Information for Patients with Cancer. Does Personalisation Make a Difference? Pilot Study Results and Randomised Trial in Progress.

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Although there are a number of groups working on the provision of personalised patient information there has been little evaluation. We have developed and piloted a method of giving patients on-line access to their own medical records with associated explanations. We are comparing, in a randomised trial, personalised with general computer based information for patients undergoing radiotherapy for cancer. We present results from the pilot study and the evaluation methods to be employed.

INTRODUCTION

The benefits of providing information to patients and patient education are widely recognised[1] and computers have been successfully used (eg [2]) as an adjunct to good doctor-patient communication. Benefits of education include reduced admissions, reduced length of stay, fewer post-operative complications, and less medication for pain[3,4]. There are now a number of computer based education systems for particular patient groups. However, educational material tailored to the knowledge, beliefs and condition of the individual patient should be more effective. Work is underway in Pittsburgh[5], Toronto[6], and Groningen[7] amongst other places to achieve this. Methods for personalising the information include: asking the patients questions at the beginning of the interaction, making use of the previous choices on the system, and making use of the medical record. However, we also need to assess the benefits of such personalisation and we describe below one current attempt to do so.

EARLIER WORK

First we describe some of our earlier work to put our current efforts into perspective. We have examined ways of using computers to give patients access to information from their medical record, on paper[8] and on-line[9-11]. In 1979 a clinical records system for diabetes clinics in Nottingham, England was set up to produce a computer-produced record summary with copies (on paper) for hospital case notes, general practitioner and patient[12]. The system is still running and nearly 10000 patient held records have been issued. The acceptability and use of the record have been investigated[13] as has the censoring by doctors of the 'problem lists' which appear on the patients' copies[8]. No attempt was made to explain or convert the terminology in the record for the patient and 14% of patients said that they did not understand something on the record[13]. Others have also shown that patients may not understand the medical terminology used in their records[14]. It is clear therefore that we should aim to help patients understand their records and could use this as the basis for patient education.

In a subsequent study, patients in a shared-care scheme for hypertension were given a booklet which included 'lay translations' of their problem lists[13] Others have given patients personalised information on paper. Osman et al produced personalised booklets for patients with asthma by manipulating data from the Patient Record System of Grampian Health Board[3]. Booklets were prepared using spreadsheet and mailmerge software. Jimison et al also used the medical record as the basis of their patient-specific explanations in chronic disease[15]. However, on-line access offers the opportunity to expand these explanations, to link them more fully to educational material and to monitor patient choices.

We had previously shown the feasibility and acceptability of giving patients on-line access to their medical records in general practice[9], in an outpatient clinic for hypertension[10] and for patients with diabetes[11]. In the first study[9], 70 patients in a general practice were offered a menu which included medical history, medicines, smoking, drinking, clinical examination, general health information, and information about the health centre. Sixty-five patients used the system which had a simplified keyboard The sections on medical history (52/65) and medicines were the most popular (28/65). More than 1 in 4 of the medical problems were not understood by the patient until a further explanation had been seen. One in four also queried items or thought that something was incorrect. Most patients enjoyed the opportunity to see their own record and talk to the researcher and 84% said they would use the facility again although 61% thought they obtained enough information from their GP.

In this study the on-line records were developed from uncoded manual general practice records. However, if we are to do this on a routine basis we need to be able to link the health education material to the clinical record rather than 'build' individual records. The UK is now adopting the Read Codes for use throughout the NHS. Read codes include a

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number of synonyms and a 'preferred term'. In our second study[10] we examined patients' understanding of the Read preferred term, a 30 or 60 character 'lay translation', and further screens of explanation. Twelve patients at a hypertension outpatient clinic were given the opportunity to look at their problem list (with explanations) or general health information (Healthpoint[16]). All 12 looked at one or more of their (Read coded) problems and spent between 11 and 24 minutes (mean 16) using the touch screen computer. Nine out of 12 looked at all their problems, and 11 out of 12 also accessed Healthpoint. No one felt that using the computer made them more anxious or worried, and if it were routinely available 10 would probably or definitely use it. The 12 patients had a total of 47 problems of which 17 were 'censored'. Patients looked at 23 out of the 30 available: nine because the Read code was not understood and 14 just because they wanted more information.

Longer term, it is obvious that we can not 'handcraft' explanations. In our third study in diabetes[11] we started to use text generation techniques and a knowledge-base making use of Read codes. There are obviously a number of issues which need to be addressed to make further progress. Will we be able to interface to clinical record systems and will they, in the future, be able to provide a fairly standard record ? Will there be knowledge-bases available to use in producing explanations? Carenini et al in Pittsburgh made use of the UMLS to construct their explanations[5]. A lay axis to the Read codes may have helped our approach[10] but we will probably be using Galen[17] in the main cancer study described below.

Having demonstrated the feasibility of on-line access for patients and having found a suitable technique for developing personalised information provision we were able to address the question 'Is personalisation worthwhile?' Because of public health priorities in the west of Scotland we have attempted to answer this in the context of radical treatment for cancer.

PILOT STUDY

Location. The Beatson Oncology Centre (BOC), provides specialised non-surgical treatment for cancer, for patients throughout the West of Scotland. After Manchester, it is the second largest cancer centre in the UK, with approximately 6,300 new patients referred for treatment each year. It is the only cancer centre to incorporate three academic departments of medical, radiation and palliative oncology.

Aims. The aim of the pilot study was to develop a prototype system applicable to cancer, to test the feasibility and general acceptability of the personalised system and to test the data collection procedures proposed for the main study.

System. The system uses a hypertext style interface: patients initially can choose between problems, medications, treatments and investigations by touching the screen. Patients can continue to touch on items entering a hypertext network of short texts (perhaps with additional pictures). A given text might contain both general information, and information specific to the patient. For example, one screen starts 'Malignant tumour of the breast is another term for breast cancer. According to your record, you have this problem. Your breast cancer was recorded as being an invasive ductal carcinoma grade 2 of the left breast.' where the underlined words appeared in a different colour on the screen and provided hypertext links to further information. We decided to use the more 'technical' term as the starting point for the explanation as this was the term which would normally be used by the clinician.

Patient Numbers. We originally identifed 35 patients as eligible for the pilot study. Eleven of these were excluded as not meeting the criteria for the study and five refused to join the study. Of the remaining nineteen, four patients did not have the opportunity to use the computer in the timeframe of the pilot study and 15 patients saw their 'explained' record on computer. These comprised 11 breast cancer patients, 3 prostate and 1 cervical cancer patients. Reasons for exclusion included: being too ill or depressed, the wrong type of cancer, receiving palliative treatment, having radiotherapy changed to chemotherapy, having treatment moved to another hospital, being 'missed' on the recruitment day and then (due to the short period of study) having insufficient time to contact. The reasons for refusal were time and family commitments (2 people), 1 patient who was newly diagnosed and felt unable 'to cope with anything else' and 2 people who gave no reason. Therefore, we had a fairly high 'attrition' in recruiting patients to the study. We think that this should be reduced slightly in the main study but have nevertheless been able to plan for such attrition.

Acceptability. The patients who used the system were aged between 37 and 74 and all found the touch screen easy to use. Six out of 15 had used a computer before. None of the patients who saw their medical record on screen appeared to be distressed by the experience although the researcher noted that 'external' pressures (such as whether they were accompanied by a relative or friend who was eager to get home or if there was transport waiting) was a major influence on the level of interest they showed in the system. Interest shown in accessing information also appeared to correlate with other measures of whether the patient was an 'information seeker' (although numbers were too small in the pilot to confirm this).

Workloads. One aspect of feasibility that concerned us was the workloads which would be generated in the main study. In particular as we are having to extract information from manual records we needed an estimate of this aspect of the work. We estimate that after the first 10-20 patients the time taken to enter patient data from the medical record (once the record has been located) will take on average between sixty and ninety minutes. Note that we are trying to summarise the whole hospital case record and not just the oncology section and some of these case records are of poor quality.

Data Collection Procedures. A number of small changes were made to questionnaires, interviews and other data collection forms but essentially all these appeared practical and acceptable. We hypothesise that giving information to patients undergoing radiotherapy for cancer should reduce anxiety although there is a possibility that it may also increase anxiety. One of our outcome measures for the main study is the Hospital Anxiety and Depression Scale[18] (HADS) which had been queried in our application. For some patients we completed both a HADS and a Zuckerman Affect Adjective Checklist[19]. Together with the researcher's subjective assessments this showed that HADS seemed to have validity in these circumstances. Another recently published study[20] whicb examined the effect on patient's anxiety of providing information successfully used HADS.

Access to the computer. One thing which became clear in this pilot study is that patients were unlikely to make further use of the computer if it is only available in the room used by the researcher. We will therefore have a further (password controlled) computer available in a more public place (a waiting area) but 'screened' to give some degree of privacy.

MAIN STUDY

Having shown the feasibility and acceptability of the personalised system and the proposed data collection procedures etc we have now been awarded funding to carry out a randomised trial. We describe the study proposal here to promote comments and discussion of how such systems should be evaluated. The study will start on June 3rd 1996 and we will be able to report on progress at the conference.

Aims. The aims are to investigate in a randomised trial, the difference between presenting information 'personalised' using the medical record ('medical records group') and more general information ('general information group'), and using standard preprinted leaflets ('leaflets group'). A fourth group which will have access to both 'personalised' information and general information on computer ('combined group') will be used to assess patient preference between the two types of information.

Objectives

* To determine the feasibility of giving large numbers of patients with cervical, breast, prostate cancer or cancer of the head and neck undergoing radiotherapy treatment, on-line access to computers at the BOC.

* To estimate workloads and cost of maintaining the different systems in routine practice compared to the use of leaflets.

* To examine differences in the doctors assessment of (i) active/passive role adopted by patients (ii) their knowledge of their condition and (iii) their anxiety at the 'post-intervention' consultation, between groups.

* To examine differences in the use made of the printed material, and differences in satisfaction with information between groups and between information seekers and non information seekers.

* To estimate the demand to use such systems by patients, the time they spend using them and the information sought. For the 'combined' group, to examine preferences between using the 'personalised' system and 'general' system.

* To measure, using HADS, the 'levels of anxiety and depression' before and after the intervention, to examine differences between intervention groups, between information seekers and non-seekers and between breast cancer and the other cancers.

* To investigate the use made of printed materials by patients at home.

* To investigate differences in use of and attitudes towards computer systems between those who used other technologies and those who did not, by newspaper read, by deprivation category, age and gender, cancer type (breast vs other), and anxiety and depression scores.

Study design. Patients in the study population will be randomly allocated to one of four intervention groups. Three of the groups will be asked to carry out a 'computer consultation' at the beginning of their course of radiotherapy. Patients will be offered the opportunity to use the computer again after this first use. Two computers will be available for use by patients, one in the 'researchers' office'and a second, more 'public' computer, sited in a waiting area with suitable shields and the use of a password to provide privacy and security. The three treatment groups will differ in the computer system used. The fourth 'control' group will have a specific opportunity to obtain appropriate pre-printed leaflets.

'Medical records group'. Will use the previously piloted system that generates explanations tailored to the individual based on the medical record. One of the features of this system will be the production of a summary of the 'dialogue' between patient and computer. This will be sent to the patient at home shortly after.
'General information group'. Will use a 'general' system, with similar 'look and feel' to the personalised system, which contains information about the cancer chosen but not based on the patient's own medical record. Printed copies of computer-patient dialogues will also be produced for this group.
'Combination group'. Will be able to use both medical records or general information system.
'Leaflets group'. Although all patients at BOC have access to a leaflet rack, these patients will be given a specific opportunity to browse and choose leaflets from a 'cabinet' of all the appropriate leaflets.

Patient population and sample size. A total sample size of 900 (150 in the 'personalised group', 150 in the 'combination group', 300 in the 'general information group' and 300 in the leaflets group) will allow us to differentiate at the 95% level, for example, between 20% and 10% of patients assessed as becoming more active in the consultation between personalised and general information groups. It would also allow differentiation between 90% and 83% satisfied with the information given between all computer groups and the leaflet group.

Recruitment. We will approach 25 new patients with cervical, prostate or cancer of the head and neck and every other (systematic sample) patient referred with breast cancer per week with the aim of recruiting a minimum of 15, who then have an interaction with the computer and the post-intervention interview. Recruitment should be achieved in 16 months between July 1996 and October 1997. Patients excluded will be those: receiving palliative treatment, no knowledge of their diagnosis, visual or mental handicap, severe pain or symptoms causing distress, only a single treatment planned, no follow-up planned after treatment, those not giving informed consent, medical or nursing students or staff.

Data Collection

Recruitment interview. The initial patient interview will assess what information patients have already been given, from what source they received it, and what information they would like. Patients will also be asked to complete HADS at this interview, and a further questionnaire ('first home questionnaire', covering demographic details, type of newspaper read and computer use, and information provision) at home after their recruitment interview.
Intervention: use of the computer. The time spent using the computer and the type and number of choices made by the patients using the two systems will be recorded. For those in the combined group, the time spent using the personalised and the general system, and the order in which they were accessed will be recorded. Patients will be able to use either the computer in the researcher's office by arrangement with the researcher or the more public access computer. Patients in the three computer groups, will have a short interview after using the computer about the acceptability of the system.
Intervention: use of leaflets. The 'leaflets' group will choose from a dedicated supply of leaflets. Choices will be recorded.
Researcher assessment. Observations on patient's attitude, anxiety, enthusiasm for the project and whether they had 'external pressures' at recruitment, intervention and post intervention consultation will be recorded. The researcher will assess the patient as information seeker or not, passive or active.
Second home questionnaire. This asks about the utility and relevance of the information.
Post intervention consultation. Patients will be met by the researcher before seeing the doctor at the first consultation after the intervention. The second home questionnaire will be collected and a second HADS completed. The patient will have a 'prompt sheet' to give to the doctor which lists topics they would like to discuss. The consultant will complete a questionnaire on their perceptions of the patient.
Follow-up postal survey. A follow-up questionnaire will be sent to all patients three months after recruitment. This will ask about satisfaction with information provision throughout their treatment and in particular their intervention and their use of the printed material with family and friends.
Costs. Current time costs in developing and maintaining both personalised and general

information systems will be recorded, various future scenarios modelled and compared with the costs of providing leaflets.

LIMITATIONS OF OUR STUDY.

Medical records do not necessarily tell you what type of information the patient wants. De Rosis et al have produced a system which generates different printed explanations of drugs for patients, GPs and nurses[21]. Moore et al in Pittsburgh have developed a system for migraine which collects data from the patient and employs a user model to provide personalised education.[22]. The best approach may be to combine the use of the medical record with a 'user model' indicating the type of information that the patient wants. In this study we will not be addressing this, but aim to do so in other parallel studies[23].

ACKNOWLEDGEMENTS

Janne Pearson was funded by a grant from the Scottish Office.Health Service Research Committee.

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