary medicines) was given in 74 (20.4%) conversations. Relatively infrequently (in 21 (5.8%) conversations) was advice given to see someone other than the doctor — nine to see the pharmacist and five other health care professionals. Advice to see an osteopath was given only once. Other advice occurred in 57 (15.7%) conversations.

The importance of conversations in deciding to consult

Of the 101 patients, 72 (71%) reported one or more conversations that were very important, or of some importance. Very important conversations were reported by 17 patients, and conversations of some importance by 55. Viewed from the different

Table 1. Comparison of responders with non-responders.

Symptoms	Responders (n = 101)	Non-responders (n = 57)	Significance
Respiratory symptom			
Yes	56	19	$c^2 = 6.29$ $P = 0.01^b$
No	45	38	
Musculo-skeletal symptom			
Yes	26	30	$c^2 = 10.37$ $P = 0.001^b$
No	75	27	
Consulting for child			
Yes	38	7	$c^2 = 10.28$ $P = 0.001^b$
No	63	50	
Sex			
Female	76	32 ^a	$c^2 = 3.53$ $P = 0.06$
Male	25	22	
Average age	37 years (range = 14–80)	41 years	$P = 0.2$
Jarman score of 20 or less	51 (50%)	20 (35%)	$P = 0.09$

^aSex of three non-responders not known; ^bsignificant at the *P*<0.05 level.

Table 2. Context in which the conversations occurred (n = 412).

Context of conversation	Number (%)
Conversation in passing	189 (45.9)
Aware of the problem anyway	129 (31.3)
Understood to have some expertise	38 (9.2)
Other	56 (13.6)

perspective of the total number of conversations, only 21 (6%) were considered 'very important', 88 (24%) of 'some importance', and the remainder of 'no importance'.

Conversations with partners were more important than conversations with non-partners to patients deciding to consult ($P < 0.0001$; Table 3).

Sex differences

Female patients talked to an average of 3.7 people and male patients to 3.4 (non-significant). Although all patients combined talked to more females than males, male patients talked equally to males and females but female patients talked to more females (Table 4).

SF-36 results

Patients who had talked to large numbers of people (four or more) were more likely to have a low 'role physical' score — the extent to which physical illness limits roles — (Mann-Whitney U test = 4.42, 1 df, $P = 0.04$) and to have a low social functioning score — the extent to which social activities are restricted — (Mann-Whitney U test = 6.08, 1 df, $P = 0.01$). There were no other significant differences in SF-36 scores.

Age, sex, social class, type of symptom, consulting for child or self

These were not associated with differences in use of lay referral networks.

Discussion

This study provides a contemporary description of conversations patients hold with others before seeing a doctor in a British urban area. It extends previous work by studying, not only the advice received, but also whether the advice received was important in deciding to consult GPs.

There was no evidence of an extensive network described by Friedson⁵ — patients talked to people they came into contact with in the context of conversations occurring for other reasons,

but were not referred to progressively more remote, expert, people. On the contrary, those with greatest influence were partners. Rarely were patients advised to see other lay people.

The sex differences were interesting. Previous studies² have found that patients with symptoms are more likely to talk to women than men, but, to our knowledge, no study has differentiated between men and women with symptoms.

There were few differences in the various aspects of the lay referral networks for patients varying according to age, social class, and symptom type. One prior hypothesis was that patients with worse perceived health status would be less likely to be influenced by the lay discussions — would speak to fewer people and have fewer conversations that were important in the decision to consult. In fact, only two of the scales of the SF-36 were significantly correlated with differences in numbers of people talked to, and these were in opposite directions to those expected. Therefore, patients with a lower health rating on the 'role physical' and 'social function' scales talked to more people. There are two possible explanations for this. One explanation^{13,14} is that more extensive networks cause the sick person to delay consulting until a later and more severe stage of the illness. A second, simpler, and more likely explanation is that the illness of the patient determines the interaction with other people; i.e. that people who feel more ill speak to more people about their illness.

The non-responders differed in type of presenting symptom and whether consultation was for themselves or for children. However, symptom type and consultation for self or child were not associated with differing uses of lay referral networks, and, therefore, the non-response rate is unlikely to have altered the main findings. The definition of 'new symptom' could have been better defined. For the patient to be interviewed, both patient and doctor had to consider the symptom 'new'. This resulted in a low percentage of consultations (29%) being classified as consultations for new symptoms. It is likely therefore that the definition of 'new symptom' was, if anything, over-strict and unlikely to substantially alter the main findings.

This study has investigated conversations with consulting patients and could usefully be extended to include conversations of non-consulting patients. A further interesting study would be the contribution of worries of patients' partners in the decision to consult, since we found that conversations with patients' partners are particularly important.

Illness is socially and culturally constructed.¹⁷ This study shows how conversations with others are part of that social construction of illness. The conversations were at least of some importance for 70% of patients deciding to consult. Many conversations were 'passing conversations' occurring for a purpose other than discussing illness. Other conversations could barely be described as 'conversations' at all since the person was aware of the problem anyway. What was said needs to be distinguished from the meaning and the importance to the patient of what was said. Therefore, half the 'advice to consult the doctor' was considered of no importance in the decision to consult, and perhaps was often simply given as a device to allow conversations to proceed smoothly. Nevertheless, the type of relationship was significant — the closeness of the person determining the importance to the patient of what was said. The sex differences reflect the different culturally constructed ways that men and women speak; for instance, the evidence that they have different purposes in conversations and use different styles of talking.¹⁸

The implications for GPs are that these conversations are often important in the decision to consult. Explanations for why some people consult for symptoms for which many others, with apparently similar symptoms, do not,^{1,4} may involve the conversations

Table 3. Comparisons of the importance of conversations between patients and partners and patients and non-partners in the decision to consult.

Relationship with patient	No importance	Some importance /very important	Total
Partner	20	48	68
Non-partner	234	61	295
Total	254	109	363

Yates' corrected $\chi^2 = 63.16$; $P < 0.0001$.

Table 4. Relationship between the sex of the patient and the sex of the person with whom they had a conversation about their illness.

Sex of patient	Sex of contact		
	Female	Male	Combined
Female	197	81	278
Male	41	46	87
Combined	238 (65%)	127 (35%)	365

Yates' corrected $\chi^2 = 15.43$; $P = 0.00009$.

held with close family members including particular concerns of those members. Opening comments in consultations, such as 'I'm only here because of my family', may well be true.

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