The role of a telephone helpline in provision of patient information


Abstract

Aim To explore why individuals contacted a telephone helpline specialising in neurological conditions and their level of satisfaction with the service.

Method Callers were asked to complete a confidential postal questionnaire.

Results The majority of callers found the helpline useful and all respondents would use the service again. The main reasons for contacting the helpline were to obtain medical information or request an information booklet. Health professionals and the internet were the other main sources of information and support.

Conclusion A telephone helpline is important in the provision of information and support on neurological conditions. Through close collaboration, the NHS and voluntary organisations can fulfil many of the needs of patients with complex medical conditions.

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Keywords

Helplines; Neurological system and disorders; Telephone use

Some high profile NHS initiatives have acknowledged that patients, especially those with chronic diseases, wish to play a more active role in their care. The Department of Health (DH) says health authorities and service providers should ensure good quality information is available to patients. Better Information, Better Choices, Better Health (DH 2004) launched a strategy to improve access to health information. Improving access to information about health will improve self-care, help patients to seek appropriate help and encourage them to become more involved in decisions about their care. This has been supported by government initiatives that promote patient empowerment, such as Patient Advice and Liaison Services (PALS) (DH 2002) and the National Service Framework (NSF) for Long-Term Conditions (DH 2005). The NSF states that good communication and providing appropriate information are essential features of a quality service. These initiatives have contributed to an increase in the number of people searching for health information and have happened in parallel with the development of the internet.

Literature review

The helpline industry reflects a trend in people searching for health information. The number of helplines has increased in the past ten years, and the range of services offered and topics covered are more diverse. In 2005 there were more than 1,100 registered helplines and every year more than 22 million calls are made to helplines (Telephone Helplines Association (THA) 2005). The role of health professionals in helplines has not been fully explored. In the United States telephone nursing is becoming a specialty (Blanchfield et al 1997). In the UK, it has been seen as a way to encourage more appropriate use of NHS services (White 1998).

NHS Direct, the 24-hour telephone helpline, provides basic medical advice from qualified health professionals. It is an advice line and triage system, assessing whether an individual’s condition needs medical attention. In contrast, most helplines are not concerned with the diagnosis of a medical condition but provide information and support once a diagnosis has been made. Callers have a broad range of information needs, including psychological and emotional support and written information (Venn et al 1996). Twomey (2000)
found, for example, that those who called Macmillan nurses were seeking psychological support, symptom management and treatment.

These findings support the view that patients want to be fully informed about their illness (Cassileth et al 1980, Meredith et al 1996), which, in turn, reduces anxiety and increases patient satisfaction and knowledge (Coudrey et al 2002). In addition, O’Cathain et al (2005) explored the different functions of NHS Direct by interviewing service users who felt more able to manage their own care and to recognise when they needed to contact health professionals. They also reported feeling more assertive when using health services and more informed about the choice of services available.

However, evidence suggests patients and carers are not routinely given information or additional sources of support by health professionals. For example, McIntosh and Shaw (2003) reported that patients with lower back pain were dissatisfied with information from their GP, particularly about diagnosis and treatment. Patients with neurological conditions have particularly complex needs, including information and support. It is difficult to quantify the number of people in the UK with a neurological condition, as the term encompasses a diverse range of medical disorders. About one in eight GP consultations is for neurological symptoms (Association of British Neurologists (ABN) 2003). Only a small proportion of these patients are referred to a neurologist. Currently, there are only 352 consultant neurologists in the UK, or one for every 170,000 people (ABN 2003). It is difficult to obtain a clear diagnosis for complex neurological disorders and this is a barrier to appropriate support.

The Brain and Spine Foundation (BSF) is a registered charity founded in 1992 by neurosurgeons and neurologists to improve the quality of information provided to individuals. The Brain and Spine Helpline, launched in 1998, is staffed by neuroscience health professionals and has responded to more than 25,000 enquiries. Individuals contact the Brain and Spine Helpline for information and support. A key consideration is that this should be available at a time when the individual chooses, which is not necessarily at the time of diagnosis. Information provided at the time of diagnosis may not be fully understood (Sawyer 2000). It is important that an individual has access to different sources of health information and is, therefore, not solely the responsibility of NHS healthcare professionals.

**Aim**

The aim of the study was to explore why individuals contacted a telephone helpline specialising in neurological conditions and their level of satisfaction with the service.

**Method**

Two hundred questionnaires were posted with a Freepost reply envelope to helpline callers who requested patient information over a six-month period. Respondents were asked to read an information sheet and sign an informed consent form. They were given the option of returning the consent form and questionnaire separately if they wanted anonymity. The questionnaire consisted of ten questions to explore callers’ opinions of the helpline. Respondents were asked to comment on different aspects of the service they received, for example, accessibility, quality and information. Closed questions, which included a choice of categories, were used, and respondents were invited to make additional comments to elaborate on answers.

**Results**

Of the 200 questionnaires sent out 70 were returned—a response rate of 35 per cent. The majority of respondents (n=61, 87 per cent) found the helpline easy to get through to, perhaps indicating it is adequately staffed and the opening hours meet the demands of callers. Fifty-one respondents (73 per cent) were patients, 14 respondents (20 per cent) were carers and the remainder were health professionals (n=5, 7 per cent). Figure 1 shows how callers were directed to the helpline. The majority of callers discovered the helpline through a newspaper or magazine article (n=25, 35 per cent). Those who discovered the helpline via a hospital, a GP or a nurse numbered...
Callers expressed a high level of satisfaction with the Brain and Spine Helpline. Respondents found the information, including written information sent out in response to their calls, useful. The questionnaire highlighted the range of information providers, including the NHS, voluntary organisations and the internet. Only 20 per cent (n=14) of callers found out about the service through a health professional, including NHS Direct. The results indicate the role of a helpline is multifaceted. Callers were seeking written information, answers to medical questions and emotional support, which is consistent with previous published research (Twomey 2000). Previous research on the impact of patient information on the management of minor injuries found that it had little effect on the demand for primary care services (Heaney et al 2001). In contrast, research on chronic illness has concentrated on the impact of patient information on psychological factors, such as coping and anxiety levels (Coudeyre et al 2002). A leaflet on lower back pain did not significantly reduce anxiety before administration of a steroid injection, but the patients’ knowledge about adverse events improved (Coudeyre et al 2002).

Providing health information benefits patients and can reduce demand on NHS resources. For example, leaflets on back pain distributed at general practices reduced referrals to physiotherapy and admissions to hospital (Roland and Dixon 1989). A number of respondents indicated they would have preferred to have been provided with information at diagnosis. However, fear and apprehension can prevent patients asking questions when they are given a diagnosis. This is exacerbated by lack of time and access to specialist consultants (Neurological Alliance 2002). A number of neurological conditions are diagnosed through an acute episode requiring urgent medical investigation. In these cases patients are unable to ask questions or assimilate much information. It is, therefore, important that patients have information and support in the weeks and months following their diagnosis and treatment. It could explain the condition, what treatment or surgery they may have undergone and their prognosis.

Knowledge of relatively common neurological conditions, such as epilepsy and subarachnoid haemorrhage, is poor outside specialist neurological units. Consequently, appropriate information and support is absent in general hospitals (Neurological Alliance 2002). Swain (2005) reported that nearly 60 per cent of patients and carers affected by brain and central nervous system tumours were not given the contact details of an organisation that could provide information and support. McIntosh and Shaw (2003) found that GPs may not give out information because of the limited time in a consultation and lack of funding to buy external resources. This was also reflected in this study, with only 20 per cent (n=14) of callers being referred to the helpline by health professionals. While a high proportion of callers sought information from health professionals or voluntary organisations, a large number (n=21) reported accessing information via the internet. A survey at the Pew Internet and American Life Project revealed that people seek information from the internet for a number of reasons, including how to treat an illness or condition and whether to seek a second opinion from another doctor (Fox and Rainie 2000). However, there has been considerable concern in the medical profession about the quality of this information and the ability of patients to distinguish good from bad information (Ferguson 2002).

In response, a number of different quality standards and guidelines have been established in the UK, for example, by the Centre for Health Information Quality and by the THA (2000). Another function of a telephone helpline is to assist people who are trying to find information about their condition on the internet. This may involve performing the internet search on behalf of the caller or directing the caller to appropriate websites. Only 14 per cent (n=10) of callers knew, before calling, that the helpline was staffed by health professionals. However, comments made by respondents revealed that they felt more confident with the information they had been given after they discovered it had been provided
by health professionals. Health professionals are not only an important source of information but can direct people to voluntary organisations that can provide more specific information and support. However, little research has been conducted on the relationship between the NHS and charitable organisations.

Health professionals in the clinical setting may be reluctant to refer patients to external helplines because they are unaware of the contribution they can make towards an individual’s wellbeing and may be concerned they will provide the patient with inaccurate information. It is evident, therefore, that increased awareness of the services charitable organisations provide is needed to enable health professionals to collaborate with staff in these organisations and make the best use of each other’s skills, knowledge and resources. This, in turn, may assist in meeting some of the standards outlined in the NSF (DH 2005). In Better Information, Better Choices, Better Health (DH 2004) different initiatives are suggested to support people seeking health information. These include a health search engine and a healthcare information service provided through interactive digital television. The strategy also outlines plans to design an information accreditation scheme. These initiatives could also include improving awareness of non-NHS information sources and a signposting service. The development of an information toolkit for health professionals to access would also provide a source of appropriate accredited organisations to which they could refer patients. One indication of the liaison between the NHS and charitable helplines is the number of calls to the Brain and Spine Helpline in this study from staff at NHS Direct. While the results of this small study indicated callers were satisfied with the helpline, further studies are required to explore this in more detail – for example, whether providing information and support through a helpline enhances a patient’s perception of his or her ability to manage the condition.

CONCLUSIONS

While this study involved only one helpline and a small sample of patients, it indicates that telephone helplines have an important role to play in the provision of patient information. Further studies are needed to explore the impact of information and support on areas such as symptom control, coping and psychological distress.

IMPLICATIONS FOR PRACTICE

- Health professionals should explore how they can provide patients with information
- Identify the various voluntary organisations, locally and nationally, which provide information and support to patients and carers
- Display contact details of sources of further information and support in public areas

REFERENCES


