

Analysis of the question–answer service of the Emma Children’s Hospital information centre

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Abstract The information centre of the Emma Children’s Hospital AMC (EKZ AMC) is a specialised information centre where paediatric patients and persons involved with the patient can ask questions about all aspects of disease and its social implications. The aim of the study was to evaluate the question–answer service of this information centre in order to determine the role of a specialised information centre in an academic children’s hospital, identify the appropriate resources for the service and potential positive effects. For this purpose, a case management system was developed in MS ACCESS. The characteristics of the requester and the question, the time it took to answer questions, the information sources used and the extent to which we were able to answer the questions were registered. The costs of the service were determined. We analysed all questions that were asked in the year 2007. Fourteen hundred thirty-four questions were asked. Most questions were asked by parents (23.3%), healthcare workers (other than nurses; 16.5%) and nurses (15.3%). The scope of the most frequently asked questions include disease (20.2%) and treatment (13.0%). Information on paper was the main information source used. Most questions could be solved within 15 min. Twelve percent to 28% of total working hours are used for the question–answer service. Total costs including staff salary are rather large. In conclusions, taking over the task of providing additional medical information and by providing readily available, good quality information that healthcare professionals can use to inform their patients will lead to less time investment of these more expensive staff members. A

specialised information service can anticipate on the information need of parents and persons involved with the paediatric patient. It improves information by providing with relatively simple resources that has the potential to improve patient and parent satisfaction, coping and medical results. A specialised information centre is therefore a valuable and affordable asset to an academic children’s hospital.

Keywords Patient information centres · Data collection · Consumer health information · Information need · Information resources

Introduction

Patient information centres provide information about disease, treatment, diagnostic procedures, social aspects and implications of disease to patients and in case of paediatric patients to their parents. Recent studies have shown that information leads to better coping, better disease control and fewer hospital appointments [3, 7].

Repeated medical information does not always imply that parents feel that they have received sufficient information about the condition as such and its implications [1, 2]. Parents are often dissatisfied with the information provided by the physician. They are often left with many unanswered questions. Even when provided with sufficient information, a common reaction to handle the fact of having a child with a (chronic) disorder is to seek additional information and gain extensive knowledge about the diagnosis [4] in an attempt to reduce uncertainty. Most parents find internet useful [5], but assessing the accuracy and reliability of information from the internet is difficult especially for those without appropriate skills. Unfiltered information can also

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lead to more questions and even anxiety. A majority of parents are in favour of personal assistance in finding information [6]. Patient information centres can support parents of paediatric patients with personal assistance and support in finding accurate and reliable information.

In The Netherlands, there are only a few information centres that are specialised in paediatric health (related) problems. Specialised information centres are important because the health information needs of (parents of) paediatric patients are clearly different to those of adults because various age-specific associations such as growth, development, education, behaviour and congenital diseases need to be taken into account. The aim of the study was to evaluate the question–answer service of the information centre of the Emma Children’s Hospital in order to determine the role of a specialised information centre in an academic children’s hospital and identify the appropriate resources for the service and potential positive effects.

Materials and methods

The information centre of the Emma Children’s Hospital AMC (EKZ AMC) is a specialised information centre that was founded in 2004. It was introduced as a patient information centre where paediatric patients, their parents, their relatives, healthcare professionals and other persons and institutions (for example school) involved with the patient can ask questions about all aspects of disease, diagnostic procedures, treatment and social aspects and implications. The information centre is situated in the paediatric clinic but is also open for requesters from the paediatric outpatient clinic, other non-paediatric departments of the EKZ AMC and requesters from outside the EKZ AMC.

The core of the centre’s activities is in the question–answer service. The information centre is open for questions 4 days a week. Questions are asked by visitors, by telephone, by e-mail or in writing. Every requester gets personal help to find the answer to the question asked. This personal help is provided by three (part-time) employees who together represent one full-time-equivalent (FTE) and three volunteers. The employees are a nurse with additional education in social work, a librarian and a pedagogic worker with special training in the area of patient education. For children, a special service is provided for the preparation of school papers and presentations.

The information sources used in the information centre are paper and digital information brochures from the EKZ AMC and other organisations. The information centre has its own book collection with medical books for non-professionals and children, a special online CD-ROM with quality-controlled medical, legal and social patient infor-

mation developed by the national information centre for care, social security, law and legislation and well-being (ZWCD-online: <http://2zw.host.diskad.nl/admin/login.asp?target=home>), magazines from patient organisations, its own website (www.amc.nl/emmainfotheek) and medical literature. If necessary, a question leads to a thorough search through all of these information sources and the internet. All information is reviewed on quality with strict available quality criteria (www.amc.nl/emmainfotheek) and in case of reliability or accuracy issues by a specialist on the subject, before it is handed over to the requester.

We developed a computer database structure in MS ACCESS to prospectively evaluate the question–answer service which also serves as a case management system. It is used to follow requesters from the time they ask their question until the question is answered. It is also possible to search in old questions, answers and used search strategies.

The full-text question, main characteristics of the question (information content area) and the answer are registered during or immediately after the visit, call or e-mail. This provides a close approximation of questions asked. Twenty-eight information content areas were defined (Table 1) based on previously asked questions.

Characteristics of the requester (parent, patient, healthcare professional etc.) and information sources that are used are registered as well. To estimate the complexity of a question, the time it took to answer questions and the extent (fully, partly, not) to which we were able to answer the questions were registered by the employees. Information from the registration of the financial department was used to estimate the costs of the service.

We analysed all questions that were asked in the year 2007. Because individuals may have asked more than one question, we treated questions rather than calls, visits or e-mails.

Results

In 2007, 1,434 questions were received. An analysis of the requester characteristics (Fig. 1) shows that questions were mainly asked by parents (23.3%), healthcare workers (other than nurses; 16.5%), nurses (15.3%) and students (10.5%) and less frequently by physicians (6.9%), patients (5.1%) and relatives (5.1%). Requesters came from the paediatric clinic (53.3%), outside the EKZ AMC (31.2%), the paediatric outpatient clinic (7.1%) or other non-paediatric departments of the EKZ AMC (6.7%).

Types of questions most often asked involved disease (20.2%) and treatment (13.0%). The frequency of other information content areas was less than 10%. A question could contain more than one information content area and thus could be classified to more than one group. Table 2

Table 1 Information content areas

Information content area

Disease
 Treatment
 Showing the way^a
 School presentation or paper
 EKZ AMC information^b
 Information development^c
 Social aspects and implications^d
 Preparation^e
 Diagnostic procedures
 Aftercare^f
 Patient support groups
 Information management^g
 Donations^h
 Information centreⁱ
 Death and mourning^j
 Patient experiences^k
 Contact information^l
 Traineeship information^m
 Activitiesⁿ
 Human body^o
 Guidelines/protocols/methods^p
 Volunteer work^q
 Job application
 Other medical centres^r
 Complaints^s
 Fellow sufferers^t
 Other
 Unknown

^a Location of a patient, department or other facility

^b General information about the Emma Children's hospital AMC

^c Information about the procedure of development of new information materials

^d Social aspects and implications of disease and information about possible support

^e Information about how to prepare a child for a procedure or admission

^f Information about the care for a child after a procedure or admission

^g All questions involving the management of the information in the information centre

^h Information about donations to the EKZ AMC

ⁱ General information about the information centre

^j Information involving the death of a child and mourning

^k Patient stories and experiences

^l All information that is needed for contacting a person

^m Information about traineeships in the EKZ AMC

ⁿ Information about activities for patients organised by the EKZ AMC

^o Information about functioning and anatomy of the human body

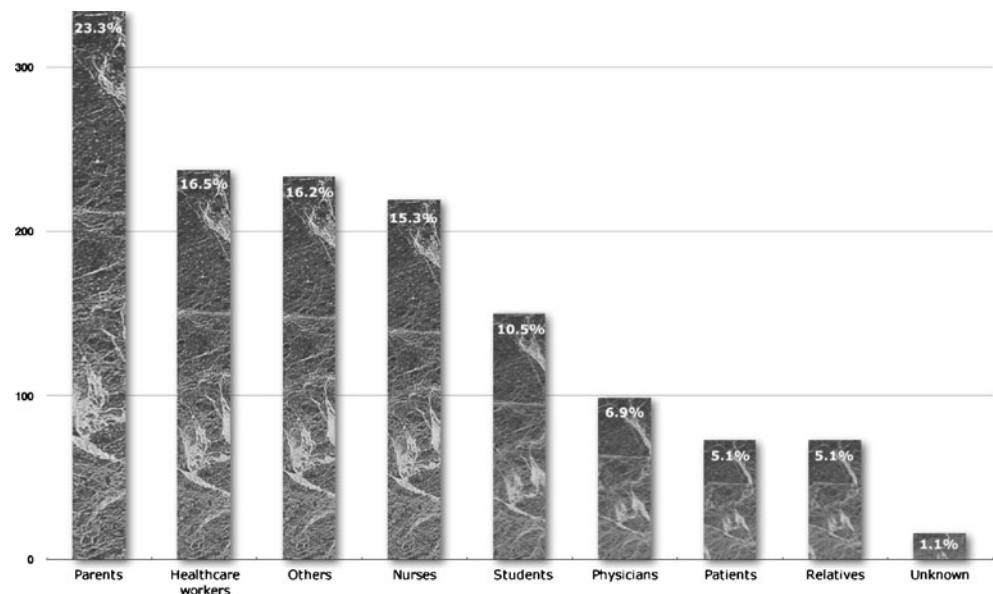
^p Information about guidelines, protocols and methods used in the EKZ AMC

^q Information about volunteer work in the EKZ AMC

^r Information about other medical centres and treatment facilities

^s Information about the procedure for complaints

^t Request to come into contact with other (parents of) patients with the same disease

Fig. 1 Requester characteristics**Table 2** Frequency and percentage of questions within each information content area

Information content area	No. (%)
Disease	331 (20.2)
Treatment	214 (13)
Showing the way	163 (9.9)
School presentation or paper	107 (6.5)
EKZ AMC information	101 (6.2)
Information development	89 (5.4)
Social aspects and implications	60 (3.7)
Preparation	58 (3.5)
Diagnostic procedures	55 (3.4)
Aftercare	47 (2.9)
Patient support groups	33 (2.0)
Information management	28 (1.7)
Donations	21 (1.3)
Information centre	20 (1.2)
Death and mourning	14 (0.9)
Patient experiences	15 (0.9)
Contact information	13 (0.8)
Traineeship information	10 (0.6)
Activities	10 (0.6)
Human body	10 (0.6)
Guidelines/protocols/methods	9 (0.5)
Volunteer work	4 (0.2)
Job application	3 (0.2)
Other medical centres	3 (0.2)
Complaints	3 (0.2)
Fellow sufferers	2 (0.1)
Other	180 (10.9)
Unknown	38 (2.3)
Total	1,641 (100)

presents the frequencies and percentage of questions within each information content area.

Table 3 shows the information content areas of interest for the different kinds of requesters. The information content areas that involved less than 1% of the questions are added to the information content area 'Other'.

Questions about disease were asked relatively more by parents, patients and physicians. Patients often asked their questions to prepare for a school presentation or paper.

Questions about diagnostic procedures were asked relatively more by parents and relatives. Questions asked by nurses involved mostly development of information materials. Other healthcare workers like social workers and pedagogic workers asked especially questions about preparation, aftercare, social aspects and patient support groups and about disease and treatment as well. Relatives needed mostly information about the location of patients, departments or other facilities.

The following information sources were mainly used to solve the questions (Table 4): paper brochures developed by other organisations (30.9% of questions), books from the information centres own collection (14.1% of questions) and paper brochures developed in the EKZ AMC (13.5% of questions). Information acquired from the Internet was used in answering 8% of the questions. Questions were usually solved using several information sources so that the final percentage exceeds 100%.

According to the registration of the employees, we were able to fully answer 89.6% and partly answer 3.4% of the questions. More than half of the questions could be solved within 15 min with immediate answer, available information materials or other direct available information sources;

Table 3 Association between requester characteristics and information content area

Information content area (%)	Disease Treatment (%)	Showing School the way (%)	Information presentation or paper (%)	EKZ AMC information development (%)	Social aspects and implications (%)	Preparation (%)	Diagnostic procedures (%)	Aftercare support groups (%)	Information management (%)	Donations centre (%)	Information Other (%) ^a	Unknown Total (%)					
Requester characteristics																	
Parent	29.7	18.6	7.7	2.7	5.6	0	7.3	2.4	6.0	2.9	3.4	0	0.5	0.7	11.4	1.2	100
Patient	26.7	8.9	6.7	33.3	4.4	0	1.1	3.3	2.2	3.3	0	0	1.1	0	6.7	2.2	100
Relative	17.4	5.8	44.2	8.1	1.2	0	0	1.2	3.5	0	0	0	0	0	14.0	4.7	100
Nurse	13.4	19.3	1.7	2.9	5.4	23.9	2.1	2.9	2.9	4.2	0.8	3.4	0	0.8	14.6	1.7	100
Physician	23.8	5.7	19.1	1.0	6.7	6.7	0	1.0	1.0	1.0	3.8	1.9	0	2.9	25.7	0	100
Healthcare worker	21.3	13.6	5.5	2.6	7.7	2.9	6.6	6.3	2.6	7.0	2.6	2.6	0	2.6	12.5	3.7	100
Student	15.9	12.5	4.6	19.3	6.3	2.8	1.7	6.8	2.3	0	0.6	0	1.1	0.6	22.7	2.8	100
Other	9.4	3.8	15.7	3.4	8.9	4.3	1.3	3.0	1.7	0.9	2.1	4.7	6.8	1.3	31.1	1.7	100
Unknown	17.4	17.4	13.0	8.7	0	8.7	0	0	8.7	0	0	0	0	4.4	4.4	17.4	100
All requesters	20.2	13.0	9.9	6.5	6.2	5.4	3.7	3.5	3.4	2.9	2.0	1.7	1.3	1.2	16.7	2.3	100

^a In this table, the information content areas ‘Death and mourning’, ‘Patient experiences’, ‘Contact information’, ‘Complaint’, ‘Traineeship information’, ‘Activities’, ‘Human body’, ‘Guidelines/protocols/methods’, ‘Volunteer work’, ‘Job application’, ‘Other medical centres’ and ‘Complaints’ are added to the information content area ‘Other’

Table 4 Information sources used to solve the questions

Information source	No.	% of questions
Paper brochure other organisation ^a	443	30.9
Book ^b	202	14.1
Paper brochure EKZ AMC ^c	193	13.5
Internet ^d	114	8
ZWCD-online ^e	98	6.8
Patient support group	49	3.4
No used information sources	49	3.4
Digital brochures ^f	35	2.4
Website ^g	34	2.4
Magazine ^h	21	1.5
DVD ⁱ	18	1.3
Medical literature ^j	14	1
Other	297	20.7
Unknown	587	40.9
Total	2,154	150.3

^a Paper information brochure developed by another organisation than the EKZ AMC

^b Book from the information centre's own book collection with medical books for non professionals and children

^c Paper information brochure developed by the EKZ AMC

^d Free available information on the internet

^e Online CD-ROM with quality controlled medical, legal en social patient information developed by the national information centre for care, social security, law and legislation and well-being (ZWCD online: <http://2zw.host.diskad.nl/admin/login.asp?target=home>)

^f Information brochure developed by the EKZ AMC that are digital available on the website of the EKZ AMC (<http://www.amc.nl/index.cfm?sid=5>)

^g Website of the information centre of the EKZ AMC (www.amc.nl/emmainfotheek)

^h Magazines with a variety of especially medical and social information from the information centre's own collection

ⁱ DVD with medical subjects from the information centre's own collection

^j Medical literature from the medical library

88.1% of questions could be solved within 30 min. More complex questions took more than 30 min to find an answer (11.9%) (Table 5).

Total time spent to solve questions was between 232 and 529 working hours for one person. The three (part-time) employees together represent one FTE which represents a week of 36 h. Not taking into account vacations, holidays and absence because of illness, the total working period in 2007 is 1,872 h. The core activities comprise between 12% and 28% of the total working period.

Variable costs of the service for 2007 were approximately 3,900 euro. Fixed costs (mainly salary of staff) were calculated on 51,000 euro.

Discussion

This is the first report of analysis of activities of an information centre specialised in paediatrics. Analyses of requester characteristics show that parents are the main group to ask questions to our information centre. Patients on the other hand are only a minority (5.1%) of the requesters. This is mostly because most of our patients are young children. Of a total of 7,621 admissions and 13,085 first consults at the outpatient clinic, 5,648 (74.1%) and 8,774 (67.1%), respectively, were under the age of 10 years. However, only a few older patients visit our information centre by themselves, many of them (33.3%) gathering information for a school presentation about their disease or other hospital-related subjects. Possible explanations for the small number of patients are that they are being informed by their parents, are not interested in more information, that there is not enough connection with daily reality, like school and other activities of these children or because information about the information centre that is sent to every parent did not reach the older children. Improving information about the existence and possibilities of the information centre to children and improving the accessibility for children will need further research on information resources that have more connection with daily reality and activities of the children and other ways of communicating using, for example, SMS and MSN.

Our analysis of questions demonstrated a broad range of requests for information. As was expected, parents asked relatively more questions about disease, diagnostic procedures and treatment.

Most questions asked by physicians involved the information content area 'disease' as well. Knowing about the information need of parents and patients and in their duty to inform them properly, they collect readily available, good quality information to give to their patients.

Questions asked by nurses involved mostly questions about development of new information materials. In the

Table 5 Time spent answering questions

Time spent	No. (%)
0 to 5 min	326 (22.7)
5 to 15 min	605 (42.2)
15 to 30 min	332 (23.2)
30 to 60 min	118 (8.2)
1 to 2 h	34 (2.4)
2 to 3 h	3 (0.2)
Unknown	16 (1.1)
Total	1,434 (100)

EKZ AMC, they are the most important initiators and active participants in developing new information materials.

Other healthcare workers, like social workers and pedagogic workers, asked especially questions involving the information content areas preparation, aftercare, social information and patient support groups and information involving the information content areas disease and treatment as well. This can be explained by the supportive way these healthcare workers are involved with parents and patients.

Relatives needed relatively the most information about the locations of patients, departments or other facilities. This improper use of the facilities can be avoided by improving route information to wards and other facilities and to enable parents to provide adequate information to the relatives about the exact location of the patient.

In spite of the availability of many digital information resources, the need for paper information resources remains. Paper brochures developed by other organisations were used to answer 30.9% of questions. With the diversity in questions, it is impossible to develop our own information material on all subjects. Although the Internet is a rich source of information accessible to everyone, it is for many people very difficult to find good information and to assess reliability and quality of this information. The information centre of the EKZ AMC uses its own quality criteria (www.amc.nl/emmainfotheek) to assess information from the Internet, and in case of reliability or accuracy issues, a specialist on the subject is asked to review the information before it is handed to the requester. In 8% of the questions, information from the Internet was used.

According to our own registration, almost 90% of requesters were supplied with complete information. This information is biased because it reflects the opinion of the employees and not that of the requesters. For that, a customer survey is needed.

Most questions asked to our information centre were of low complexity. These are questions that can be answered immediately (0–5 min) or with available information material or easy accessible information sources (5–15 min). More than 10% of questions were complex or very complex questions in which it took much effort to find suitable information. Registration of questions is necessary to identify and anticipate on gaps in information. Improving the information centre's information resources will probably not lead to less complex, less time-consuming questions because in a tertiary referral academic hospital, children with rare diseases are diagnosed and treated, and it is impossible to develop information materials for all of these diseases. Information centres need good search strategies, especially on the internet where a lot of information is available. Further evaluation of the complex questions and used search strategies is needed to find out in what way search strategies can be improved.

Variable costs of the service were low but the total costs including staff salary are rather large. On the other hand, supporting more expensive healthcare professionals at information provision can save time and reduce costs. If the additional information for parents and patients were to be given by medical specialists, the costs would be three times as high. Analysis of the cost–benefits was not an aim of this paper but is subject for further study. One FTE employee and three volunteers are sufficient to provide service to the current EKZ AMC patient population for 4 days a week, with only 12 days of closed hours because of illness or vacation.

Providing health-related information to parents, patients, relatives and other persons involved is time-consuming but, as earlier studies [3, 7] have shown, remains very important because of the positive effects on coping with disease and medical results. In The Netherlands, it is stated by law (Law on Medical Treatment Agreement (WGBO)) that patients and in case of paediatric patients their parents are entitled to information in understandable language about their disease, the treatment, the impact and dangers of that treatment and possible alternative treatment strategies. This information should be given by the care provider and, if wished by the patient, in writing (<http://www.hulpguids.nl/wetten/wgbo-tekst.htm>).

Despite provision of information by their physician or other healthcare professionals that treat them or their child and despite access to information on the Internet, parents and patients want more and more thorough information about all aspects of disease and social implications. This study has shown that a specialised information centre anticipates in an effective way on this information need with relatively simple resources by providing additional information to parents and patients and by supporting physicians and other healthcare worker with readily available information materials for their patients. Direct feedback about identified gaps in information to these professionals contributes to improvement of information providing at that level as well. A specialised information centre is therefore a valuable and affordable asset to an academic children's hospital.

Conflict of interest The authors declare no conflicts of interest.

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