International Journal of Medical Informatics (2005) **74**, 839—849

ELSEVIER

International Journal of Medical Informatics

www.intl.elsevierhealth.com/journals/ijmi

Involving the patient: A prospective study on use, appreciation and effectiveness of an information system in head and neck cancer care

Jaap L. van den Brink[a,b,*], Peter W. Moorman[a], Maarten F. de Boer[b], Jean F.A. Pruyn[c], Carel D.A. Verwoerd[b], Jan H. van Bemmel[a]

[a] *Department of Medical Informatics, Erasmus MC, Dr. Molewaterplein 50, P.O. Box 1738, 3000 DR Rotterdam, The Netherlands*
[b] *Department of Otorhinolaryngology, Erasmus MC, Dr. Molewaterplein 40, P.O. Box 2040, 3000 CA Rotterdam, The Netherlands*
[c] *Institute for Health and Environmental Issues (IGO), Hoeksestraat 26, 4721 SP Schijf, The Netherlands*

Received 10 January 2005; accepted 22 March 2005

KEYWORDS
Computer communication networks;
Head and neck cancer;
Continuity of patient care;
Social support;
Telemedicine

Summary
Objective: To determine use, appreciation and effectiveness of an electronic health information support system in head and neck (H&N) cancer care.
Design: A prospective evaluation study. The evaluated system has four different functions: (1) *communication* amongst health care providers and between health care providers and patients, (2) *information* for health care providers and patients, (3) *contact with fellow sufferers* and (4) *monitoring* of discharged patients by means of electronic questionnaires. Evaluation of the system was done both objectively using automatically created log files and stored messages, and subjectively by using paper questionnaires from patients and general practitioners (GPs).
Setting: Department of Otorhinolaryngology and Head and Neck Surgery of a tertiary health care centre in the Netherlands. The system was put at patients' disposal for a period of 6 weeks following discharge from the hospital after surgery for H&N cancer, and was additional to standard care.
Participants: Head and neck cancer patients, hospital physicians, members of a hospital-based support team, GPs, district nurses and speech therapists.
Main outcome measures: Actual use of the system by patients and health care providers. Patients' appreciation for each of the system's four different functions. GPs' appreciation for the system. Capability to detect potential patient problems with the system.

* Corresponding author. Tel.: +31 10 408 7050; fax: +31 10 408 9447.
E-mail addresses: j.vandenbrink@erasmusmc.nl (J.L. van den Brink), p.moorman@erasmusmc.nl (P.W. Moorman), m.f.deboer@erasmusmc.nl (M.F. de Boer), igo.pruyn@wxs.nl (J.F.A. Pruyn), kroeskarper@hotmail.com (C.D.A. Verwoerd), j.h.vanbemmel@ext.eur.nl (J.H. van Bemmel).

1386-5056/$ — see front matter
doi:10.1016/j.ijmedinf.2005.03.021

Results: The system was used by 36 H&N cancer patients, 10 hospital physicians, 2 members of the support team, 8 GPs, 2 district nurses and 2 speech therapists. The total number of patient-sessions was 982: an average of 27.3 sessions per patient during the 6 weeks study period.
In total, 456 monitoring questionnaires were completed. The support team in hospital responded with 231 actions. In 16 cases, an extra appointment was made for a patient with the hospital physician. Out of these cases, immediate action was considered necessary eight times.
Patients appreciated the system highly, rating it with an average score of 8.0 on a 10-point scale. All patients used the monitoring function, and rated 'monitoring' with a mean score of 8.0 on a 10-point scale. Least used and appreciated was the 'contact with fellow sufferers' function.
Only 8 out of possible 36 GPs used the system, rating it with an average of 5.6 on a 10-point scale.
Conclusions: The electronic health information support system was used intensively and highly appreciated by H&N cancer patients. The system enabled the early detection of occurring health problems that required direct intervention. ICT can play an additional role in the management of patients, also in a relatively elderly and computer illiterate patient population.

1. Introduction

Many researchers have argued that Information and Communication Technology (ICT), in principle, is able to solve the communication and co-ordination needs of health care [1,2]. However, adequate evaluation of most ICT-projects in health care is lacking [3], and 'research goals are often limited to proving the feasibility of implementing new technology' [4]. Besides, evaluation of ICT in health care is generally considered as complex [5].

In head and neck (H&N) cancer care, many information and communication bottlenecks exist [6,7]. A well-recognised problem in multidisciplinary H&N cancer care is that as many as twenty different disciplines may be involved in the management of a patient [6]. When many care providers are involved, inter professional communication often is sub-optimal [8]. As a result, care is rarely functionally integrated [9]. Especially the period following discharge is a communication 'pitfall': the patient is transferred from a well looked after hospital bed to the home environment, where the care providers usually have little experience in H&N cancer.

Based on an analysis of the information and communication bottlenecks in H&N cancer care we designed, and subsequently built, an electronic health information support system [10].

In this paper, we report the actual use of the system. We focus on two questions. First, we assessed patient involvement by investigating the use and appreciation of the system by the patients. Second, we explored whether the system enabled the early detection of potential health problems of patients who were discharged from the hospital after surgery for H&N cancer.

2. Methods

2.1. Functional description of the electronic health information support system

Prior to the study, we developed an electronic health information support system for H&N cancer patients and their health care providers. The system was designed to:

1. facilitate *communication* between all involved health care providers and between health care providers and patients;
2. provide *information* to health care providers and patients;
3. facilitate *contact with fellow sufferers*;
4. facilitate the early detection of patient problems by means of *monitoring*.

Access to the functions 'communication' and 'monitoring' was restricted to authorised users only, whereas the functions 'information' and 'contact with fellow sufferers' were readily accessible to anyone with access to the Internet.

In this paper, only a limited description of the system's functionality is given. For an extensive description of this system, including an overview of the bottlenecks in H&N cancer care, and considerations on the protection of patient data see: [10].