Rheumatology telephone advice line – experience of a Portuguese department

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ABSTRACT

Background: Telephone helplines for patients are a tool for information and advice. They can contribute to patient's satisfaction with care and to the effectiveness and safety of treatments. In order to achieve this, they need to be adequately adapted to the target populations, as to incorporate their abilities and expectations. Aims: a) Evaluate the adherence of patients to a telephone helpline managed by nurses in a Portuguese Rheumatology Department, b) Analyse the profile of users and their major needs, c) Analyse the management of calls by the nurses.

Material and Methods: The target population of this phone service are the patients treated at Day Care Hospital and Early Arthritis Clinic of our department. Nurses answered phone calls immediately between 8am and 4pm of working days. In the remaining hours messages were recorded on voice mail and answered as soon as possible. Details of the calls were registered in a dedicated sheet and patients were requested permission to use data to improve the service, with respect for their rights of confidentiality, anonymity and freedom of decision.

Results: In 18 months 173 calls were made by 79 patients, with a mean age of 47.9 years (sd=9.13). Considering the proportions of men and women in the target population, it was found that men called more frequently (males= 32.7% vs females= 20.4%, p=0.016). The reasons for these calls can be divided into three categories: instrumental help, such as the request for results of complementary tests or rescheduling appointments (43.9% of calls); counselling on side effects or worsening of the disease/pain (31.2 %); counselling on therapy management (24.9%). Neither sex nor patient age were significantly related to these reasons for calling. Nurses resolved autonomously half (50.3%) of the calls and in 79.8% of the cases there was no need for patient referral to other health services.

Conclusions: About a quarter of patients adhered to the telephone helpline. Patients called to obtain support in the management of disease and therapy or to report side effects and/or symptom aggravation in addition to reasonable instrumental reasons. This suggests that this service may provide important health gains, in addition to comfort for the patient.

Keywords: Telephone helplines; Education; Nursing; Rheumatology

INTRODUCTION

The telephone has been recognized as a useful vehicle for managing patient care since the early 1960s[1,2]. For people with a long-term health problem, such services can be invaluable because they provide immediate expert advice on demand, when management strategies fail to achieve health benefits or to control symptoms[1].

Telephone advice lines are a welcome extension to specialist rheumatology outpatient management[3], as much as to other medical specialities, such as cardiology, diabetes or chronic pain management, which have longer experiences[4–8].

Rheumatology helplines are devoted to provide professional advice and support on the self-management of rheumatologic conditions, including the monitoring and adaptation of medication. Moreover, they offer an opportunity to discuss the need for an outpatient consultation or referral to other members of the multidisciplinary team, increasing the efficiency of health services[9]. They also play an important role in the mana-

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gement of psychological and social impact of disease and medication upon the patient's daily life[10,11].

As a consequence, many rheumatology departments in the UK, The Netherlands and Canada offer support and advice through a helpline[10,12,13] and many studies have reported high levels of patient satisfaction with this service[9,10,14,15]. Such studies also highlight that better patient education leads to more appropriate use of healthcare resources and relevant cost savings[16,17]. However, different cultural contexts need to be taken into account when implementing and evaluating such services.

The aims of this paper are: a) evaluate the adherence of patients to a telephone helpline managed by nurses in a Portuguese Rheumatology Department, b) analyse the profile of users and their major needs, c) analyse the management of calls by the nurses.

MATERIAL AND METHODS

This helpline, designed to serve patients under biological therapy followed at the Day Care Hospital (DCH), and for patients of the Early Arthritis Clinic (EAC) of the Rheumatology Department at Centro Hospitalar e Universitário de Coimbra, Portugal, was established in September 1st 2011. This target population includes 327 patients. The support service was advertised through: a) direct information by involved health professionals during patient visits – patients and/or family members were offered a business card and an information leaflet on the phone line and b) posters inside consulting offices. Both business cards and leaflets clearly stated that this was not to be used as an emergency service and provided advice on what to do in such situations.

The telephone helpline is a manned service, managed full-time by a registered nurse with one year of experience and in-house training in rheumatology at the start of this service. This nurse carries a mobile phone during the normal working hours (8am to 4pm). Outside this period or when a prompt answer is not possible, a voicemail greeting message asks patients to leave a voice message, which is answered as soon as possible. Supervision and support are provided by another registered nurse (with rheumatology nurse specialization and three years of experience) and by three rheumatologists.

Details of each phone call were collected and registered on a standardized data sheet, either during or immediately after the call. The following data was registered: callers' name; hospital file number and/or date of birth; phone number; patients diagnosis; current therapy; reason for calling; action recommended; referral; with whom was the call decision debated; and any further information and comments. Oral consent was obtained from patients in order to make further calls or satisfaction audits.

After six months a first evaluation was done, including 69 calls from 47 patients[17]. Results were presented and discussed within the team and some adjustments were made, namely on the recording sheet content and on the voicemail greeting message (appealing more for patients to leave a voicemail message).

Data was entered into an IBM® SPSS® version 20.0 database for statistical analysis. Results are presented as proportions and percentages for qualitative data and as mean and standard deviation for continuous data. These descriptive statistics, namely the percentage, allows to evaluate either the patients adherence and the management of calls by nurses. In order to analyse the profile of users, beyond the descriptive statistics we used the Qui-square test for proportions difference (for nominal data) and the ANOVA one way test (for continuous data) An α=0.05 was considered as level of significance.

RESULTS

ADHERENCE AND CALLER'S PROFILE

A total of 173 calls were registered during the first 18 months of operation (September 1st 2011 to March 1st 2013). It corresponds to a mean of 2.93 calls for 100 patients per month.

The mean age of callers was 47.9 (sd=13.9) years, ranging from 18 to 82 years, with a normal distribution. Callers were, on average, 5 years younger than de target population (mean age=53.1±14.6 years). A total of 79 patients (24% of the total target) used the helpline at least once. 94 calls were second or further calls by the same person. Table I presents the relation between first and further calls, according to disease and the relation of these calls with the number of target patients. Considering the proportion of patients with each type of disease that called, we observed that the frequency is highest among patients with Juvenile Idiopathic Arthritis (6 in 13 patients, 46.2%) followed by Systemic Lupus Erythematosus patients (2 in 5 patients; 40.0%). The lowest frequency of callers was observed among patients with Early Arthritis (10.8%). Among the

TABLE I. CALLS RECEIVED FROM PATIENTS FOLLOWED AT DAY CARE HOSPITAL AND AT EARLY ARTHRITIS CLINIC OF CENTRO HOSPITALAR E UNIVERSITÁRIO DE COIMBRA. EPE

	Number of patients (% of total target population)			Number of calls (%)			Proportion (%) of first callers within disease category
Disease	**Total**	**Female**	**Male**	**Total**	**First**	**Further**	
Rheumatoid arthritis	170 (52.0%)	147 (86.5%)	23 (13.5%)	80 (46.2%)	43 (53.7%)	37 (46.3%)	25.3%
Spondyloarthropathy	57 (17.4%)	24 (42.1%)	33 (57.9%)	40 (23.1%)	15 (37.5%)	25 (62.5%)	26.3%
Psoriatic arthritis	36 (11.1%)	17 (47.2%)	19 (52.8%)	13 (7.5%)	7 (53.8%)	6 (46.2%)	19.4%
Juvenile idiopatic arthritis	13 (4.0%)	10 (76.9%)	3 (23.1%)	19 (11.0%)	6 (31.6%)	13 (68.4%)	46.2%
Erythematosus sistemic lupus	5 (1.5%)	4 (80.0%)	1 (20.0%)	5 (2.9%)	2 (40.0%)	3 (60.0%)	40.0%
Other	9 (2.8%)	6 (66.7%)	3 (33.3%)	10 (5.8%)	2 (20.0%)	8 (80.0%)	22.2%
Early arthritis	37 (11.3%)	18 (48.6%)	19 (51.4%)	6 (3.5%)	4 (66.7%)	2 (33.3%)	10.8%
Total	327 (100.0%)	226 (69.1%)	101 (30.9%)	173 (100.0%)	79 (45.7%)	94 (54.3%)	–

other diseases 19.4% and 26.3% of the patients called at least once.

The patient who called more times – a woman with Scleroderma – did it 9 times, for different reasons (one resulted in hospitalization).

Focusing on sex differences, our target population is predominantly female (226; 69.1%). However, females represented only 58.2% of all patients who called at least once (46 woman), revealing a statistically significant difference between sex ($\chi^2_{(1)}$=5.782; p=0.016; Φ =0.133). Therefore, men seem more willing to use this service: 20.3 % of our female target population called at least once, in comparison to 32.7% of the males.

REASONS FOR CALLING

Considering the subject of calls (Table II), the largest number was made to obtain lab or imaging results (49 calls; 28.3%), or to request medical prescriptions. Reporting adverse events (37 calls; 21.4%) and changing appointment dates (27 calls; 15.6%) were the second and third motive/subject, respectively. Queries on management of the disease (22 calls; 12.7%) – eg. to ask what to do if a wound appears or if a surgery is programed – and management of the medication (21 calls; 12.2%) are other important reasons for calling. Patients called also to report flares or pain aggravation (17 calls; 9.8%). Statistically, the reasons for calling did not differ significantly according to age ($F_{(2)}$= 0.224; p=0.463) or sex ($\chi^2_{(2)}$=0.449; p=0.799).

MANAGEMENT OF CALLS

The responsible nurse resolved autonomously about half of all calls (87; 50.3%). Additional advice was sought in the remaining: 45.1% (78 calls) with the rheumatologist and the remaining 4.6% (8 calls) with another nurse.

OUTCOMES OF CALLS

On 138 calls (79.8%) the problem was resolved and the reply was effective: patients were instructed on how to handle the situation in their homes. In 20 of the cases (11.6%), patients were advised to come to the rheumatology department for better evaluation. Callers were advised to visit their General Practicioner (GP) on 9 occasions (5.2%) and to seek the emergency department on 6 cases (3.4%), two of which led to hospital admission.

TABLE II. REASONS FOR CALL BY SEX

	Gender n (%)		
Reason for call	**Male**	**Female**	**Total**
Report flares/pain	10 (58.8%)	7 (41.2%)	17 (100.0%)
Change appointment	11 (40.7%)	16 (59.3%)	27 (100.0%)
Obtain lab results/prescriptions	23 (46.9%)	26 (53.1%)	49 (100.0%)
Report adverse events	17 (45.9%)	20 (54.1%)	37 (100.0%)
Medication management queries	6 (28.6%)	15 (71.4%)	21 (100.0%)
Disease management queries	13 (59.1%)	9 (40.9%)	22 (100.0%)
Total	80 (46.2%)	93 (53.8%)	173 (100.0%)

DISCUSSION

ADHERENCE

After 18 months of operation, 24.2% of target patients (79 of 327) used this service at least once, with an average of 2.93 calls per 100 patients per month. In a survey with 146 units within England and Wales, the average number of calls was from 2 to more than 100 each week, with the largest number of units having 21--30 calls/week[18]. Unfortunately data on the number of the target population is not provided in these publications.

We had more second/further calls (54.3%) than first ones (45.7%). Although a usual concern with telephone helplines is that a few recurrent callers in need of social contact might dominate it[16], this was not supported by our experience. Hughes *et al.*[10] reported having 10-12% of repeated calls in each month (they analysed calls on 3 specific months). Repeat calls were either from those patients with an acute problem requiring several updates or from a small number requiring contact for reassurance[10].

Another concern with disease-specific helplines is that they will increase demand for specialist consultations[16]. This was not our experience until now. Only in 20 calls (11.6%) patients were invited to an additional or earlier appointment with the rheumatologist, results similar to other studies[9,10]. These cases were generally related to disease flares, which Hughes considers as an optimization of service rather than an overload[16]. The two hospitalizations reported in our study were a clear sign of that need.

CALLER'S PROFILE

Our study is the first testing differences for sex and it showed that men seem more inclined to call. Other studies only refer that calls are more frequently from women than from men – which is true also for our study – in a 3:1 proportion. However, this may simply represent the sex distribution of the target population.

Despite the information given to patients that GPs or other primary care professionals could use this helpline, we have registered only one phone call from a pharmacist from another hospital. This can be explained because this kind of services is uncommon in Portugal. Further information should be spread about this (for instance, a leaflet for primary care workers).

REASONS FOR CALLING

About one quarter of all calls was due to the need of complementary information about medicines – mainly biologics – and disease management. Another important fraction (about 31%) was related to health problems such as symptom worsening and adverse events. Together, these reasons represented approximately 56% of all calls. These results are in agreement with the literature[9,10], as the greatest proportion of calls (32–44%) among all units studied is related to worsening symptoms, but patients also frequently seek advice about drug management and side effects. However, similar to the percentage found in other studies[9,10] about 44% of all callers in our study presented instrumental requests. Given that this is not the main objective of the helpline, it should be questioned why patients use this helpline for these instrumental requests instead of the proper telephone number.

Our results showed no relation between age and the reasons for calling. From our knowledge, no other study tests this relation. We did not assess if the age of users correlates with the number of calls. Regarding this, Hughes *et al.* found that patients aged 66–79 were more likely to call[10].

MANAGEMENT OF CALLS

In the great majority of calls (79.8%) there was no need to refer the patient for further health professionals (i.e. GP, Rheumatology, emergency). This is also in agreement with other studies[10].

Our helpline nurse dealt with 50.3% of calls autonomously, a very similar number to that reported by Hughes et al. (50%)[10]. In their study, 60% of callers stated they would otherwise have contacted their GP had the helpline not been available. These authors made a cost calculation concluding that well prepared nurses could be a huge improvement on care and cost savings[10]. Based on their numbers, an economy of resources for the patient and for the health system has, presumably, been achieved with our helpline, in addition to increased feelings of safety by the patient and family. The hospitalization of two patients following a call to the helpline illustrates its use as a safety resource.

MULTIDISCIPLINARY TEAM COLLABORATION

In 45.1% and 4.6% of calls the nurse needed advice from rheumatologists or from the more specialized nurse, respectively. None of the calls presented queries about exercise, work difficulties or diet. Patients probably do not expect that nurses or doctors would answer these queries, at least through telephone helplines. Future clarification should be done regarding this.

TIME AND TRAINING

The nurse who managed this helpline had no specific training in telephone consultation beyond some readings[1] and team discussions. The Royal College of Nursing[1] considers that training for staffing advice lines should be given in addition to key clinical skills in the practitioners' specialist field of practice. Training is required for the use of non-visual communication skills (listening, questioning, empathizing…), advice giving (clear communication, following protocols, checking that advice has been understood), negotiation skills and, in some cases, counselling skills[1,19]. Practitioners should also have access to clinical supervision to ensure that they are adequately supported and can cope with the stressors related to telephone consultations[1]. The quality and scope of helplines could certainly be increased if they were viewed as an essential part of the nurse practitioners' clinical work, with protected time available to provide the service[16]. However, it is unclear where such training can be accessed and even whether appropriate training courses for medical helplines exist[16].

DIFFICULTIES

In spite of the good adherence, some patients demonstrated a bit frustration because they needed to call a few times to establish contact with the nurse. This can be explained by the clinical workload and multiple tasks developed by the nurse, which also affects the registry of calls. In fact, most helplines are manned by nurse practitioners in the context of concurrent clinical work, which limits their ability to respond rapidly to many queries[16].

Possible solutions to face these limitations are: have more nurses prepared to answer these calls; use only recorded calls (voicemail) instead of a live/manned service. In other units[18], nurses have specific hours each day (usually 1h) to answer recorded calls. Previous studies comparing patient satisfaction with these two methodologies showed a preference for manned service[14,20]. We believe that Portuguese patients would not like to have only a voicemail service. Obviously, "the method of helpline provision may be determined by the resources available"[18] (p. 524). This issue will be addressed in future surveys of our patients. Meanwhile, we have recorded an answer phone message strongly advising patients to leave a voice message when the nurse does not attend in time, which resulted in more recorded messages in the last months.

The registry of calls presents another difficulty. Almost all calls were registered in a helpline record sheet, but only a fraction of them were registered on medical notes. The reason is that medical notes are made on paper files kept in a central archive. This problem was also described by 14 of 119 units surveyed by Thwaites *et al.*[18], which documented helpline calls in the medical notes only when the call resulted in a change in medications or reported a change in the patient's condition, whereas 12 units documented the call in medical notes only.

Health professionals who administer telephone helplines are legally accountable for what they say or what they might omit to say to patients[14,21,22]. Thus meticulous record keeping should be cross-referenced to patients' existing medical files where appropriate and policies addressing patient confidentiality should be documented and implemented[9,14].

FUTURE PERSPECTIVES

Future perspectives are to disseminate this helpline to more patients and to extended hours. One possibility is to redirect calls to the rheumatology ward after 4 pm. This will depend on the resources and training al-

located for this service by the nursing administration.

Hughes suggests that each department should develop protocols for their helplines to ensure that the information and advice given is consistent and reliable and that these should be used as the basis for regular audits[16]. We have already established web and postal surveys, addressing all our patients, to evaluate the satisfaction and/or the interest and value of this service. Developing and implementing protocols, guidelines and specific training for our health professionals serving in the helpline are also in our plans.

CONCLUSION

About one quarter of target patients adhered to this telephone helpline, which could improve considering that it was recently implemented. Men showed to be more willing to call than women and younger patients called more frequently. We had calls from patients with an ample range of ages and with all types of rheumatic diseases. Patients called to obtain support in the management of disease and therapy or to report side effects and/or symptoms aggravation in addition to reasonable instrumental needs. The great part of patients who called did not need to search for further health services, but a few were referred to the GP or even to the urgency department. This suggests that this service may provide important health gains, in addition to comfort for the patient.

The results presented on this article could not be generalized to other settings and even in the setting in which the study was conducted, some fluctuations on the quality of the service could happen. Thus, further studies are required in other Portuguese departments in order to better analyse the feasibility and possible gains of this kind of helplines managed by nurses. This study did not test differences on reasons to call according to age, which could be interesting to study in the future.

Each time this project is evaluated some practical improvements happens, which shows that it is necessary a continuous quality assessment and improvement.

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