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An intelligent partner system for improving chronic illness care

Tibor Deutsch PhD
Chief Research Fellow, Applied Logic Laboratory and Semmelweis University, Budapest, Hungary

Tamas Gergely DSc
Scientific Director, Applied Logic Laboratory, Budapest, Hungary

ABSTRACT

Chronic care consists of a sequence of actions to treat a specific clinical disorder over time as a function of the ways in which illness progresses and patients respond to management actions. Outcomes depend on physicians' skills to select the actions best suited for their patients and competent self-management. This paper presents the architecture of an intelligent partner system (IPS), which helps to provide doctors with relevant data and skills and empowers chronically ill patients with the information and confidence to manage their health wisely. The services of this intelligent system are presented as 'therapies' for the information-processing 'pathologies' associated with traditional chronic illness care.

Keywords: chronic care, intelligent partner system, medical problem solving

Introduction

Control of chronic diseases has been substantially improved over recent years through a variety of educational interventions and structured care offering patients regular consultations and instructions on how to handle deviations from normal care on a daily basis.[1] Both patient education and structured care have benefited greatly from the use of computer and telecommunication techniques to deal with the storage, retrieval, transfer and processing of clinical data and medical knowledge, which overcomes the severe limitations of the human memory and paper-based methods. These limitations may lead to inadequate therapies or clear-cut management errors. Like dysfunctions in human physiology, these 'intellectual pathologies' also need adequate 'treatment'.

Such 'treatment' constitutes an integral part of a comprehensive chronic care model which predicts that improvement in self-management support, clinical information systems and decision support (information provision and processing services), complemented by the re-engineering of healthcare organisations, delivery of chronic care and community resources, can produce system reform in which informed and empowered patients interact with prepared and proactive practice teams.[2]

This paper describes the main functions of an IPS, which integrates available methods and techniques to assist both clinicians and patients in planning and implementing individualised management regimens. The majority of chronic illness management is performed within the primary care setting so this system may help redesign primary care practice and close the quality gap between current practice and optimal standards.

The information model of chronic care

Patients with chronic illnesses such as hypertension, diabetes or asthma require periodic interactions with their physician. Figure 1 shows the information model of chronic care – two interacting management loops run by patients and their physicians.

The upper loop shows the information processing associated with regular patient visits, during which general practitioners (GPs) process home-monitoring data along with those recorded at visits and instruct their patients how to monitor chronic illness measures and manage their illness in the future. GPs use information (interpreted data) derived from collected

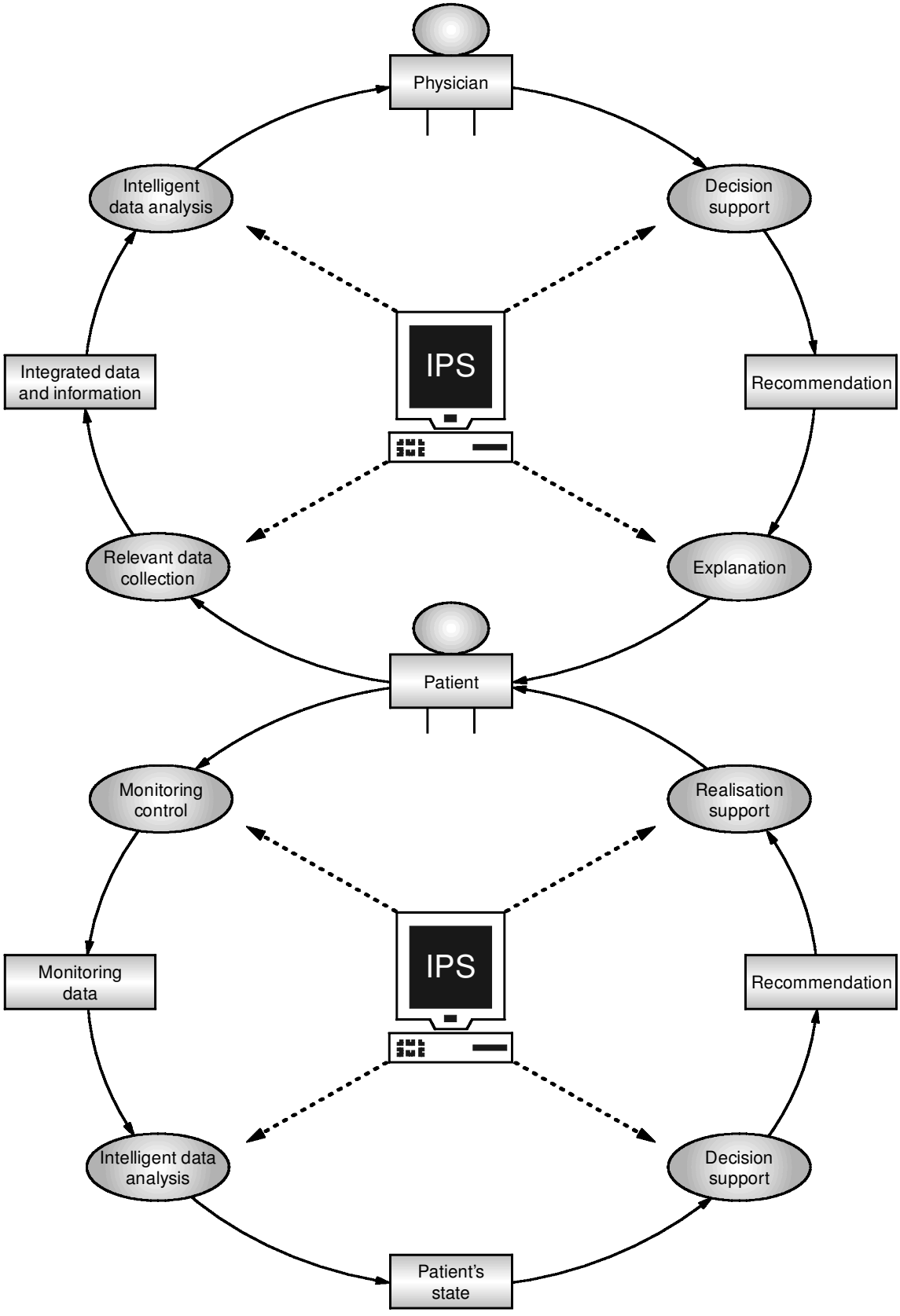

Figure 1 Functions of the IPS in chronic care (ellipses indicate information processing steps, boxes denote output of information processing, arrows indicate information flow, dashed arrows denote IPS support)

data. Once patient data have been interpreted, GPs face the task of selecting the best management regimen, which usually involves clinical reasoning and choosing from alternative options (decisions). Different components of the management regimen need to be tailored for the patients' individual needs.

Recommended actions should be explained and justified if we expect patients to comply with the instructions. Educating patients in general, and explaining recommendations in particular, are seen as efficient means for improving compliance.

The lower loop corresponds to 'self-management' operating on a daily basis; this involves self-monitoring and responses to actual and anticipated problems. Patients need to be able to interpret home-monitoring data to reveal actual problems or anticipate future risks. As diet, exercise, self-monitoring and medication use are under the direct control of patients, they also need to understand their disease, the benefits, risks and side effects of the different therapeutic options, and follow the instructions which have been provided. Many disabled or elderly patients also need support for following the guidance with which they have been provided. It is understood that patients and GPs might well also communicate with each other outside regular visits, but such interactions are not displayed in this figure.

Both patients and their GPs face several information-processing tasks when collecting data, and must try to understand what the data mean and avoid or respond to problems that have been detected or anticipated. Errors in information processing can lead to management errors. In the subsequent section the main sources of these errors will be outlined, followed by the presentation of an IPS which helps to plan and implement management regimens according to customised clinical guidelines.

'Pathologies' of information processing

Delivering adequate chronic illness care becomes difficult if:

- the GP does not have enough data about the patient and/or doesn't understand properly what these data mean
- they lack the expertise, knowledge or skills to solve the problem which has been encountered
- the patient is reluctant or unable to comply with the instructions provided. Several authors have analysed the intellectual pathologies underlying suboptimal therapies and management errors.[3,4]

Generic methods and techniques have also been suggested to avoid or overcome difficulties associated with obtaining and manipulating clinical data.[5] Table 1 summarises some of the major information-processing 'pathologies' associated with chronic illness care and shows 'therapies' for solving them.

Some mistakes follow from data shortage or abundance. Medical records are often incomplete and insufficiently structured. GPs, for example, often do not follow their patients between visits, hence they are not aware of temporary or persisting problems which might have been encountered. In contrast, they may also be overwhelmed by the quantity of data unless their ability to analyse these data can be scaled up alongside the data storage capabilities.

Table 1 Treatment of information-processing 'pathologies' in chronic illness care

Pathologies	Therapies
Data shortage or overload	• Data collection devices • Intelligent data processing • Intelligent medical record
Lack of reliable medical knowledge	• Intelligent search engines • Problem–knowledge coupling • Formalised guidelines
Erroneous clinical reasoning and decision making	• Customising generic guidelines • Relying on past patient-specific experience • Assisting guideline-based care
Bad compliance	• Customising educational materials • Explaining recommendations • Electronic reminders and advisors • Implementation support for disabled

Other errors are results of ignorance, such as when doctors don't know the most appropriate action for their patient. Although a great number of clinical guidelines exist which contain step-by-step instructions to which doctors can refer when deciding how to manage different chronic diseases, busy clinicians have little time to read and memorise these guidelines. Converting them from paper to electronic pages may not substantially change this reality as the overabundance of medical information resources results in failing to retrieve necessary information within a reasonable time. GPs may also find it difficult to integrate all the details in a complex guideline with the mass of patient data. Moreover, clinical practice guidelines provide standards for optimal chronic care, but individual patients need customised treatment, and doctors are often unable to balance arguments in favour or against some therapeutic options based on patient-specific risks and benefits. In such cases inadequate reasoning can lead to management errors.

A great variety of problems follow from the patients' attitudes. Some patients simply cannot afford the expense or the time for adequate and regular medical consultations. Quite often we do not achieve the potential benefit of the recommended therapy because patients do not carry out the instructions as intended.[6] Lack of compliance often results from inadequate time for the doctor to provide lengthy explanations and to make sure that the patient actually understands the information. Patients, sometimes seen as passive objects in the process, are often provided with brochures and videotapes that describe in some generic way their disease or the treatment that has been chosen. However, these static information sources do not help in understanding how therapy will affect their own plans or concerns. Different patients have different information needs but GPs are sometimes not available when patients have important questions to ask or are struggling with important decisions.

Reduced compliance often follows from physical disabilities. Many elderly patients, for example, fail to comply with prescribed medication because of memory or sight problems. Remembering which drug to take, when and how, is increasingly difficult with concurrent medication.

'Therapies' for 'pathologies': the intelligent partner system

Most of these problems can be resolved if doctors and patients rely on an IPS which integrates a spectrum of services in such a way that they are available at the time needed. Figure 1 also shows how such an IPS fits into the information-processing loops of chronic care. It helps to provide doctors with relevant data, knowledge and skills for detecting and solving therapeutic problems, and empowers chronically ill patients with the information and confidence to manage their health wisely from day to day.

Supporting GPs

At visits GPs deal with patient data and make recommendations about management plans. The IPS helps to:

- collect, store and structure patient data (*relevant data collection*)
- understand what these data mean (*intelligent data analysis*)
- choose the best management regimen (*recommendations*)
- explain why this management regimen is thought to be the best option (*explanation*).

Relevant data collection ensures that the GP has access to all relevant patient data collected since the last visit. For diabetic patients, for example, insulin doses, eye and foot examination, and laboratory test results such as fasting blood glucose, HBA1c and urine microalbumin are entered electronically into the medical record.

GPs need interpreted data. The IPS offers a 'pair of glasses' to look at, and extract meaning from, raw data. Data visualisation and summarisation involve plotting and tabulating some statistical characteristics of raw data, such as arithmetic means, standard deviations, highest and lowest values, percentiles, histograms, etc., over a given period of time. The different parameters can be plotted with different chart types (such as line graphs or histograms) to enable the user to explore past and current measurements. The IPS uses different numerical and reasoning techniques for interpreting patient data. Quite often interpretation results in clinically relevant motifs (for instance, trends, cycles or complex patterns such as 'excessively fluctuating, high blood glucose levels over two weeks') hidden behind patient data.[7] The IPS is able to generate a summary report of events recorded between two subsequent visits, including the problems that have been detected.[8] 'Diagnosing' problems (that is, explaining what has happened) is an essential step to selecting interventions that affect pathophysiological processes as desired.

Abnormalities, however, may often have different underlying causes. The IPS also offers specific causality assessment methods, which help the clinician to come to some reasonable judgement about whether, or how likely, a specific intervention or event was the cause of the observed problem.[9] In addition, the IPS attempts to keep explanations consistent. If the extracted patterns or explanations contradict those that

have been expected, patient data will be re-analysed in a dialogue with the patient. This process tries to rule out false conclusions from incomplete (missing or wrong) data. The process of intelligent data analysis is shown in Figure 2.

As the IPS processes data of the same chronically ill patient several times, it helps to synthesise interpretations and conclusions made at subsequent visits. This synthesis leads to building an intelligent medical record that is revised and updated at each visit. This record reflects:

- disease progression (for example, complications are slowly emerging)
- the effects of different therapies (such as 'drug X administered twice daily with a dose of 10 mg has caused vomiting')
- what the patient knows (or is believed to know) about the disease and its management
- the patterns of compliance, including monitoring habits and the frequency with which the patient is willing to take management actions on their own.[10]

There are a number of ways the IPS can support customised care.[11,12] Generic support may involve provision of medical knowledge which is relevant to the problem to be solved. The IPS supports the search for existing evidence-based clinical practice guidelines and facilitates context-sensitive access to various resources.[13] Problem–knowledge coupler systems embedded in the IPS allow care providers to consult available relevant knowledge automatically.[14] It is also able to access formal descriptions of clinical practice guidelines. For example, 'Publets' may serve as means to translate best practice into effective and efficient routine health care at the point of need.[15]

In addition to supplying problem-specific information, the IPS also provides systematic procedures for customising standard guidelines for individual patients.[16] Uncertainty and value judgements about which risks are worth taking, patient preferences and trade-offs concerning the possible outcomes of treatments are combined in reaching a clinical decision.[17] Evidence-based medicine estimates of therapeutic benefits and risks of different interventions are revised in the light of the patient's prior experiences, and preferences are stored in the intelligent medical record in order to adapt generic interventions to the patient's individual needs.[18]

The IPS offers a number of decision support functions for integrating generic practice guidelines and customised treatment planning into daily practice.[19] Computerised reminders may help primary care teams comply with practice guidelines. A reminder pop-up message on the electronic medical record may flag, for example, laboratory work or examinations not performed according to schedule.

The IPS can also operate in assistant and critiquing modes. Advisor programs use patient data and suggest problem-specific recommendations as solutions for the problem presented.[20,21] In contrast, surveillance and critiquing systems serve to focus attention on avoiding wrong decisions. In critiquing mode the IPS takes patient data and sends messages whenever it detects conflicts between the condition of a patient and the treatment proposed by the doctor. It can also recognise when a reasonable decision has been

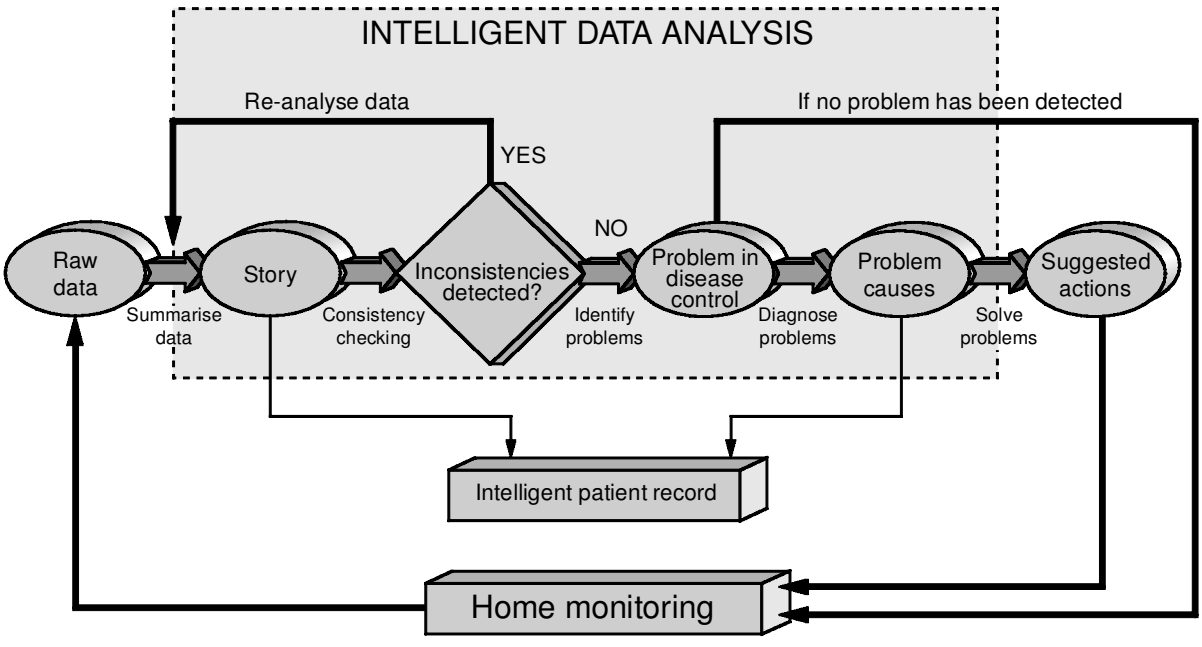

Figure 2 Schema of intelligent data analysis

proposed, even if that approach differs from its own preferences.[22]

Supporting patients

Between visits, patients face a variety of self-management tasks. Self-management support involves helping patients and their families acquire the skills and confidence to manage the chronic illness. The IPS helps patients to:

- monitor relevant variables (*monitoring control*)
- identify current problems and/or forecast risky situations (*intelligent data analysis*)
- choose timely actions to correct actual problems or to avoid anticipated risks (*decision support*)
- implement the interventions which have been suggested (*realisation support*).

The IPS provides efficient access to self-monitoring devices. These data collection devices are connected to the IPS for monitoring chronic illness measures (not shown in Figure 1). Measurement devices with memory chip and data ports, for example, allow systolic and diastolic pressure, resting pulse rate and blood glucose data to be uploaded into clinical workstations which host the IPS.[23] The IPS supports the validation of these raw data in order to arrive at reliable values and then stores them in electronic log books.[24]

Patients act on the basis of interpreted data. The IPS offers a number of visualisation and interpretation functions which serve to highlight undesired (abnormal) patterns in patient data (such as persisting hyperglycaemia) or predict future risks (like nocturnal hypoglycaemia). It provides comprehensive decision support based both on current state and anticipated events.[25] The system may send a warning message if the blood glucose level falls below a critical threshold or instruct a patient to inject less short-acting insulin before breakfast in anticipation of intensive physical activity scheduled around 11 a.m. Such instructions may be derived from look-up tables customised for that particular patient at the last visit.

In addition, the IPS acts as a remote triage point for clinical services, reminding the patient when a visit to the clinic is indicated. It will provide patients with necessary tools to establish email connection to medical staff or other patients, or access to supporting newsgroups when facing a situation not covered by the IPS.

The IPS assists patients in following the recommendations in many ways. It allows patients to interact with online information networks to suggest information of interest. In contrast to traditional monographs and leaflets, however, the patient may receive fully customised instructions and information according to their sex, age, preferences, experiences and the degree of severity of a situation. Methods of computational linguistics help to automatically produce texts that are sensitive to the patient's needs and the history of questions and answers that have been exchanged thus far.[26] In addition to receiving customised information, the elderly and disabled, for example, can use various types of memory and/or packaging aids to take the medication as intended. These support tools include calendars, pre-packaged doses in envelopes (marked with the time and day of administration) and the Dosette, a plastic box with 28 compartments for holding seven days' medication.[27] The IPS can be connected to microprocessor-based devices, such as Medminder which provides both auditory and visual reminders to guide patients as to when to take their medication and how much to take on each occasion.[28]

Conclusions

Chronic care involves monitoring of patient conditions and adapting treatment according to the problems encountered. Both monitoring and management actions are closely bound to information processing and decision making. Mistakes clearly indicate that medical practice requires tools to extend the mind's limited capacity to recall and process large numbers of relevant variables and to reason with complex medical knowledge.

The IPS offers assistance both in retrieving and organising information in a usable form so as to exercise judgement based on that information to arrive at a decision. The IPS supports protocol-based care, including data acquisition, clinical decision making and therapy monitoring. The core of such an IPS is the intelligent medical record, which stores not only raw patient data but an understanding of the patient's health status and sensitivities evolving over time and the patient's interest in health-related issues, along with the actions and thought processes of care providers. Building and maintaining this repository is essential if we want to avoid repeating past errors and adapt chronic illness management to the individual patient's needs.

Developments in telecommunications technology offer efficient ways for implementing the IPS described in this paper. It is important that the IPS is platform-independent, runs on widely available hosts and has access to various Internet resources.[29] The principal benefits for doctors and other healthcare providers include the ability to extend communication with the patient, thus accessing accurate and comprehensive data, and to send instructions whenever the patient's state is deteriorating dangerously or deviating unexpectedly from the anticipated course of therapy.

It is noted that the IPS is not meant to replace doctors, but rather to assist in formulating decisions or monitoring those which have been made. The clinician is able to override the computer or evaluate the outcome of the process by analysing clinical evidence. Better informed patients are able to take greater responsibility to make informed decisions concerning their own care.

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ADDRESS FOR CORRESPONDENCE

Dr T Deutsch
Centre of Informatics
Semmelweis University
Faculty of Medicine
Ulloi Street 78/b
1082 Budapest
Hungary
Tel: +36 1 2100 328, ext 1840
Fax: +36 1 2100 328
Email: tibor@inf.sote.hu

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