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## UPDATE ARTICLE

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# Patient Recall – Strengths And Shortcomings Of A Major Information Source

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### Abstract

*Physicians rely on patients for needed information about past medical events, implying a belief that patients are able to understand, recall and verbalize past medical events accurately and reliably. Is this belief valid? This article discusses: 1) whether patients are accurate and reliable reporters of their own health status, medical events and medical history; 2) whether the physician is able to make correct diagnoses and prognoses based upon information provided by patients; and 3) factors that affect recall. In some ways patients are good reporters of their medical history. However, there are numerous factors that affect reporting accuracy and reliability such as: anxiety, mood, severity of illness, type and duration of a procedure, and length of time since the medical episode. Good communication appears to be a key element in eliciting accurate and reliable patient recall. Physician records remain the best source of patient information and many points of information gleaned from patients may be used with confidence. Recognizing that physician records are the repository of the best medical information about individual patients means that more needs to be done to ensure that high priority is placed upon medical record documentation, format, and sharing. It is unlikely that physician records will ever fully replace the role of the patient as a personal medical historian.*

### Introduction

The main source of general medical and epidemiological information such as episodes of infectious disease, familial illness and medical histories are patients\*\* themselves and physicians' records. Many of the details in the latter also derive from information provided by the patient and not from direct observations. Patients' recall of illnesses, events and treatment is therefore very important to the physician's assessment of many illnesses and serves to aid clinical decision making. It is also essential to many epidemiological research studies.

While all family physicians rely on some amount of input from the patient, this source of information is even more important in Hong Kong where long-term doctor-patient relationships, and long-term comprehensive medical records are often rare. This is because people are highly transient and tend to "doctor shop." Hence, the medical history portion of physician records is frequently incomplete, or based solely upon input from the patient, with no means of verification. Doctor shopping is defined as multiple consultations with different providers for the same problem. (This may be compounded by the fact that some physicians address the presenting symptoms only.)

Physicians' reliance on patients for needed information implies a belief that patients are able

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\*\* and the parents of young children or guardians of persons deemed incapable of reliable information giving

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to understand, recall and verbalize past medical events accurately and reliably. Is this a valid assumption? In order to answer this question, it is necessary to examine the following:

1. When other complete sources of data are lacking, can physicians be assured that patients are accurate (that is, they provide complete and correct reporting of both exposure and absence of exposure) and reliable (consistent) reporters of their own health status, medical events and medical history?
2. Will the physician be able to make correct diagnoses and prognoses based upon patient provided information; and can researchers, who frequently rely on information gleaned directly from patients when conducting studies or from case notes, be confident that their study findings are accurate?

## Methodology

To answer the above listed questions, a search of the literature was carried out using Medline and Wilson databases from 1989 forward. Key words searched for included: recall, memory, memory and events with medical history. Out of the 11 English selections in Medline and 16 in Wilson, that were deemed relevant to the topic, 15 were available to the authors and have been reviewed for this paper.

## Recall Defined

Recall is broadly defined as "bring back to memory" and "serve as a reminder to recollect<sup>1</sup>," and as "call back" or "remember<sup>2</sup>". The Wordperfect<sup>3</sup> thesaurus links recall with "reminisce" and "summon". As might be expected, the antonym of recall is 'forget'.

## Why Patient Recall is Important

Physician records are usually considered to be good sources of past medical information. However, it is known that for numerous reasons, medical records may have gaps and may be incomplete. Hence, physician records may be inadequate and inaccurate repositories of patients' medical histories. Therefore, clinical diagnoses, clinical decision making and medical research rely largely on patient recall of prior illness, symptoms, treatment and possibly pain. If patient recall cannot be shown to be either accurate and / or reliable, this would have serious consequences for the whole of medicine. Moreover, certain conditions can seriously bias or otherwise affect accurate recall. For example, patients who are depressed selectively recall more negatively evaluated experiences and events than they do when not depressed<sup>4</sup>. For these reasons, consideration of the accuracy of recall is important.

## Research About Patient Recall

There has been a variety of research carried out about the nature of patient recall. Most studies compare two data sources (patient reports and documentation from medical records) to evaluate the reliability of patient reporting. While this method of confirmation is straight forward and reasonable, it is not 100% accurate because the probability of a note appearing in the medical record is likely to be higher for some events than for others. Large studies of self-reported chronic illness indicate wide variation in agreement between questionnaires and medical records by specific diagnosis, for example, patients tend to report respiratory ailments more frequently than do medical records<sup>5</sup>.

Are patients good reporters of their medical history? Tables 1 and 2 below present a summarized view of recent studies that have

examined this topic. The literature generally finds that patients are reasonable reporters of some types of illness and treatment, however there are

numerous factors, such as time since event, severity of illness and level of pain that affect accuracy and reliability.

**Table 1: Studies About Recall of Health & Medical Events**

Harlow & Linet. 1989 (7)	Literature review	Approximately 30 studies on patient recall	Identified studies comparing data from questionnaires with information from medical records	Limited number of medical events, appear accurately recalled, recall to other exposures / illness is not good
Boerma, <i>et al.</i> 1991 (13)	Assessment of data collected in the Demographic & Health Surveys (DHS) program in U.S.A. DHS surveys	19 National DHS surveys of developing countries	Accuracy & completeness of parental recall of diarrhoea in preschool children	Diarrhoea is underreported if recall period is longer than 2-3 days – very recent or current diarrhoea may be over-reported
Brown, & Adams. 1992 (5)	Comparison of Mail & telephone survey results with medical records	380 new enrollees of a HMO	10 prior medical events	Patients were sensitive but not specific reporters of diagnostic tests – small association between increasing age and decreasing confirmation
Nischan, <i>et al.</i> 1992 (9)	Case-control study; interviews & comparison with medical record	239 women who had used an IUD	Relationship between oral contraceptives & breast cancer, and contraceptive information	Excellent agreement on IUD episodes & use; Suggests physician records should be used as an additional source of information

**Table 2: Studies About Recall in General**

Authors	Study design	Sample size	Focus	Findings
Smith, <i>et al.</i> 1987 (10)	Experimental	22 older adults and 19 younger adults	Event recall immediately after event and one week later	Old & young performed equally well – elderly may have less difficulty remembering events than other types of material
Launer, <i>et al.</i> 1992 (19)	Retrospective	318 Bedouin Arab women in Israel	Infant feeding events (age when breast feeding stopped & solid food was introduced)	Accuracy of mother's recall varied with child's nutritional status but not with socio-demographic or other infant attributes. As length of recall increased accuracy decreased somewhat; breastfeeding recall was most accurate
Howes, <i>et al.</i> 1992 (14)	Experimental	24 elderly with 24 middle-aged	Recall of autobiographical & public events using word-cued Galton Tasks	Memory for public events decreases with increased age, but this effect is not generally found for autobiographical events
Skowronski, <i>et al.</i> 1991 (20)	Assessment of self and other diary	67 undergraduates	A self and other diary method was used to investigate factors affecting memory for different aspects of events	Clarity of event recall appears to important to the accuracy of dating events – pleasant events were dated more accurately than other events
Friedman, <i>et al.</i> 1993 (21)	Literature review of laboratory & autobiographical studies	Recall studies from 1970 to 1991	Normal adults' memory for the time of past events	No single, natural temporal code exists in human memory – instead, a chronological past depends on a process of active, repeated construction

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It is often difficult to directly compare studies on this topic because of methodological differences. Literature reviews, case control studies and interviews were used, for example, in different studies. As only select medically related events have been evaluated, many other types of medical exposures still need to be assessed. Furthermore, although several studies have evaluated the accuracy of reports of recent medical events, illnesses that occurred decades ago are more difficult to validate<sup>6</sup>.

Many of these studies are well-designed and avoid the usual types of study bias. However, other problems exist. Terminology becomes confusing as studies incorporate a variety of epidemiological and statistical terms to define the characteristics being evaluated. Most of the studies measure "agreement" between self-reported events with medical records, yet when it comes to measuring "agreement", there is a lack of consistency in analytic methods. The values of "agreement" measures vary with event prevalence; considering that prevalence varies among health plans, these are inappropriate measures for comparison. Therefore, sensitivity and specificity have been recommended as possibly better measures<sup>5</sup>. Furthermore, some study populations may be biased. Harlow and Linet found that 54 per cent of the studies compare interview data with medical record information sources only if a subject is classified as exposed by the medical record or by self report<sup>7</sup>. Thus, the conclusions drawn should be made only for people whose exposure has been noted through one of these two sources. Finally, recall studies fail to assess the accuracy of medical records or shortcomings of questionnaire design, particularly in the nature of the questions asked, a factor found to have significant bearing on data.

## Diagnosis

In Harlow and Linet's detailed literature review of epidemiological studies, it was found

that "for all diagnoses combined, the proportion of illnesses reported by the respondent ranged from 30-53 per cent of those illnesses recorded by the physician, while the proportion of illnesses recorded by the physician ranged from 36-70 per cent of those illnesses reported by the respondent<sup>7</sup>." Patient reports are highly reliable for some diagnoses but differences occur between patient reports and physician records for "minor" illnesses such as measles, hay fever and asthma for which patients are likely to over-report as compared to the medical record.

Large studies of self-reported chronic illness indicate wide variation in agreement between the two data sources. Patients tend to agree with medical records for diabetes and heart disease while thyroid diseases appear to be under-reported by patients. The authors note that in an article by Colditz, *et al.*, reporting is likely to be more accurate for diseases that have clear, unambiguous diagnostic criteria. Hence, accuracy appears to be a function of the ability to define precisely the nature of the event to be recalled. For example, pregnancy-related events appear to be accurately recalled and documented, yet historical reporting of diagnostic radiographs and specific chronic illness is not as good. Oddly, fluoroscopic examinations were found to be better recalled than either diagnostic radiographs or x-rays<sup>7</sup>.

## Hospitalization and Surgery

Studies evaluating recall of prior hospitalization and surgery noted slight under-reporting, but almost no over-reporting, of hospitalizations. Recalled date of admission was often correct and symptoms were remembered moderately well, especially for longer lengths of stay. Patients' memory of major illness and treatment, generally tends to be better than for minor problems; however, for those in an intensive care unit, recall is dependant mainly upon several factors, the type of illness/procedure

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and level of sedation<sup>6</sup>. Harlow and Linet note that Young, *et al.*, found a tendency for patients to over-report symptoms. However, as in other studies, when very specific information was asked about operations, a high level of agreement was found<sup>7</sup>.

## Ambulatory Care

Although few episodes of outpatient treatment care are dramatic or severe, patient reports for ambulatory care have been found to have relatively high accuracy. Brown and Adams reported that when responses from a telephone survey of patients enrolled in a health plan were compared with the medical records, patients were accurate, sensitive (able to identify a disease/treatment when it was really present) and specific (able to identify the absence of a disease/treatment<sup>5</sup>) reporters for outpatient procedures such as chest radiograph, mammogram and electrocardiogram (EKG). For serum cholesterol levels, patients were sensitive but not specific reporters.

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Not surprisingly, patients are reluctant to admit to documented but "embarrassing" events. For example, in telephone interviews, health actions such as testicular self exams were under-reported<sup>5</sup>. However, other potentially "embarrassing" topics such as birth control use, are reported accurately. Reports from women using intrauterine devices (IUD), were in excellent agreement (for total duration and number of IUD episodes) with physicians' records in the 1991 study by Nischan, *et al.*<sup>6</sup>. Recall of the name of the contraceptive first used was found to be highly accurate; agreement about duration of use improved when month or year of use was evaluated instead of exact date. On the other hand, Bean, *et al.*, found that reports of exact age at menarche, length of

menstrual cycle and dates of surgical and natural menopause were imprecise<sup>7</sup>.

Studies examining pregnancy history noted high levels of accuracy, even over extended periods of time however, unfavourable clinical events were not so accurately remembered. Tilley, *et al.*, found that recall of spontaneous abortions increased with length of gestation but decreased with longer recall periods<sup>7</sup>.

## Medication Use

In a 1982 study, agreement between records and patients was moderate for recall of hypertensive and thyroid medications but only poor to fair for use of barbiturates, steroids and reserpine. Phenothiazine use was assessed in another study which found wide disparity between questionnaires and general practitioners' records. Near perfect agreement was found for labour-related use of epidural anaesthetics, general anaesthetics, meperidine and oxytocin. Agreement for use of hypnotics was moderate but it was poor for tranquillizer use. This is attributed to failure to ask more specific questions about tranquillizers<sup>7</sup>.

## Children's and Parents' Recall

General studies of children's recall indicate that they sometimes provide detailed descriptions of events yet in other situations they are vague or require considerable cueing<sup>10</sup>. Adversity may stimulate children's recall. For example, children's recall of pain has been assessed by Lander, *et al.*, and found to be quite good after a two month period. Interestingly though, memory of affective pain was found to be better than that for sensory pain<sup>11</sup>.

Because very young paediatric patients are not capable historians, their parents are the main external source of past medical information.

Recent research has provided some insights into the accuracy and reliability of parents' recall of their offspring's health and development.

Parents report birth weight, age of first independent walking and academic achievement reliably. They are also good reporters of developmental and intelligence test results<sup>12</sup>. Information provided via maternal recall of infant feeding up to 18 months of age is accurate and can be used with confidence. However, as Launer, *et al.* report, recall on formula feeding is less accurate than recall of solid foods and breast-feeding. Other literature suggests that mothers with better education tend to have fewer recall errors than do uneducated mothers. However, according to Boerma, *et al.*, it is likely that children of poor, uneducated mothers may suffer many episodes of illness that are not seen, and therefore not recorded by physicians<sup>13</sup>.

In the study by McKinney, *et al.* regarding infectious diseases and vaccination history, it was found that mothers and General Practitioners (GP) are both inadequate data sources. When considering recall of infectious diseases, mothers tended to over report (as compared to GP records) and were incorrect in reporting the time when the illness occurred<sup>6</sup>. On the other hand, GPs' records systematically over-reported infectious episodes, indicating that mothers' recall is frequently inaccurate for minor illnesses or that many minor illnesses are not seen by the doctors. This latter interpretation seems more probable in places where physician visits are not free and physician access is otherwise difficult. Also, visits may be more frequent with infants and toddlers than with older children who may none the less have illnesses, though these may be of lesser concern to parents.

### Other Dimensions of Patient Recall

Patient's memory of major illness and treatment, generally tends to be better than it is

for minor medical problems. Yet, additional factors play an important role. Overall, studies show that a patient's ability to recall past medical events depends largely upon how well physicians or medical staff communicate with them as well as anxiety level at the time of the episode, education, expectations placed on the physician, type of illness/procedure and level of sedation. There is also a temporal dimension to recall. Reporting accuracy deteriorates as the length of time since the illness or episode increases, and varies with duration of treatment and length of discomfort and/or disability. It is more difficult to forget having spent a week in intensive care than having spent 3 days sniffing with a cold. Frequency and recency of physician visits or the singularity of an event also play a role.

Studies by Brown, *et al.* and Howes and Katz, found only negligible differences in ability to report medical events accurately that are attributable to gender, age and race<sup>5,14</sup>. It appears that patients of all ages are generally able to recall childhood illnesses quite easily. McKinney, *et al.* found that at age 50, self-reporting of childhood illnesses was determined to be highly accurate<sup>6</sup>. As long as the individual is of sound mind, increasing age does not appear to drastically alter medical recall although some studies have found an association between increasing age and decreasing confirmation<sup>15,16</sup>.

For short time frames following ambulatory care visits, there appears to be a very high level (88%) of recall of patient education. Other studies indicate that physician advice is less likely to be recalled than are diagnostic statements. Further, patients may not comprehend what is said to them; Krall, *et al.* found that 53 to 89 percent of primary care patients do not understand what they are told about prescriptions and treatment advice<sup>15</sup>. Longer time frames, level of medical knowledge and increasing age and anxiety may also affect the patient's ability to remember physicians' advice or information.

## Communication

The nature of questions asked and the manner in which information is presented to patients influences their recall of medical advice. Patients report more accurate histories if they are asked specific as opposed to general questions, and asked about explicitly defined events than poorly defined events. It is clear that the quality of information obtained by a physician from a patient is as much a function of the degree of skill and sophistication the physician shows in his/her questioning strategy, as it is of the patient's memory.

Apparently, reliability errors appear in both patient recall and physician's medical records. Even the best physicians' records tend to under-report minor medical events while patient reporting tends to be erratic; excellent in some areas and poor in others. Are the combined reporting and recording errors serious enough to cause concern? It appears that they are not because major illnesses and problems are most often of interest and these, by and large, seem well recalled and documented.

## Implications for the General Practitioner

The literature generally finds that in some ways patients are good reporters of their medical history. They accurately report pregnancy, vaccinations and having had childhood diseases. However, they are just as often inaccurate. There are numerous factors that affect accuracy and reliability, and in certain areas their value as information sources may be problematic.

Well documented physicians' records obtained from careful questioning are among the most reliable sources of patient information. Overall, *information from patients that has been gathered in haste is generally not as accurate as well organized and comprehensive physicians' records.* However, in Hong Kong, few physicians maintain

records, and those who do, hold records that are probably less comprehensive and detailed than desired. Even well organised records may present a further problem. On the occasion that histories are taken by a physician, if the patient has forgotten elements of his/her history, then the information in the record will be incomplete. The record then represents an inadequate tool against which to evaluate the patient's recall and upon which to make sophisticated clinical decisions.

Factors affecting patient reporting accuracy and reliability are many and varied. Age, gender and race have only a small impact on the patient's ability to remember episodes of illness or treatment. It appears that many recall errors are due to poor communication and confusion about the questions being asked or information being sought.

To ensure that patients are providing the best possible information, physicians should begin with broad questions then narrow in more specifically and use prompts to aid memory without encouraging the patient to over-report. Medical questioning should take place as soon after an event as possible, although this is not always feasible in practice. Using lay terms during questioning may be helpful; asking specifically "did you have German Measles", is preferable to asking "did you have Rubella?" Focused questions about a specific disease or episode of illness will elicit more reliable responses than will open-ended questions such as "were you a healthy child?" By increasing the specificity of a question and limiting the length of time over which the individual is being asked to recall an illness, the accuracy level can be increased.

## Conclusions

*Physician records can be a good source of patient information, however, the accuracy of information gleaned from patients depends very much on the doctor's questioning skills.*



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Recognizing that physician records are among the best repositories of medical information about individual patients, means that more needs to be done to ensure that high priority is placed upon medical record documentation, format, and sharing. However, it is unlikely that physician records will ever fully replace the role of patient as a personal medical historian. Hence, physicians are encouraged to be highly specific when questioning patients and to provide concise, memorable verbal and written information to patients that will add to the patient's repertoire of historical knowledge. One possibility might be to encourage patients to keep their own health diary (a patient held record) which would contain relevant and accurate health information. This is already done for children to record weight, inoculation history and other relevant information. This idea could be extended to adults as a life-long diary of health information<sup>17</sup>. The information would be entered by the patient (or his/her doctor) as the event occurs and then be referred back to for details. This would serve as a highly accurate and reliable adjunct to both patient recall and physician records that would not be subject to the vagaries of fickle memory. ■

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