Concise Report

A survey of rheumatology nurse specialists providing telephone helpline advice within England and Wales

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Objective. To characterize provision of telephone helpline services in rheumatology units in England and Wales.

Methods. A questionnaire study of rheumatology nurse specialists (RNS) providing advice by a designated telephone helpline in England and Wales.

Results. Responses were obtained from 164/185 rheumatology units (89%). Of the responding units, 154 (94%) employed RNS and 146 units provided telephone advice either by Allied Health Professionals or RNS. A total of 135 units confirmed that only RNS gave telephone advice via a designated helpline. Completed questionnaires were analysed from 126 RNS working in 121 rheumatology units with a designated telephone helpline. Most RNS implemented both a manned and answerphone helpline service. The average number of calls varied from <10 to >100 per week. Fifty-six percent of RNS had performed an audit of the service. Twenty-four percent possessed helpline protocols or standards. RNS’ rheumatology experience ranged from 4 months to 25 yrs. Seventy-five percent had undertaken post registration study. Three out of 126 RNS reported having specific training in giving telephone advice and 25% had received in-house training or supervision. Seventy-eight percent had not been assessed in providing this service.

Conclusions. The telephone helpline is an established service in many rheumatology units. Provision varies throughout England and Wales and a lack of protocols, formal training and assessment in giving telephone advice is common. This prompted the Royal College of Nursing Rheumatology Forum to form a working party to compile a guidance document for nurses and practitioners providing telephone advice.

Key words: Rheumatoid arthritis, Education (patients), Attitude of health professionals, Nursing.
delivery, and to identify the academic and clinical experience of RNS providing the service. The findings from the survey would identify service provision prior to the implementation of the RCN telephone advice guidelines and therefore provide a benchmark from which to evaluate the implementation and effectiveness of the new guidelines in subsequent research.

Method

Questionnaire development

The questionnaire was developed following consultation with a consultant rheumatologist, consultant physiotherapist, a senior rheumatology nurse and the researcher (C.T.). This group discussion centred on how to address the aims of the study and resulted in the development of a questionnaire that would enable the following data to be collected:

(i) The academic and clinical experience of the nurse providing the telephone helpline service.
(ii) Demographic information regarding the rheumatology department, e.g. size of the population.
(iii) How the telephone helpline service operates.

The relevance of the questions proposed by the members of the group was debated to justify their inclusion or exclusion.

The questionnaire consisted primarily of closed questions allowing for descriptive statistical analysis. Open questions allowed respondents to add free text comments whereas closed questions were assessed with fixed answers of yes/no or numerical responses. The questionnaire piloted by three experienced RNS, was subsequently modified to ensure clarity. The content of the questionnaire was not altered but some of the wording was changed to avoid ambiguity. For example, one question which required the respondents to state the number of health professionals in the rheumatology team included the title ‘rheumatology practitioner’. This related specifically to allied health professionals (AHPs) and was subsequently clarified in brackets to avoid confusion with the nurse practitioner role.

Sample identification

This survey was conducted between July 2004 and July 2005. The exact number and location of RNS was unknown, therefore, to identify them, a letter was sent to a named consultant rheumatologist in each of the 185 departments in England and Wales listed in the British Society for Rheumatology (BSR) handbook. Each rheumatologist was asked to confirm whether they worked with an RNS (using a reply paid envelope) and, if so, to pass on the study information and questionnaire to that nurse. Participating RNS were asked to complete and return a consent form and the questionnaire. Obtaining RNS’ written consent enabled the researcher to contact individuals directly if necessary. Non-responders were followed up by a second mailing and a telephone call. Telephone contact via the consultant’s secretary was not an emergency service and stated the expected response time. A designated telephone helpline service redirected calls to a rheumatology ward after 5 p.m.

Analysis

Data from the completed questionnaires were entered onto an Excel database for descriptive statistical analysis. Questionnaires completed by AHPs or RNS providing telephone advice other than via a designated helpline were not included in the analysis.

The closed questions were analysed by totalling the number of positive and negative responses and recording the frequency of responses provided. The data from the open questions were analysed by recording the number of responses with similar content.

Ethics

A favourable ethical opinion was obtained from the Metropolitan Multi-Centred Research Ethics Committee and the host Research and Development Consortium (North Staffordshire). Written consent was obtained from participating RNS.

Results

Responses were obtained from 164/185 (89%) of rheumatology units. Of the responding units, 154 (94%) employed RNS. Out of these units, 146 provided telephone advice: 140 via a designated helpline and 6 indicated via a mobile phone or pager system. A designated helpline was run by RNS in 135 of the 154 units. Completed questionnaires from 126 RNS working in 121 rheumatology units were included in the analysis.

Operational aspects of the telephone helpline service delivery

Number of calls received. The average number of helpline calls received per week, per unit ranged from <10 to >100 (Fig. 1). Four rheumatology units reported receiving >100 helpline calls per week.

Answerphone vs manned service. Of the 121 units, 120 responded to the question about the mode of delivery of the helpline service. Of the 120 units, 23 provided an answerphone service only; 92 provided both manned and answerphone service and 5 provided a manned service only. The number of hours it was manned ranged from 1 to 24 h/day. The one unit reporting a 24-h manned helpline service redirected calls to a rheumatology ward after 5 p.m.

Identity of callers. The majority of callers to the helpline were patients (or their relatives) under the care of the rheumatologist. Other callers included GPs or primary care workers, staff from other hospital departments and sometimes, members of the general public. Of 121 units, 110 confirmed whether they provided patient information sheets describing the aim and purpose of the service. These were used by 36/110 of RNS respondents. Several RNS added free text comments highlighting that the answerphone greeting message explained the aim of the helpline, clarified that it was not an emergency service and stated the expected response time.

Documentation of calls. Of the 121 units, 119 responded to the question confirming whether every call was documented. Of 119 units, 96 reported that every call was documented whereas 19 stated calls were sometimes documented. One respondent clarified the reasons for not recording calls, which included cross-site working, lack of clerical support and high clinical workload. Of 119 units, 40 used a specifically designed helpline record sheet.

![Fig. 1. Average number of helpline calls per week.](image-url)
and 42 recorded the calls in a helpline record book. Whereas 12/119 documented the call in the medical notes only, 19/119 stated that they recorded the calls both in the medical notes and on the helpline record sheet. Of 119 units, 14 stated that they documented helpline calls in the medical notes only when the call resulted in a change in medicines or reported a change in the patient’s condition. Two RNS sent a record of the helpline call to the patient’s GP. The majority of RNS documented patients’ demographic details, the reason for the call and the outcome. Free text comments highlighted the fact that providing a helpline service could be time consuming, especially if the caller was difficult to contact. Where there was a lack of clerical support, accessing the medical notes could be complicated. One RNS stated that giving adequate time to distressed callers was problematic. Other comments highlighted that the number of calls was unpredictable and that audits showed increasing numbers annually. Of 119 respondents, 67 reported that they had performed an audit of their service. Of 121 units, 105 responded to the question clarifying whether they possessed specific helpline guidelines, protocols or standards. Of 105 units, 80 declared they did not.

**Clinical and academic experience of RNS providing telephone advice**

**Clinical experience.** Clinical experience included providing nurse-led services such as drug monitor clinics, follow-up clinics and group patient education programmes. Of 121 units, 118 confirmed whether they ran nurse-led drug monitor clinics of which 65/118 stated they did. Of 119 responding units, 113 provided nurse-led follow-up clinics. Of 121 units, 63 reported whether they ran group patient education programmes. RNS’ rheumatology experience and time in post ranged from 4 months to 25 yrs.

**Academic experience.** Of 126 RNS, 20 did not respond to the question about post-basic education. Table 1 shows the academic achievements of RNS who replied to the question.

**Training and assessment of RNS providing the helpline service**

Whereas 32/126 respondents stated that they had received in-house training or supervision in giving telephone advice, others stated they had looked at the relevant literature or learned from experience. Of 126 respondents, 34 replied they had received no training and only three RNS had received specific telephone training. Of 126 respondents, 27 stated that they had been assessed by peers.

**Discussion**

This study was the first national survey of rheumatology telephone helpline provision in England and Wales. Patient access to a nurse-led telephone helpline is recommended by ARMA [4], Arthritis Care [17] and the Arthritis Research Campaign (ARC) [22]. Results show that 82% of responding units provide a nurse-led designated telephone helpline service. However, there is marked variation in many aspects of the service and service provision, including number of calls received, the number of RNS involved in running the service, manned vs answerphone, and training and assessment in providing telephone advice. Little evidence is currently available to indicate the optimum structure of a service, and may depend on local circumstances.

Data obtained from this survey support previous conclusions by McCabe et al. [16] who identified the wide variation in helpline provision in six rheumatology units in the South West of England, which was influenced by location and resources. Whereas McCabe et al. [16] focused on six local units, this study obtained information from RNS in 121 rheumatology units throughout England and Wales. No responses were obtained from 21 units and it is uncertain whether these units have an RNS and/or run a telephone helpline service. It is possible that other units were missed in this survey—for example, if the rheumatologist was not included within the BSR handbook—but the potential numbers here are very small. We have attempted to ensure coverage of all sites, where rheumatologists work on more than one site, although it is possible that this was not always the case. Nevertheless, it does seem likely that the results quoted here are a good representation of what is currently happening in England and Wales. Scotland and Northern Ireland were omitted from this study solely for logistical reasons; a second part of the study involved interviews with a sample of RNS [23].

There was a large variation in the number of calls received per week by the units (2 to >100). The variation was not explained by differences in the size of the unit or the population it served, e.g. one unit reporting a catchment of 250 000 received >100 calls per week. The explanations for the variation are not clear, but could include differences in publicity, differences in response to calls, perceived usefulness of the service and how well established the service was. No benchmark exists for the mean number of calls an effective service would expect to receive for a given population. This survey shows that only one-third of units provided a patient information leaflet explaining the helpline service and a minority of units used a business card, stating the helpline telephone number. Although we did not establish how many units implemented the latter, there does seem a missed opportunity in terms of highlighting a valued service in many units.

Callers’ preference in the method of helpline delivery has previously been explored [14, 24]. Brownsell and Dawson [14] performed a patient satisfaction survey with 75 randomly selected helpline callers (54% response rate). Following the introduction of an answerphone service, a postal questionnaire revealed that 46% of respondents rated the manned service more favourably, whereas 27% preferred the answerphone service and 27% were indifferent. Thwaites et al. [24] conducted a patient satisfaction survey 3 months after removing the answerphone and reintroducing a manned service, available for 1 h/day. Of 71 postal questionnaires, 58 were returned (82% response rate). Although 91% of respondents were satisfied with the manned service, 41% reported having to call on more than one occasion due to difficulty in getting through. The method of helpline provision may be determined by the resources available.

The results from this survey and the qualitative interview study [23] were used to inform the development of the RCN document. The survey identified the lack of any formal training in the provision of telephone advice. The guidelines have addressed this, highlighting the importance of developing good communication and consultation skills without visual clues and the relevance of clinical decision-making skills. Peer assessment and clinical supervision may help to ensure that the practitioner is adequately supported during training and once competence is achieved. However, there is scope to develop a formal training programme.

Other results from the survey highlighted the disparity in documentation and concerns regarding the legalities of record keeping. The Nursing and Midwifery Council [25] has standards for documentation, but these may be widely interpreted. It may be argued that not all calls need be documented, but in order to

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<th>TABLE 1. RNS academic achievements</th>
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<tr>
<td>Post-basic courses orthopaedic/rheumatology course</td>
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<tr>
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reduce medico-legal risks [26] and maintain good communication and accurate records of helpline activity, all calls need to be logged, including the length of time spent dealing with the query. Of 121 units, 119 responded to the question about auditing the helpline service and 67 confirmed that an audit had been performed. Of 121 units, 105 specified whether they had specific helpline standards guidelines or protocols. Whereas 25/105 stated they had, 80/105 revealed there were no standards, guidelines or protocols in place. To address this issue, the guidance document included examples of call sheet proforma, to provide examples of good record keeping from which an audit could be conducted.

In conclusion, the rheumatology telephone helpline is established in many rheumatology departments and often run by RNS. Although recommended by patient support groups [4, 13], many rheumatology helplines have been introduced with little training or business planning. In relation to the latter, it is unclear how ‘Payment by Results’ [27] will support designated helplines. In terms of staff training, there is a compelling argument for the development of learning opportunities in this area. This study confirms the widespread use of designated rheumatology helplines and there remain issues of staff training, clear documentation and guidelines against which a service can be audited. As a direct result of this study, a generic guidance document has been produced by the Royal College of Nursing Rheumatology Forum [28]. It is unknown at present whether there is evidence to suggest practice has changed following the introduction of the guidance document but this could be an area of further research through the RCN Rheumatology Forum. Finally, whereas considerable research exploring telephone advice has been performed with NHS Direct, in the context of rheumatology this area remains under-researched.

Rheumatology key messages

- The RCN telephone guidance document provides a framework for practice outlining principles of good practice.
- There remains a lack of formal training and assessment for practitioners providing telephone advice.

Acknowledgements

The authors would like to thank the RNS who took part in the survey, the rheumatologists who responded to mailings, and to acknowledge the support of Kath Jones, Academic Secretary at the Staffordshire Rheumatology Centre.

Disclosure statement: The authors have declared no conflicts of interest.

References