

Review Article

Patient held medical record: solution to fragmented health care in Sri Lanka

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Abstract

Sri Lanka has an extensive network of health care institutions, but there is no registered population for any particular health care institution. Patients are free to select which doctor to consult and which hospital to get admitted. Also there is no established referral and back referral system in practice. This free movement of patients within and between the primary, secondary and tertiary levels of care by patient's choice has given rise to a situation where each episode of an illness or disease process is managed by different doctors in differing specialties.

As in most care settings, the patient's medical or health record is held by the health service or doctor that is providing care to the patient for a specific ailment. This leads to a gap in communication between multiple caregivers leading to poor co-ordination of care. These difficulties faced and lessons learnt suggest the use of a medical record that is kept with the patient.

Patient Held Medical Records (PHMR) are formal and structured records that are given to patients to enable the continuity and quality of care which he takes with him when he goes for medical consultations. PHMRs aim to improve communication between patients and the multiple clinicians and health care workers who are involved in patient management.

The PHMR we propose comprises of a folder, clinical notes, problem list, flow sheet and other optional items. The PHMR can be used as a tool to empower and educate the patients. It will improve transparency and trust and facilitate continuity of care. Increased work load, cost, restriction of freedom in writing notes, confidentiality and retention of records by patients are the disadvantages which need consideration.

Introduction

The health system in Sri Lanka is enriched by a mix of Western, Ayurvedic, Unani and several other systems of medicine that co-exists. Of these systems 'western medicine' is the allopathic system which has become dominant and is catering majority of health needs of the people. Ayurvedic treatment comprise of traditional medical practices from North India, whilst Unani treatment is mainly traditional Graeco-Arabic teachings and is followed mainly by the muslim population.

Similar to most countries in the world, the Sri Lankan health system too consists of health services offered by both the state and the private sector.¹ Also, Sri Lanka has an extensive network of health care institutions, but there is no system for registering a patient population to any health care provider. Therefore, patients are free to select which doctor to consult and where to get admitted.

Also there is no established referral and back referral system in practice. This results in pa-

tients accumulating in secondary and tertiary care centres. Therefore, these centres have to cater to a relatively larger number of patients, who could have been amply managed at a primary care unit.

This free movement of patients within and between the primary, secondary and tertiary levels of care by patient's choice has given rise to a situation where each episode of an illness or disease process is managed by different doctors in different specialties.

Another frequently encountered scenario with Sri Lankan patients is that they are seen in one specialist clinic for the diabetes mellitus and another specialist clinic for arthritis. In occasions when they suddenly visit the general practitioner with gastroenteritis, the patient has no medical records with him and is not aware of the medication he is on creating a management dilemma to the attending doctor.

As in most health care settings, the patient's medical or health record is held by the health service or doctor that is providing care to the

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patient for a specific ailment. This leads to a gap in communication between multiple care givers leading to poor coordination of care. The ultimate result being that the patient does not receive best services that is available and due to him.²

These difficulties faced and lessons learnt demonstrate the need for a medical record that is kept with the patient.

What is a Patient Held Medical Record (PHMR)?

PHMR are formal and structured records that are given to patients to enable the continuity and quality of care which he takes with him when he goes for medical consultations.² PHMRs aim to improve communication between patients, multiple clinicians and health care workers who are involved in patient management.

Example 1: Child health and development record (CHDR) which is issued to all newborns in Sri Lanka contains details such as growth parameters, mile stones, immunization schedule, infant feeding instructions.

Example 2: The obstetric record that is maintained by the health care team involved in the care of the pregnant mothers. This record also has important details such as parity, risk factors of the pregnancy, serial fundal height measurements, investigation results and also items of information that might be necessary in case of emergencies such as blood group.

Our experiences with PHMR are limited to the above examples. These two groups are considered to be vulnerable groups in society needing special attention and care. Use of these medical records has helped to advance maternal and child health care sectors in Sri Lanka. Therefore, the government actively promotes use of these special types of medical records, that are kept with the patients.

Another example from the Sri Lankan setting is the basic medical record maintained on an exercise book by many medical/surgical clinics in the country. This is kept with the patient and has information that would be helpful to another doctor who sees the patient. But aspects such as patient education, involvement of the patient in the management are not addressed.

Much research, surveys and reviews have been conducted all over the world regarding the advantages and disadvantages of PHMR. There is no published data available regarding a similar study in a Sri Lankan setting. In view of the available data, there are conflicting opinions on the effectiveness of PHMR.³

Experiences

Patients today demand more information and transparency from their doctors. Studies have shown that patients are highly motivated to be more informed about their own health.⁴

A study from Australia showed that patients receiving PHMR improved their knowledge of health promotion and were more aware and therefore, more likely to change their lifestyle.⁵ In the setting of caring for a patient with cancer, the

PHMR was found to have a positive impact by helping the patients to feel more in control.⁶ Experiences in UK have shown that PHMR facilitate communication between doctor and patient.⁷ It also gives patients an opportunity to audit the quality of data.⁴ There is a variable degree of patient retention and utilisation of PHMR seen in different settings.^{2,8} Patients have been found to be highly satisfied with the enhanced continuity of information afforded by using a PHMR.⁹ In an Australian assessment of a PHMR system, non English speaking participants have stated the importance of including a section in their preferred language.¹⁰

Experiences with the PHMR in other countries have been taken into account in developing the proposed format for a PHMR given below.

Proposed format for PHMR

Features of an ideal PHMR format for the Sri Lankan setting

1. Comprehensive and concise structured format facilitating easy recording and retrieval of health information.
2. Be acceptable and user friendly to all doctors in different disciplines.
3. Facilitate involvement of multiple care givers in patient management.
4. Empower patient by providing relevant health information (education).
5. Avoid duplication of work when possible. The currently available CHDR can be used as a supplement to the PHMR therefore, introducing immunization schedule, weight charts etc. to the PHMR should be avoided.
6. Facilitate simultaneous use of clinic based medical records for physicians who intend to do so.
7. Affordable; in the absence of provisions from the state cost should be bearable to the patient.

Components of the PHMR

Folder

The folder provide housing to all the components of the PHMR. To withstand the wear and tear, the folder should be made of a durable material (Figure 1). The front cover will contain contact details of the patient and clinical registration number. The back cover contains explanatory notes signifying the importance of PHMR (Figure 2a & 2b).

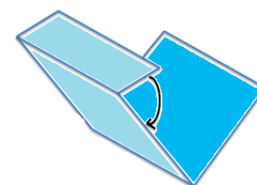


Figure 1: Folder of the proposed CHDR

Figure 2a: Outer view of the proposed PHMR

Figure 2b: Inner view of the proposed PHMR

Clinical notes

This section of PHMR is designed (Figure 3) to document information related to a single encounter with a patient. Each encounter should be recorded on a new leaf. If the physician intends to maintain an office copy (clinical based medical record - CBMR), a carbon copy can be made without duplicating the work.

Diagnosis is coupled with the problem definition to cater primary care physicians dealing with the undifferentiated ill-

nesses making “difficult to make a diagnosis” formally acceptable.

Within the context of PHMR, plan of management is divided into two components that are a) medication and b) instructions to patients. Medication section is meant to provide space to document the pharmacological management (Figure 4) while instructions to patients will contain the non-pharmacological management of the illness.

Any action to be carried out in the next visit should be documented in the section; plan for next visit. Such items of information may include a) date for the follow up visit and b) the next step in the management for example, increase the dose of a particular drug (if blood pressure not controlled), referral if poor response.

This section helps in the coordination of care by functioning as a tool for communication between the current care provider and the next. This would be very helpful in settings such as a group practice and in a culture where frequent change in doctors is a norm. It will also remind patient of the next clinic visit and indicate what to expect at the next consultation.

The last three sections (instructions in taking medications, information to patient and plan for next visit) are of paramount importance to the patient giving essential bits of information enabling them to take an active role in managing their condition. Therefore, it is important that any entries in these sections are legible and written without using medical jargon in a language understandable to the patient.

Problem list

This gives a summary of the patient’s problems (Table 1). Each consultation can be summarized in a single row. The problem could be an illness, disease, fear, concern or the reason for the encounter. How the problem was solved can be documented as the comment. Since the problem list gives a well updated summary, older clinical notes can be removed from the folder from time to time to reduce the bulk.

Flow sheet

Chronic diseases need regular follow up and monitoring. It is

Figure 3: Clinical notes section of the proposed PHMR

Table 1: Problem list of the proposed PHMR

Date	Problem	Comments
02/04/2011	Exacerbation of asthma	Commented on low dose inhaled steroids
04/05/2011	Fear of developing breast cancer	Reading material on breast cancer and self breast examination

a very tedious task for a busy physician to go through each page of the patient's record to retrieve information regarding control of a chronic disease, screening of complications, compliance and pharmacological management and could lead to an unsatisfactory standard of care.

A flow sheet is a table that summarize activities of each consultation. The left most column gives the list of items carried out during each consultation (history, examination, prescription, etc.). It can be designed to match the requirements of the disease (Table 2) as well as the physician. Given below is a list of items to be included in a flow sheet. This reminds doctor the different aspects of disease management.

1. Parameters which determine control of the illness
2. Other risk factors that should be monitored
3. Screening for complications

4. Patient compliance regarding medication and lifestyle modifications

5. Pharmacological management

Medications prescribed and how those have been altered can be seen from the sheet. Any adverse effects can be noted down. Abbreviations can be used to indicate compliance (S- satisfactory, NS- not satisfactory). Blank rows will allow any additional information to be included (Table 2).

This provides comprehensive information regarding several years of follow up of patient's long term diseases to be available at a glance. It reduces cost, improves overall management of the patient and is a valuable source for documentation for audits and research.

Optional items

These are mainly for patients with chronic diseases.

Instructions for emergencies

These are detailed instructions for patients to be followed in an emergency. These should be designed to address common emergencies occurring in the disease of interest. For example, instructions to a diabetic patient on managing an episode of hypoglycemia.

Table 2: Flow sheet of the proposed PHMR

Parameter	08/01/2011	25/01/2011	23/02/2011	24/03/2011	25/04/2011	26/05/2011	... so on
FBS - mg/dL	224	120	115	112	120	110	
BP - mmHg	160/100	140/90	130/80	130/90	120/90	120/80	
BMI - kg/m ²	22						
Total Cholesterol - mg/dL		202					
LDL - mg/dL		103					
HBA1C - %				6.5			
IHD	No						
PVD	No						
Neuropathy	No						
Retinopathy	No						
Nephropathy - micro albumin				No			
Compliance medication		S					
Diet		NS	S	S			
Exercise		NS	NS	NS	S		
Foot care		NS	NS	S			
Smoking		Y			No		
Alcohol		Y					
Metformin	500mg tds	√	√	√	√	√	
Enalapril	5mg bd	√	√	Cough			
Lorsatan	50mg no			√	50mg bd	√	

Where Y: present, No: absent, S: satisfactory, NS: not satisfactory, √: continue

Regular or annual review checklist

This too should be designed to suit the chronic disease of a particular patient. Given below (Table 3) is an example of a review checklist for diabetes mellitus. In addition to the date the next service, procedure or test is scheduled for, the targets too are mentioned. This will help patients to self evaluate their disease control and further strengthen the lifestyle measures as necessary.

Education checklist

Having a check list for topics to be discussed during health education sessions will ensure that all patients receive an input on all the listed topics (Table 4). Patient can identify if any session has been missed by the health care provider. Documenting health education sessions will also discourage patients from denying awareness on already discussed topics, thereby minimizing chances of disregard of medical advice. Each topic should be re-discussed from time to time to refresh the memory and improve compliance.

Space for patient's own notes

Free text pages can be made available for the patient or care taker to note important symptoms or events and questions to ask the nurse or doctor during their next consultation.

Discussion

Retention of records

A problem with patient retention of records is often cited as a disadvantage of this record system. This could be a simple case of "Oops! I forgot to bring the record with me today". This can be addressed as follows:

1. If the record is in loose leaf format and the patient forgets to bring the record, the notes can be placed within the record later.
2. If it is not in loose leaf, today's consultation can be done on a separate sheet of paper and then taped to the original medical record later on.

Another problem that can occur is misplacing the PHMR. This would result in the patient not having any records with him about his previous medication. This is the main drawback of having only a PHMR. It is more common to find that most patients with chronic diseases do retain their medical records, but those who visit a doctor infrequently seeking treatment for acute illnesses fail to maintain records.

Impact on patient education and empowerment

One of the most important functions of the PHMR is education of patients on aspects of health care and health promotion relevant to them. Therefore, health education messages are incorporated into the record.

Transparency

The PHMR allows for increased access to information for patients and therefore, leads to improved transparency and trust. Increased trust in the doctor patient relationship had been shown to improve compliance.

Some doctors may be less compliant with the PHMR system due to fears regarding scrutiny of their management of a patient and this could prove to be a formidable barrier to their acceptance of this system. However, this also indicates that the PHMR could be an important tool to increase accountability of health professionals.

Forging entries

When the patient holds on to his record, he has the ability to add entries or notes in to the existing documentation. But this can be recognized by the difference in the handwriting and the disarray in the new entry that has been squeezed in.

Also the healthcare provider can have his own 'clinical note' sheets which can have his seal and signature. This would mainly be a problem in court cases and is not a very common problem.

Continuity of care

The family physician is often faced with the dilemma of having to manage a patient with multiple health problems on the

Table 3: Regular or annual review checklist of the proposed PHMR

Diabetes Review Checklist			
Name:			
Parameter	Recommendation	Date	
HbA1c	Every 6 months		
Cholesterol	Annually		
Kidneys	Annually		
Eyes	Annually		
Foot	Annually - at clinic		
Blood pressure	Every 6 months		
HbA1c target =			
Cholesterol =			

Table 4: Education checklist of the proposed PHMR

Diabetes Education Checklist			
Name:			
Topic	Dates Discussed		
What is diabetes?			
Hypoglycaemia			
Hyperglycaemia			
Diet			
Tablets			
Physical activity			
Insulin & injection technique			

basis of a history related to him by the patient. PHMR may improve communication of information among different health professionals caring for the patient. It allows for more accurate transfer of information.

The PHMR may be of special interest to the family physician as it assures access to records when making house calls.

Administrative aspects

PHMR may ease load on the clinic staff if it is used as the sole method of record keeping as there is no filing or need for record retrieval. The space required for storage may also be saved.

Confidentiality

With the PHMR the confidentiality of records is the responsibility of the patient. However, in certain instances patients could have difficulties protecting the confidentiality of their records, especially from household members as well as nosy colleagues and friends if left unattended.

Also in the management of conditions such as sexually transmitted infections (STIs), the patient will be reluctant to have the record with him due to fear of it being read by a known person. Furthermore it could cause relationship problems and other social complications if found out by a third party.

The above argument would mean that we can consider hospital based medical records to be safer and more appropriate in maintaining patient confidentiality. But in small countries like Sri Lanka, hospital staff in-charge of record keeping may be related to patients who are being treated. Therefore, there still remains a threat to the confidentiality of medical records regardless of whether it's patient held or hospital based.

Increase in workload

Often there is a duplication of work to enter data in the clinic record as well as in the PHMR depending on the institutional procedure which will increase the workload. Possible solutions are the use of shortened case notes, use of carbon copies, etc.

Computer based medical records could be a solution to duplication of work as records can be entered into the computer and a print out can be handed for addition to the patients records at the same time requiring no additional work. The cost of maintaining computer based records could be the limiting factor in our situation and currently a paper based system is preferred.

Restriction of freedom in writing notes

Another possible problem with patient held records is when the doctor has to record sensitive information for example, suspicion of child abuse needing further follow up which information must be shared with other health care professionals involved in the care of the patient.

There is also the possibility that access to medical information

may lead to increased anxiety in some patients.

Cost of maintaining the PHMR and acceptability throughout the healthcare sector

Sri Lanka has an open health care system where patients are free to move from one health professional to another as they please. Therefore, the question of who will bear the cost of the PHMR is important. The doctor may be reluctant to spend on a record with the possibility that the patient may not return to him. This problem will be worsened when doctors maintain both clinic held and PHMR.

Government intervention and approval of a PHMR system may itself lead to a better compliance among multiple caregivers involved in managing the patient. Other option would be for the patient to incur a nominal cost for the maintenance of his own PHMR.

As recording on a PHMR is not compulsory, some practitioners might not document on the PHMR. This can be remedied by attaching the documentation that is provided by him on to the folder containing rest of the documentation that is contained as the PHMR. This would provide some information, which is better than 'no information'.

Language used in the PHMR

It is important that care is taken regarding the language used for patient instructions and patient education in the PHMR in order for patients to achieve maximum benefit from the record. Ideally this section should be in the native language of the patient and wording should be simple and clearly understandable.

Aid to structured care in chronic diseases

The PHMR ideally has built in prompts for follow up of chronic diseases. Therefore, it may lead to patients being more diligent in their follow up visits.

Conclusions

PHMR is an effective form of offering comprehensive care to a patient continuously throughout the life for different health care needs at each stage. This is a cost effective method that can be provided at a nominal cost to the patients. Maintenance of the PHMR requires motivation of its owner.

This is an attractive tool in the management of chronic illnesses with the ability to provide details of care over a period of years at a glance. It ensures transparency and provides patient education promoting health of the patients. If patient interest is low, there can be problems with retention of the record and confidentiality of the medical notes.

If a computer based record keeping system is used together with this PHMR, a copy of the medical record can be given to the patient as well as having a hospital based copy with just a click of a button. Sri Lanka at the moment does not support infrastructure for such a venture.

This paper discusses the advantages and disadvantages of

using a PHMR. Authors believe that for a low-middle income country such as Sri Lanka, the benefits of using a PHMR greatly outweigh the drawbacks.

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