Telephone hotline is an important part of overall patient management in upper gastrointestinal malignancies

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ABSTRACT

INTRODUCTION: As seven out of every ten patients with upper gastrointestinal malignancies (UGIM) are not eligible for curative treatment, life after diagnosis is characterised by a rapid deterioration and uncertainty. To accommodate these issues, we established a telephone hotline. MATERIAL AND METHODS: In a two-year period, all patients evaluated for UGIM were given the hotline phone number. The hotline was staffed by either a nurse or a secretary, and subsequently the specialist in charge of the patient would return the call. All calls were registered in a prospective database. The following data were recorded: diagnosis, time from call to return call, problem and solution to the problem.

RESULTS: A total of 477 patients were included, and 172 (36%) patients used the Hotline a total of 254 times. Of the 254 calls, 210 (83%) were returned the same day. A total of 104 (41%) calls were made due to elaborative questions and 89% of these were solved over the phone. Dysphagia was the problem in 51 cases which gave rise to an endoscopy in 86% of cases. Pain was the problem in 35. Overall, of the 254 calls, 152 (60%) problems were solved over the phone. Furthermore, 75 calls triggered a hospital visit and 27 calls led to the patient being referred for further examinations.

CONCLUSION: The establishment of a telephone hotline was feasible and it was used by some patients. Most of the callers only made one call. Nearly all calls (96%) were returned the day after the initial call, at the latest. The problem pattern did not differ between disease groups apart from dysphagia in oesophageal cancer. We found that the hotline was an effective and inexpensive part of overall patient management.

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Patients with upper gastrointestinal malignancies (UGIM) have a dismal prognosis [1]. The majority of these patients are not eligible for curative treatment and life after diagnosis is often characterised by deterioration in general well-being and commonly also dysphagia, pain and weight loss. The need for counselling of patients and relatives at the time of diagnosis and during palliative treatment is unclear as very little has been published on this topic. We have experienced a rise in the number of telephone contacts to our department from patients and next of kin due to uncertainty among patients as well as their families. Since 2005, we have systematically used a hotline for this group of patients.

The aim of the present study was to clarify the cause of and need for telephone counselling following an UGIM diagnosis.

MATERIAL AND METHODS

Patients evaluated for UGIM at the Department of Gastrointestinal Surgery, Odense University Hospital in the period from 1 April 2005 to 31 March 2007 were included in this study.

The patients were all examined with endoscopic ultrasound in an out-patient setting as part of a standard evaluation. The patients were sedated with midazolam during the procedure. Later the same day, patients and relatives were informed of the findings and of any further treatment options. They also received information



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Specialist doctor returning calls made to the hotline.

TABLE 1

Distribution of patients and their use of the hotline.

Site of tumour	Patients, n	Patients using the hotline, n (%)	Male/female using the hotline, n (%)	Age of patients using the hot- line, years, average (range)
Oesophagus	88	49 (56)	38/11	66 (46-84)
GEJ	56	17 (30)	14/3	62 (46-76)
Stomach	76	24 (32)	12/12	66 (44-81)
Duodenum	21	4 (19)	2/2	63 (57-69)
Pancreas	164	55 (32)	32/23	66 (38-85)
Liver	19	18 (34)	8/10	64 (46-77)
Bile duct	40	4 (10)	2/2	66 (38-94)
Gall bladder	9	1 (10)	0/1	63
Total	473	172 (36)	108/64 (63/37)	65 (38-94)

GEJ = gastro-oesophageal junction.

about the telephone hotline and were encouraged to use it for any questions that might arise. The hotline was staffed by either a nurse or a secretary, and subsequently the specialist in charge of the patient would return the call. All calls were registered in a prospective database. The following data were recorded: diagnosis, time from call to return call, problem, and solution to the problem.

Trial registration: not relevant.

RESULTS

During the study period, 473 patients (289 (61%) male, 184 (39%) female) were included. The type of tumour and use of the hotline is shown in **Table 1**. A total of 172 (36%) patients used the hotline a total of 254 times. The caller population comprised 108 (63%) males and 64 (37%) females with an average age of 65 years (38-94 years). The average number of calls was 1.5 calls (0-8 calls). In total, 129 (75%) callers used the hotline only once (**Figure 1**).

Of the 254 calls, 210 (83%) were returned the same day and 33 (13%) the following day. The remaining 11 (4%) calls were all returned within four days. In 18 (7%) instances, the patient made a second call to press for the return call and most of these calls were returned on the same day as the primary call. The number of calls by tumour type is shown in **Figure 2**. The reasons for using the hotline varied with disease group and the distribution of the problems raised by the patients is presented in **Figure 3**.

A total of 104 (41%) calls were made because the patients had questions that needed elaboration and in 93 (89%) of these instances, the answers could be given satisfactorily over the phone. The remaining 11 calls (11%) led to a consultation in the outpatient clinic or to further examinations.

Overall, of the 254 calls, 152 (60%) problems were

solved over the phone, 75 (30%) calls gave rise to a consultation or hospital stay and 27 (11%) calls triggered a referral to another medical speciality or additional examinations.

Dysphagia was the problem in 51 cases and was the most common problem in patients with oesophageal cancer (n = 41). In 44 (86%) cases, dysphagia led to an endoscopic procedure of which 40 (91%) were performed within three days.

Pain was the problem in 35 cases, 19 (54%) of these could be solved over the phone, the remaining cases required hospital admittance or outpatient clinic consultation.

These three problems were the most common and comprised 75% of all the issues presented.

DISCUSSION

Every third patient used the hotline to contact the department after the primary examination and information session. This number may be considered high, but there is a lack of studies examining the need for counselling after the diagnosis of UGIM.

Men made more use of the hotline than women. However, the ratio did not differ significantly from the male-female ratio in the studied population. This is due to the skewed number of males with cancer in either the oesophagus (the gastro-oesophageal junction) or the stomach.

Most of the callers only made one call, but some patients with dysphagia used the hotline more frequent-



ly. Nearly all calls (96%) were returned within the next day, which we consider satisfactory. Overall, the number of calls was not considered a burden to our staff.

In a Cochrane review from 2004, Bunn et al [2] showed that a common trait among the few published studies on telephone consults was that approximately 50% of the problems could be solved over the telephone, which is quite similar to what we found.

The various disease groups displayed some differences with regard to the reported problems, but with the exception of oesophageal cancer, the most frequent issue in all groups was elaborate questions. Was it not for dysphagia in oesophageal cancer, the percentage of patients using the hotline would have been approximately the same for all disease groups.

As one of the main reasons for using the hotline was further questions from the patient or relatives, suboptimal information around the time of diagnosis may be one of the reasons for the use of the hotline, i.e. the set-up employed for providing information could be the cause for the needed extra information. The patients were informed on the same day they had been in sedation with midazolam. Although the patients were given time to sleep after the examination and before the information was given, amnesia might be responsible for some of the calls. However the set-up with examination and information on the same day has previously been evaluated, and patients were satisfied with the information given both before and after the examination [3]. In recent years, we have used nurse-administered propofol sedation in some patients. Propofol is cleared much quicker than midazolam and the subsequent "hangover" and, more importantly, amnesia are considerably less severe. It is our experience that this has improved the level of communication with patients after the examination. Furthermore, we are now more aware of the need for restitution after midazolam sedation before giving the information to patients. Also, we encourage patients to bring a relative.

Another explanation why elaborate questions are the most frequent reason for calling could be that the amount and speed of information patients receive during the diagnostic stage might be overwhelming. It is a wellaccepted notion that patients in a crisis situation generally tend to "shut down" and stop listening after being told of their diagnosis, although – to our knowledge – any real evidence of this phenomenon has yet to be published. A limitation of the present study was a lack of information regarding whether the patients were aware of the suspected diagnosis prior to the examination and information. A large, but decreasing number of patients are referred without being informed of the malignant suspicion. For these patients, the information might be even more overwhelming at the day of information and

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Distribution of patients, callers and calls between diseases.



thus increase the need for subsequent telephone counselling. However, these data were not registered in the patients' file at the time of inclusion. With the recently enforced national guidelines focusing on rapid diagnostic work-up and treatment for cancer patients, the need for subsequent counselling might increase further.

Dysphagia was as expected a common problem among oesophageal cancer patients and most often led to an endoscopic procedure shortly after the problem had been reported. The advantages of the hotline in these cases were that it eliminated the need to contact the patients' GPs. In a study where patients could report symptoms of malignant cord compression via a telephone hotline, Allan et al [4] showed a significant reduction in the time to diagnosis and treatment, and subsequently reduced severity of symptoms and improved outcome. It is plausible that the same reduction in time to treatment and expert counselling may have been achieved by offering the hotline to our patients, which supports the beneficial role of such a hotline.



Pain was the third-most common problem and could be solved over the phone in half of the cases.

In the remaining cases, a hospital visit was deemed necessary to rule out treatable causes of the pain. It would seem obvious that an ongoing adjustment of the pain medication in the individual patient would be instrumental in reducing the number of these calls. However, using the hotline as an on-demand adjustment service may be the "easiest" way of achieving such adjustment. In fact, only 35 of the 477 patients used the hotline because of pain. This figure may seem somewhat low, but we suspect that the patients' GPs solve the majority of these problems.

Telephone hotlines are a well-known phenomenon in addiction counselling, suicide prevention and domestic violence prevention and are often based on the work of volunteers and private organizations (Danish examples include Kræftens Bekæmpelse, "Stop-nu", "Livslinjen", etc). The use of hotlines within the established health care services is less common. In Australia, telephone- or radio-based contact to medical help has developed out of necessity due to the vast distances between people. Phillips et al [5] described how the implementation of a nurse-managed telephone support service in palliative care is feasible and appreciated especially by the local health care professionals seeking advice. In our study, a nurse or secretary received the call, but the actual telephone consultation was with a specialist doctor and if possible the same doctor as the patient saw at their previous hospital visit.

Ridley & Gallagher [6] studied a palliative care hotline for other health care professionals and they received more than 600 calls over a four-year period. Cancer patient-related questions comprised the majority of the calls. The problems were somewhat similar to those we experienced, but as our hotline targeted patients rather than health care professionals, callers also had questions about their specific disease and treatment. We believe that the short pathway for the patients to specialist counselling is a definite advantage. Ferrer-Roca & Subirana [7] has shown that the establishment of a telephone hotline for oncological patients did not significantly reduce the number of hospital stays or visits to the outpatient clinic compared with previous years. However, they did observe a small reduction in emergency hospital admittances. In that protocol, patients' calls were automatically transferred to their contact specialists' private cell-phone around the clock. This might explain the observed reduction in emergency hospital visits; however, this principle hardly seems compliant with the Danish medical system. Whether the use of the hotline has spared clinical consultations or hospital stays cannot be assessed in the present study.

Overall, we found that many of our patients used the hotline regardless of cancer type, and many patients needed more or better information. As a consequence, we have focused on giving better information and emphasized the importance of having a family member or close friend present at the conversations.

This study shows that the establishment of a telephone hotline was feasible and that up to one third of the patients may need further counselling. From our experience, we can only recommend establishing a hotline as it is a good service with very few implications for the department. To improve the given information and determine the optimal settings for informing patients, further studies are needed.

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