

Research article

Experience with a Punjabi, Urdu and Hindi rheumatology telephone helpline

Kanta Kumar BSc, RN, Dip^{1,2}, **Alison Deeming** RGN, Dip¹, **Caroline Gordon** MD, FRCP^{1,2}, **Peter Nightingale** PhD, BSc³ and **Karim Raza** PhD, MRCP^{1,2}

¹Department of Rheumatology, Sandwell and West Birmingham Hospitals NHS Trust, UK.

²MRC Centre for Immune Regulation, School of Immunity and Infection, University of Birmingham, UK.

³Wellcome Trust Clinical Research Facility, Queen Elizabeth Hospital, Edgbaston, Birmingham, UK

Abstract

Objectives: To investigate what proportion of patients attending a rheumatology unit in Birmingham, UK, require interpretation services and to assess the use of an Asian language telephone helpline we have established for those who find it easier to communicate in Punjabi, Urdu or Hindi than in English.

Methods: Our patients' requirement for interpretation services and their ability to read the script of the language they preferred to communicate in was assessed. A second survey assessed the use of an Asian language helpline we had established. All calls were recorded over 18 months. The reasons for the calls were categorized and compared with those made to our English helpline.

Results: 171 of 512 patients (33%) stated that they required interpretation services. 128 (25%) were not able to read the script of their preferred language. In the second survey, 101 calls to the Asian language helpline were assessed and were compared with calls to the English helpline. The reasons for the calls differed between the helplines.

Conclusions: A large proportion of patients attending our rheumatology unit required interpretation services to communicate effectively with their healthcare professional. Most of these patients were unable to read the script of the language they could speak, casting some doubt over the utility of translated written information. Patients of South Asian origin who preferred to communicate in Punjabi, Urdu or Hindi made use of a helpline operating in these languages, suggesting that this may be an effective strategy to facilitate communication with this group of patients. Copyright © 2009 John Wiley & Sons, Ltd.

Key words: Rheumatology, telephone helplines, South Asian patients, English, Punjabi, Urdu, Hindi, interpretation, disease management

Introduction

Recent guidelines provide a framework within which those managing patients with chronic diseases are encouraged to operate (Arthritis Musculoskeletal Alliance, 2004; Department of Health, 2004). The involvement of patients in decision-making processes is central to these guidelines. A range of approaches are available to facilitate patient education and encourage participation in decision-making processes for those with chronic diseases. One approach which has been shown to be useful in the management of chronic disease is the telephone helpline, which has been widely used across a range of specialities (Jefford et al., 2005; Lindsay et al., 1995; Royal College of Nursing, 2006). Although there is lack of data relating to the impact of helplines on patient outcomes, evaluations of rheumatology helplines suggest that they are widely used and that patient satisfaction with them is high (Hughes et al., 2002; Linton, 2001). Helplines provide patients with a mechanism whereby they can rapidly access expert advice about a wide range of issues related to their musculoskeletal disease. However, there is widespread variation in the way that helplines are run (McCabe et al., 2000; Thwaites et al., 2008), and currently available helplines operate almost universally in English. Those patients who find it difficult to communicate in English are effectively excluded from this service.

Birmingham is a multicultural city in which 18.5% of the population is of South Asian origin. Furthermore, in the UK, the South Asian population constitutes one of the largest ethnic minority groups (Scott et al., 2001). Our experience over the years has been that patients of South Asian origin who find it difficult to communicate in English do not make use of our telephone helpline themselves and either rely on family or friends to contact the helpline on their behalf, or do not contact the helpline at all. To quantify the extent of the problem, we carried out a survey within the population we serve. Based on the results of this, and to facilitate the direct engagement of such patients in the management of their disease, we established a Punjabi, Urdu and Hindi helpline. The results of our survey and our experience with our Asian helpline are presented herein.

Methods

To understand the extent of the barriers to communication with patients within our Trust we conducted a survey in the rheumatology department at City Hospital,

Sandwell and West Birmingham Hospital NHS Trust. This survey was carried out as a service evaluation. Consecutive patients attending the department were approached by a research nurse (K.K.) with a questionnaire to collect the following data: (1) gender; (2) whether the patient felt that they required an interpreter to be present during their consultation with a health professional who could only speak English; (3) in what language the interpretation was required; and (4) whether the patient could read the script of the language they spoke. The questionnaire used to collect the data was anonymized. We recognized, through a previous study, that a proportion of South Asian patients attending our department, who were unable to communicate effectively in English, were also unable to read the script of the South Asian language they could speak. Given this, the use of written questionnaires translated into different South Asian languages would not have allowed us to capture data from the whole South Asian population. Thus, we elected to read the questionnaires to patients; to reduce bias, the questionnaire was read to all patients, irrespective of their ability to read or speak English. The questions were read out verbatim in the language that the patient was able to understand. All patients recorded their responses themselves and no prompts were given to any of the patients.

As a result of the survey, which showed that there were a large number of patients attending our unit who felt that they were unable to communicate effectively in English, we established a Punjabi, Urdu and Hindi helpline (hereafter referred to as the Asian language helpline) for rheumatology patients, using principles established by the Royal College of Nursing. The Asian language helpline was set up as a pilot scheme, using research funds. The initial aim was to assess the utilization of the Asian language helpline, with the aim of developing a business case for ongoing support, depending on the results of the pilot. The helpline was linked to an e-mail system that created an alert upon receipt of a message. The staff members who managed the helpline were able to retrieve messages via external access to ensure that calls were picked up on a daily basis. The Asian language helpline was managed by two staff members who spoke fluent Punjabi, Urdu and Hindi. Appropriate patients were informed about the helpline during their consultation. In addition, this helpline was advertised using posters in the department and credit card-sized cards, which were given to appropriate patients and, where possible, to their accompanying friends and relatives (Figure 1). Details of those who called this Asian language helpline and the reasons for the calls made were recorded over an 18-month period and categorized. To compare an equivalent number of calls made to our long-established English helpline, data were collected about calls to this helpline over a three-month period (which fell within the above 18-months period).



FIGURE 1. Sample of a card given to patients who find it easier to communicate in Punjabi and Hindi. In English, the card reads 'Rheumatology helpline', and is in Punjabi in the first line and Hindi in the second line.

Statistical analysis

Data were analysed using SPSS software version 14 (Chicago, IL, USA). Fisher's exact test and Mann-Whitney tests were used to compare the demographic data. Fisher's exact test was also used to compare the reasons for the calls and underlying disease. Logistic regression analysis was used to adjust for gender and diagnosis.

Results

Barriers to communication

The survey assessed 512 consecutive patients attending the outpatient department; 449 were female (88%) and 63 were male (12%). Of these, 171 patients (33%) required interpretation services in the following languages: Punjabi (93 patients; 18%), Urdu (54 patients; 11%), Hindi (10 patients; 2%), other (14 patients; 3%). Of those 171 patients requiring interpretation services, 128 (75%) were not able to read the script of the language they were able to speak: Punjabi, 68 patients (73%); Urdu, 41 patients (76%); Hindi, nine patients (90%); other, nine patients (64%). Of those 171 patients who required interpretation services, 156 (91%) were female and 15 (9%) were male. There was no significant difference between the proportion of women and men requiring interpretation services (Fisher's exact test; p value 0.089).

Experience of the Asian language helpline

Data were analysed for 101 calls to the Asian language helpline (all from patients) and 95 calls to the English helpline (78 from patients, nine from relatives and eight from healthcare professionals). Demographic details and diagnoses of the patients who made the calls, or on whose behalf the calls were made, are shown in Table 1. All but two calls to the Asian language helpline were from women. The reasons for the calls were categorized as follows: (1) questions about drugs (e.g. potential side effects and dosage); (2) requests for further information about the disease; (3) requests for advice about how to manage a disease flare; (4) enquiries about results of, and dates for, outpatient investigations; (5) requests for prescriptions; (6) emotional support; (7) requests for translation services; (8) other. The numbers of calls to the two helplines within each of these categories are shown in Table 1. The

TABLE 1. Demographic details of patients who phoned the Asian language and English helplines (or on whose behalf calls were made), the reasons for the calls and underlying diagnoses.

	Asian language helpline	English helpline	<i>p</i> value
Number of patients	101	95*	
Female; <i>n</i> (%)	99 (98%)	68 (78%)	<0.001 ^a
Age; years, median (IQR)	54 (47–60)	58 (45–64)	NS ^b
Reasons for calls:			
1. Questions about drugs; <i>n</i> (%)	35 (35)	48 (46)	NS ^a
2. More information about disease; <i>n</i> (%)	0 (0)	1 (1)	NS ^a
3. How to manage a disease flare; <i>n</i> (%)	44 (44)	17 (16)	<0.001 ^a
4. Enquiries about outpatient investigations; <i>n</i> (%)	10 (10)	24 (23)	0.014 ^a
5. Prescription required; <i>n</i> (%)	0 (0)	8 (8)	0.007 ^a
6. Emotional support; <i>n</i> (%)	2 (2)	1 (1)	NS ^a
7. Request for provision of translation services; <i>n</i> (%)	10 (10)	0 (0)	0.001 ^a
8. Other; <i>n</i> (%)	0 (0)	5 (5)	NS ^a
Diagnosis:			
1. Rheumatoid arthritis; <i>n</i> (%)	75 (74)	74 (78)	0.617 ^a
2. Systemic lupus erythematosus; <i>n</i> (%)	14 (14)	5 (5)	0.053 ^a
3. Vasculitis; <i>n</i> (%)	6 (6)	3 (3)	0.499 ^a
4. Psoriatic arthritis; <i>n</i> (%)	0 (0)	6 (6)	0.012 ^a
5. Other; <i>n</i> (%)	6 (6)	7 (7)	0.778 ^a

^aFisher's exact test.

^bMann-Whitney test.

*The number of calls is not equal to number of reasons for calls, as there were some calls with more than one enquiry.

reasons for the calls were different between the two helplines. The differences between helplines were significant for categories 3, 4, 5 and 7. Differences for categories 3, 4 and 8 remained significant when adjusted for gender and diagnosis.

Discussion

Our initial survey highlighted that a large proportion of our patients felt that they could not communicate effectively in English. While we recognize that this will not be the case in all units, many units located in inner cities will be faced with similar issues. Our data also showed that many patients who could not effectively communicate in English were unable to read the script of the language that they could speak, making translated information unhelpful for such patients and the need for channels of oral communication all the more important. This suggested to us that an Asian language helpline may be a useful strategy to facilitate engagement with this group of patients. Notably, there were no patients who requested to communicate in Bengali or other South Asian languages, and while this will almost certainly differ in other parts of the country, it led us to establish a helpline operating in Punjabi, Urdu and Hindi. Our data showed that patients made use of an Asian language helpline. We do, however, acknowledge that the number of calls made to the Asian language helpline was relatively small compared with the number made to the English helpline, given that 33% of our patients said that they preferred to communicate in Punjabi, Urdu or Hindi. There are a number of potential explanations for this. The survey of the Asian language helpline was carried out over the first 18 months of its life. Consequently, it is almost certain that not all patients who might have found it to be useful knew of its existence throughout the 18-month period. Secondly, it is possible that our written approaches to advertising the Asian language helpline may have been of limited effectiveness. Data from our survey showed that a large proportion of our target audience could not read Punjabi, Urdu or Hindi, making one of our strategies (of advertising the helpline using posters in these languages in the department) effective only for a small proportion of relevant patients. Thirdly, it is possible that some patients who preferred to communicate in Punjabi, Urdu or Hindi and who were aware of the existence of the Asian language helpline remained reluctant to use it.

Our data showed that, of those phoning the Asian language helpline, the most frequent reason for calls related to requests for advice about how to manage their disease flare. Perhaps not surprisingly, requests for the booking of interpreters for future appointments were also a common reason for calls. By contrast, there were more calls to the English helpline relating to enquiries about outpatient investigations and requests for prescriptions. Notably, there were very few calls to the Asian

language helpline from male patients. The results of the survey showed that a higher proportion of female than male patients required an interpreter, although the difference did not reach statistical significance. While this may be part of the explanation, it is also possible that male patients who find it easier to communicate in Punjabi, Urdu or Hindi are more reluctant to ring the Asian language helpline than their female counterparts.

As an appreciation of the influence of ethnic background on health status has increased, the need to understand the perspective of patients from different ethnic backgrounds becomes increasingly clear (Horne et al., 2004; Joshi, 1998). In a recent study, we showed that patients with rheumatoid arthritis and systemic lupus erythematosus of South Asian origin have very different views about medicines compared with patients of White British origin. Those of a South Asian background view medicines as more harmful and overused than do their White British counterparts (Kumar et al., 2008). Furthermore, across a range of diseases, health beliefs and behaviours have been identified that are specific to patients of South Asian origin (Greenhalgh, 1998; Lip et al., 2002; Lip et al., 2004). Interestingly, Helliwell and Ibrahim (2007) have reported that patients of South Asian origin terminate disease-modifying anti-rheumatic drug therapy sooner than do patients of North European origin, and suggest that this could be because of barriers to effective communication between healthcare professionals and patients who find it difficult to communicate in English.

There is now increasing interest in the development of approaches to engage effectively with members of ethnic minority groups to facilitate involvement in decision making in relation to healthcare. The UK Department of Health, and charities such as the British Heart Foundation and the Arthritis Research Campaign, for example, have supported strategies to overcome barriers to communication with some groups of patients of South Asian origin. For example, the Birmingham Arthritis Resource Centre (BARC; <http://www.barc.org.uk>) has developed bilingual audio-material that can be used to educate patients about rheumatological conditions. We suggest that an Asian language helpline may serve as an additional strategy to improve communication between healthcare professionals and some patients of South Asian origin, and that this may improve the quality of, and access to, healthcare in this population. Rheumatology departments need to provide all patients with an opportunity to engage in their care. There may be future opportunities for such helplines to flourish at a national level with organizations such as the National Rheumatoid Arthritis Society (NRAS). The non-English helpline we have established focused on South Asian languages, reflecting the needs of the population that our Trust serves. However, other NHS Trusts will serve patients from other linguistic backgrounds, and an equivalent service operating in different languages may be appropriate in such situations.

Acknowledgements

Kanta Kumar has been supported by an ICAC grant from the ARC and an unrestricted educational grant from Wyeth. The authors would like to thank Sister Chris Cooley, Sister Susan Butler and Mrs Harpal Tiwana for their support in running both of the helplines.

References

- Arthritis and Musculoskeletal Alliance (ARMA) (2004). Standards of care for people with inflammatory arthritis. ARMA, London.
- Department of Health (2004). From ideas to action: Improving chronic disease management. London: Department of Health.
- Greenhalgh T, Helman C, Chowdhury AM (1998). Health beliefs and folk models of diabetes in British Bangladeshis: Qualitative study. *British Medical Journal* 316: 978–83.
- Helliwell PS, Ibrahim G (2007). Ethnic differences in responses to disease modifying drugs. *Rheumatology* 42: 1197–201.
- Horne R, Graupner L, Frost S, Weinman J, Wright SM, Hankins M (2004). Medicine in a multi-cultural society: The effect of cultural background on beliefs about medications. *Social Science and Medicine* 59: 1307–13.
- Hughes RA, Carr ME, Huggett A, Thwaites CEA (2002). Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. *Annals of Rheumatic Disease* 61: 341–5.
- Jefford M, Kirke B, Grogan S, Yeoman G, Boyes A (2005). Australia's Cancer Helpline – An audit of utility and caller profile. *Australian Family Physician* 34: 393–4.
- Joshi MS (1998). Adherence in ethnic minorities: The case of South Asians in Britain. In Myers LB, Midence K (Eds) *Adherence to Treatment in Medical Conditions*. Amsterdam: Harwood Academic Publishers.
- Kumar K, Gordon C, Toescu V (2008). Beliefs about medicines in patients with RA and SLE: A comparison between patients of South Asian and White British origin. *Rheumatology* 47: 690–7.
- Lindsay G, Hinnie J, Gaw A (1995). Setting up a helpline on heart disease. *Nursing Standard* 10: 27–30.
- Linton SM, Meadows AJ. Patients' perception of a rheumatology telephone helpline (2001). *Rheumatology* 40: 1071–2.
- Lip GY, Kamath S, Jafri M, Mohammed A, Bareford D (2002). Ethnic differences in patient perceptions of atrial fibrillation and anticoagulation therapy: The West Birmingham Atrial Fibrillation Project. *Stroke* 33: 238–42.
- Lip GY, Khan H, Bhatnagar A, Brahmabhatt N, Crook P, Davies MK (2004). Ethnic differences in patient perceptions of heart failure and treatment: The West Birmingham Heart Failure Project. *Heart* 90: 1016–9.
- McCabe C, McDowell J, Cushnaghan J (2000). Rheumatology telephone helplines: An activity analysis. *Rheumatology* 39: 1390–5.
- Royal College of Nursing (2006). Telephone advice lines for people with long term conditions. Guidance for nursing practitioners. London: Royal College of Nursing.
- Scott A, Pearce D, Goldblatt P (2001). The sizes and characteristics of the minority ethnic population of Great Britain – Latest estimates. *Population Trends* 105: 6–10.

Thwaites C, Ryan S, Hassell A (2008). A survey of rheumatology nurse specialist providing telephone helpline advice within England and Wales. *Rheumatology* 47: 522–5.

Correspondence should be sent to Kanta Kumar, Sandwell and West Birmingham Hospitals NHS Trusts, Birmingham, B18 7QH, UK. Tel: +44 (0)121 507 5732; Fax: +44 (0)121 507 5451. E-mail: k.kumar@bham.ac.uk