

Patients' thoughts on patient-retained medical records

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ABSTRACT

Background: Patient-retained cards and, later, patient-retained booklets were introduced in an effort to improve continuity of care in a primary care setting at Tzaneen Clinic in the Greater Tzaneen Municipality of Limpopo Province, South Africa. Previously, the only continuity was maintained through a clinic-retained patient register, referral letters or information the patients provided themselves. The Patient-Retained Booklet of Lesotho provided motivation for this project.

Methods: A qualitative study was conducted using focus group discussions to explore the patients' thoughts on retaining their own records. In the transcribed interviews, themes were identified through the cut-and-paste method and the results were interpreted and compared with currently available literature.

Results: The participants thought patient-retained records were helpful. They felt that the records function as 'medical identification' and could be used in the case of an emergency, that they provide important background information about the patient, and that they enable continuation of care at other facilities. Retaining the documents was also thought to motivate the patients to act on the advice given, and the records also served as a reminder to take their medication and about the dates of follow-up visits. It also was thought to personify the clinician-patient relationship.

Conclusion: The process of exploring patients' perceptions can be empowering. The patient-retained records gave the patients an opportunity to participate in their own health. It is a simple tool to improve quality in primary care by improving continuity of care and providing a helpful tool for future behavioural change.

The recommendations that arose from this study are that the use of the patient-retained medical health record booklet should be continued and its use should be encouraged throughout the district; staff should be motivated to use it and to standardise the information that is recorded; and health planners should be motivated to implement **(SA Fam Pract 2004;46(7): 30-33)**

Introduction

Record keeping has traditionally been the responsibility of the health authority and patients have generally been excluded from this process. The result is poorly informed patients who lack an interest in their own medical care. With the changing face of medical care and the fact that it is becoming difficult and sometimes impractical to obtain continuity in care by an individual caregiver, emphasis has been placed on the

continuity of medical records and health care teams.^{1,2,3} Child and maternal care patient-retained cards have been used in the primary health context in South Africa for some time, whilst patient-retained health booklets are used for all patients in some countries.⁴

The health booklet used in Lesotho merits special mention, as South Africa shares a similar health context.⁴ This particular patient-held booklet has been used successfully

for more than 20 years. The satisfaction of patients, nurse clinicians and doctors with the health booklet was measured in a study, which found that 89% of patients preferred to keep their own health book and perceived it as belonging to them. Seventy percent of nurse clinicians and 79% of doctors rated it better than facility-retained records.⁵ The booklet was also found to be practical, durable and of a convenient size.⁴ Its availability led to fewer repetitions

of tests, a reduction in the number of errors, and a saving in time and money. The booklets were thought to increase patient responsibility and create health education opportunities. It is believed that retention of the booklet increased ownership, restored the patient's dignity and created a sense of partnership between the health personnel and the patient. Confidentiality was not found to be overly problematic. One third of patients were worried about the possibility of unauthorised reading, but it was interesting to note that a quarter were also worried about this possibility in the case of facility-held records.

In an assessment of the Road-to-Health card (a child health card retained by parents and used in South Africa since 1971), it was found that 80% of professional nurses supported the concept of parent-retained cards.⁶ The majority recommended that a notebook should replace the baby's personal health record.

The benefits of good record keeping are clearly stated by McWhinney in the Textbook of Family Medicine.⁷ Records should provide readily accessible data about the patient's demographics, illnesses, progress, treatments and prevention strategies. Stott suggests that space for a summary problem list and continuation notes should be available as a basic requirement of a record system.⁹ He also highlights that the availability of medical records at home may improve communication about illness within the patient's family.

The interest of the authors in patient-retained medical records grew from a deep frustration experienced when unable to continue patient care because records of previous consultations were unavailable. A patient-retained record system was therefore introduced in the primary health care clinic for chronically ill patients, as continuity of care is a vital component of successful care. The clinic is situated within the Greater Tzaneen Municipality in the Limpopo

Province of South Africa. Primary care nurses treat most of the minor and acute illnesses, whilst patients with chronic or recurrent health problems are referred to the clinic doctor. Difficulties are experienced when new patients arrive or when they are referred from other health facilities without referral letters. Because there is no knowledge of their diagnoses or medication, there is no way of obtaining this information. The clinic does not have an individual patient record system – only an attendance register is kept where the nurse practitioners or doctor records information. The clinic has no administrative personnel or computers.

Initially, patient cards that they had to retain were given to the patients, but this proved inadequate for patients with chronic illnesses due to the volume of information. A booklet was then introduced which was given free of charge to chronically ill patients. This system was cheap, easily obtainable, the booklet was of a convenient size (14 x 8 cm A6) to carry in a pocket or handbag, and had \pm 10 lined pages.

The patient's name, age, address, problem list and any known allergies are recorded on the first page. During follow-up visits, blood pressure, blood glucose, body mass index, peak expiratory flow rates, etc. are recorded. Risk factors, if any, are checked and recorded, as well as the prescribed treatment and follow-up dates. If lifestyle changes are prescribed, these are recorded in the book in the hope that it will serve as a reminder to the patient. Relevant contextual information is noted briefly, in such a way as not to cause embarrassment if read by others.

Blood pressure, blood glucose, weight, etc. are noted on subsequent visits and compared with previous recordings in order to ascertain progress and to serve as motivation for patients to comply with prescriptions. Patients are encouraged to present the booklet when they visit other health facilities.

It was noted that some patients protected their booklets with covers, while others replaced them if they were lost. From this it was deduced that the patients appreciated keeping their own medical records. It was then decided to evaluate the booklet by asking the patients for their thoughts on it, as it was felt that, if the information gained could be used to adapt the booklet to suit their needs, this would further enhance their ownership of it.

Method

The aim of the study was to understand the patients' thoughts on retaining their own records. A qualitative methodology was deemed appropriate.⁸ A focus group technique was used for data collection. All chronically ill patients who attended the clinic over a two-month period and who were willing were requested to complete a questionnaire. From the information requested in the questionnaires, the following criteria were used to select participants for the focus group interviews:

- All patients with a chronic illness
- Patients who had patient-retained records
- Patients who attend the clinic regularly
- Patients who were willing to participate in the study

Twenty-four patients were selected and invited to the focus group interview. The interviews were conducted in Sepedi, as the majority of the participants spoke Sepedi. Two focus groups were conducted. The first group had 11 participants and the second had 10 participants.

Focus group interviews were conducted in the Sepedi vernacular by a trained moderator (NM). The focus group interviews were recorded by audio and videotape. The exploratory question was: "I would like to know your thoughts about the booklet you were given?". This question was tested beforehand in the vernacular. Field notes were made after the interviews.

Analysis

A research assistant transcribed the focus group interviews verbatim. The moderator who conducted the focus group interviews reviewed the transcripts and translations. Her comments were included in the transcripts. The analysis was performed on the translated, English version of the transcribed interviews. Concepts were identified manually with the cut-and-paste method and grouped into common themes. The themes identified were compared with those identified by the co-researcher (GM), who identified the themes with the cut-and-paste method on the computer. The themes from the two interviews were then combined and interpreted.

To enhance validity, the focus group interviews were conducted in the vernacular. The moderator was experienced and fluent in Sepedi, and a Sepedi speaking assistant translated the interviews. The themes were identified independently by two researchers and compared later (investigator triangulation). The results of the study were later verified with four focus group participants individually at their follow-up visit. The focus group moderator also verified the results.

Ethical considerations

Only those patients willing to participate and who gave written consent were included in the focus groups. Before audio and video recording the interviews, the purpose of the interviews was explained to all participants, including the fact they would remain anonymous (no names were included in the transcribed interviews). Approval for this research was obtained from the Limpopo Provincial Department of Health and the Medunsa Research, Ethics and Publications Committee.

Results of the study

The results are presented in Table 1, which includes the combined list

Table 1: Combined list of themes identified and quotations supporting them

Patient- retained records were perceived as helpful	
Most participants expressed the view that they found the booklets helpful	<p>"The booklet I received from the clinic, I believe it is very important because it helped me through my problems. It is always in my bag. I carry it wherever I go."</p> <p>"The booklet works wonderfully for me."</p>
The booklet personifies the doctor and the medical care given	
The booklet helps with follow-up and adjustment of treatment	"She (doctor) changed the tablets and prescribed the new one for me. That's when I got the book. It helped me."
The booklet is associated with continuity of care	"I was sent to hospital I couldn't recognise anyone but I was able to recognise her because she is my doctor, she is the doctor I know and see every time at the clinic."
The booklet represents the image of the doctor between visits	
The booklet reminds of improvement and progress	"It tells you how you performed. It helps me."
The booklet motivates, reminds of advice given and serves as a behaviour modification tool	"After abiding by the booklet's rules I weighed 110kg (lost weight). It encourages me and every time when I carry it I feel as if my blood pressure has decreased. When I feel like eating fatty food I just look at the book and stop eating them. It helps me."
Compliance: The booklet encourages the patients to take medication regularly and reminds them of appointments	<p>"This booklet helps me because I once came here and they told me I have high blood pressure, I was given tablets. Now I'm still taking tablets."</p> <p>"It is my responsibility to abide by the rules."</p>
The booklet connects the patient and his/her illness with others	
<p>The booklet serves as a 'health identification document':</p> <ul style="list-style-type: none"> Identifies you in an accident Identifies risk factors: allergies Identifies medical condition Identifies treatment 	<p>"This booklet is very important and it helps a lot. If you are involved in an accident, people who help you are able to know what kind of person are you, the diseases you are suffering from."</p> <p>"It is always in my bag. I carry it (booklet) wherever I go just in case I'm involved in an accident, because in it there is everything. If I'm allergic to a certain injection people will see in this booklet. My booklet explains everything."</p>
Identification at other medical facilities: Promoting continuation of care	"Even if I'm far from home and I have finished my tablets this booklet is my identity document. I can go to any hospital with this booklet and get tablets. I say thanks to the booklet."
The booklet reminds the patient's family about the patient's management	"I got my booklet and I always carry it. My son used to read the booklet for me and reminds others at home."
A misconception was that the booklet was needed to get free medical care at the clinic	"I even consult free with this booklet I get free medication."

of themes and the quotations supporting them:

Discussion

In rural, disadvantaged communities, where it is often difficult to obtain information or contact informants, the use of retained patient booklets may well be a simple way of ensuring the availability of information. This echoes the high degree of satisfaction expressed by all users of the

patient-retained medical records used in Lesotho. This study found and reported explicitly that the owners of the record appreciated availability of information.⁴ According to the study of the Road-to-Health card, mothers feel that the card is important, but they prefer a health book ("baby's own type") with more health information.⁶ Colleagues have informed this author that patients at other clinics in the district have

brought their own booklets to the clinic for record keeping. This has been a spontaneous response to a need felt in the community.

It was encouraging to learn that the participants felt the patient-retained records had a positive effect on their behaviour. It was hoped that recording the advice given might serve as a reminder to the patients to adjust their lifestyle.³ This was also demonstrated by the evaluation of a patient-managed booklet for prevention in Sweden.⁹ It seems probable that participants' perceived self-efficacy increased by performance attainment when they saw their improved weight, blood glucose or blood pressure recorded in their records.¹⁰ It is also important for patients to feel that the record belongs to them. The trust implied by making patients responsible for their own records can be empowering and enabling.^{4,11}

Limitations of the study

It is important to remember that this study represents those who were actively using their booklets or cards and is not representative of all people who received booklets or cards at the clinic (respondents were selected from the patients who came regularly). This implies that the people who participated were those who already were compliant and positive about the patient-retained records. Bias may have been introduced through the selection process, as those who were willing to participate may already have been positive about the records. Transcribing from one language to another also may have introduced bias. In this part of the world it is considered culturally correct to answer in a pleasing way. The participants may have omitted the negative aspects of the booklets because of their cultural values.

Conclusion

The general view of the participants was that this easily obtainable, off-

the-shelf, inexpensive booklet improved care for chronically ill patients at this specific clinic. This may well be a simple, effective method to overcome barriers to medical record keeping in a rural and poorly resourced primary care area. In an age in which the emphasis is on quality, this can be a step forward in attaining continuity and quality in primary health care. It is recommended that the booklet as it is presently used at the clinic where the research was conducted also be used elsewhere, especially in the remainder of the district. As the booklets are inexpensive and easily obtainable, patients should be motivated to buy their own booklets. It is further recommended that the appearance of the booklets be standardised to make them easily identifiable and recognisable in the case of a medical emergency. Information on healthy lifestyles should be included so that it may be utilised as a tool for behavioural change. Health planners are urged to implement patient-retained records in booklet form nationally. Figure 1 provides an example of the booklet that is currently used.✚

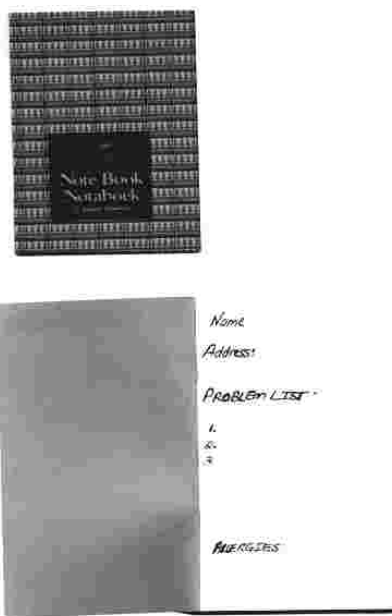


Figure 1: The patient-retained health care booklet

Competing interests

None declared.

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