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# Computerised education for consumers

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This chapter aims to provide the reader with an understanding of the rationale and methods of patient education for health promotion and management of health problems; the principles of design and evaluation of computerised patient education materials; and areas of potential future impact of IT in patient education and health promotion. The reader is assisted in acquiring skills in appraising the effectiveness of IT applications in patient and consumer education and health risk assessment

Prevention involves action to reduce occurrence of disease or disability or to minimise the damage that may result from it. There has been an increasing prevalence of chronic disease such as cardiovascular disease, cancer and mental illness which is associated with behaviour and lifestyle. At the same time, due to the increasing cost of institutional health care and medical interventions, patients and their families are being encouraged to self care and services are being provided to support this outside hospitals.

Many activities related to patient education have traditionally been carried out in institutional settings (i.e., Hospitals and clinics) and using mass media approaches (i.e., posters, radio and TV). The current trend is to target the message and activity to the individual and at their home. The emergence of Information Technology as an accepted part of the life style of society has paved the path towards this goal.

This chapter will begin with a review of principles and concepts of patient education and identify the advantages of computerised patient education. Various approaches to preventive action such as health risk appraisal and consumer education that are enhanced (or even made possible) by IT will be presented illustrated by developments in Australia and overseas. The efficacy and effectiveness of IT applications in these situations will be discussed. Finally the chapter will cover potential future developments in IT that hold promise to the practitioner and consumer.

## Patient education

### Why patient education?

With the chronic nature of many health problems today, educating patients about their condition and management is becoming an essential aspect of their management. Education

has been shown to influence the degree of patient involvement in their own care (Hansen 1990). This is desirable in itself but it is also associated with improved health outcomes as a result of behaviour change or compliance with therapy (Greenfield et al 1985). This is especially important in the elderly who are likely to suffer from multiple chronic disease, be on multiple medications and who may also suffer impaired cognition.

Opportunities for patient education exist throughout the health system. Most hospitals in Australia conduct some patient education programs. These programs cover chronic health problems such as diabetes, cancer and heart diseases. Community health services are another important venue for patient education especially in aged, diabetes and palliative care, mental and early child health.

General Practice is an important setting for patient education. Over 86% of the population consult with a GP at least once a year (Australian Bureau of Statistics 1991). GPs perceive themselves and are perceived by patients to be an appropriate source of health education and information (Ford & Ford 1983). Patients not only expect to hear health promotion messages, they welcome them and do change their behaviour as a result (Sullivan 1988). Counselling or advice was given in about 25% of encounters with general practitioners in Australia in 1990 (Bridges Webb et al 1992). This was especially common in consultations with the 15-44 year age group and much of this advice concerned treatment. One study identified opportunities for problems related patient education in a quarter of all consultations but only a small proportion of these were taken by GPs (Boulton & Williams 1983).

## Written materials and methods

Lack of health worker time is perceived to be a major constraint on patient education. In general practice lack of time and remuneration are major barriers to health promotion. Other identified barriers include patient acceptance and compliance, lack of resources and special skills in health promotion and education (Bauman et al 1989, Wilson et al 1992).

Patients also frequently fail to understand information given to them and may forget the information even when it was understood at the time. These factors diminish patient satisfaction which in turn diminishes compliance with advice or management as a whole (Ley 1985).

Written information may compensate for the lack of time in the consultation by providing information in addition to that given verbally. It also acts to reinforce the message and provide a record of the information given both for the patient and their family to review later and increases satisfaction with care (Laher et al 1981, George et al 1983). Printed materials can also serve to document that informed consent procedures were followed and that follow up instructions were given (Carr 1989).

Written patient education materials also vary widely in their readability with many requiring reading ages at least five years higher than the average patient (Davis et al 1990, Glanz & Rudd 1990, Bradly et al 1994). Most word processing packages now include readability and reading age scores and can be readily applied to patient education materials. Guidelines have also been suggested for written patient education materials (Kitching 1990, Albert & Chadwick 1992).

- Reading age of 8-9 years.
- Avoid jargon and 'unless', use short concrete rather than abstract words and avoid too many participle phrases.
- Use of headings and subheadings or questions as prompts for text.
- Short, active rather than passive sentences.
- Positive rather than negative messages.
- Order of mention is the same as the sequence of actions or events followed by the patient.
- Instructions should be specific rather than general.
- Personal style and personalised messages.
- Avoid unnecessary capitals.

The use of illustrations improves the readability of health education materials (Michielette et al 1992). Simple labelled line drawings have been demonstrated to be more useful than coloured, complex pictures or cartoons especially among high risk populations (Doak et al 1985).

Written materials should be customised to the consultation, the health worker and the patient so that they are relevant and all concerned have a greater sense of ownership (Richards 1991). They should also be regularly updated and need to be translated into the language which the patient and their family most readily understands. All this may create problems with storage and ease of access to the materials in a busy practice or service.

## Computerised patient education materials

Computerising patient education materials offers a solution to the problem of storage although leaflets with graphic images may be relatively memory intensive. It also may allow the materials to be adapted by the health worker both to their own practice (e.g., putting practice details on the leaflets) and to the individual patient (providing advice for specific problems of patients at the time of the encounter) (Kahn 1993).

Some computerised patient education materials have been designed to be accessed during the consultation acting as an aid and prompt to verbal education and providing a record of advice given (Harris et al 1993).

- Easy to use requiring few keyboard or computer skills.
- Specific providing information of relevance to one situation or problem and not confusing the patient with information that is not relevant to them.
- Able to be adapted to the health worker, patient and the encounter.
- Provide accurate and reliable information (where possible validated by appropriate authorities).
- Available in a number of languages.
- Provide a record of use for each patient.
- Follow guidelines for all written materials.
- Compatible with databases, record systems, operating systems, modems and printers.

## Efficacy and effectiveness of computerised patient education

Computerised patient education materials have been demonstrated to improve comprehension and follow up especially where combined with face to face education (Sumner III 1990).

Patient education programs run in institutions require the patient to come back to the facility and use staff time repeating the same message to a number of groups. A project in Aberdeen for Asthmatics, addressed this issue by using a computer based system to generate personalised health education booklets. A computer system was used to merge patient risk factors with relevant blocks of information on prevention. In addition answers to questions made to the consultant were included in the quarterly booklet. In assessing the project, the patients given the computerised booklets had fewer hospital admissions and sleep disturbance due to asthma (Osman et al 1994). The results suggest that the booklets made patients aware of warning signs and reinforced advice and management instructions for controlling symptoms.

The main obstacle to the wide spread use of computerised patient education materials is the fact that few primary health workers have computers available for use during consultations. Another obstacle is unfamiliarity with computers and keyboards by health workers, especially general practitioners. This may be overcome by more user friendly programs and pen based computers. Training is also of great importance and this is an important task for academic departments, the RACGP training program and Divisions of General Practice.

There are a number of computer patient education systems designed to give information independent of the health worker. These involve patients accessing information with the use of a keyboard or touch screen technology (Mitchell 1993). Some studies have shown that these have the acceptability of face to face education while providing the recall comparable with written format leaflets (Deardoff 1986). In particular such systems may allow the patient time to ask questions which they were unable or unwilling to ask during consultations (Roter 1977) or are intimate and embarrassing to ask from a care provider. There have also been suggestions that such systems may be used as a supplement to face to face education.

## Health risk appraisal

Health goals and targets in many countries also have included proposals for preventing death and disability due to major illnesses by reducing the prevalence of health risk factors (Health Targets Implementation Committee 1988). Thus, current interests in preventive actions have created a corresponding interest in developments of strategies and techniques to foster personal health behaviour change. Health Risk Appraisal (HRA) programs were developed. These personal risk assessment programs are usedto convey the impact on mortality and morbidity risks of clients' personal characteristics, family history and health-related behaviours. HRA is used as a framework for client education about determinants of health and for motivating them to modify the behaviour to reduce health risks and adopt healthy lifestyles (Schoenbach et al 1993).

Health Risk Appraisal instruments developed as a prospective medicine practice tool was popularised by Robbins and Hall in 1970, initially to prevent cancer by identification and

reduction of cancer precursors at an early stage of disease process and prevent progression. Computerised Health Risk Appraisal has been used in the USA and Canada since the mid 1970's and a number of studies have been conducted for its efficacy and effectiveness (Schoenbach et al 1993).

Risk factor intervention strategy at an individual level has been viewed as a reflection of the 'medical model'. On the other hand, directing efforts for risk factor reduction by accumulating information on a computer database and implementing a preventive intervention for risk factor reduction at a total community (e.g., mass screening for cardiovascular risk factors, a North Coast experience in NSW) has received special attention by broadening the community approach to stimulate change (Lefebvre et al 1988, Van Beurden et al 1993).

Traditional model of HRA uses mortality data of major causes of death to estimate a person's risk of death/disease based on person's current profile of age, sex and risk factors in the next ten years. Developers of the instrument used United States epidemiological data for calculation of average risk which have been replaced by Australian mortality data to develop an Australian version by the Shephard Foundation (Larsen 1987). HRA provides individualised risk assessment based on:

- major causes of death for people of the same age and sex category;
- the health related behaviours and personal characteristics of that individual as recognised precursors for specified diseases;
- risk factors for that person in order of importance;
- the estimated risk of death in the next ten years and an average risk for that person (appraised risk) and the risk level of that individual after reduction of specific risk factors for that person (achievable risk) adjusting for the effects of changes in health (Ruth 1985).

However, it is not always possible to reduce the risk factors such as those contributed by family history and environmental factors over which an individual has no control, except for its raising awareness and potential for early detection and possible treatment. Therefore achievable risk can become a source of frustration in some clients. Advocates of socio-environmental factors impact upon health, consider this approach to be 'victim-blaming'.

## Computerised health risk appraisal

During the last two decades, the growing use of HRA instruments has been facilitated by expanding the initial model, such as, to include lifestyle inventory and fitness evaluation. An Australian microcomputer based program developed by the Shepherd Foundation included positive aspects of good health such as, high cardiovascular reserve, stress handling ability, abstinence from tobacco, alcohol and drugs, nutritional awareness, personal life goals and prevention of common chronic disease (Larsen 1987).

Since their early development stage, most HRA instruments have expanded the range of applications while continuous refining and extending of technological aspects of the measurements goes on. More recently, the educational component particularly for uni-focus instruments such as alcohol, drugs and AIDS/STD risk appraisal is accompanied by correct

information provided with effective and interesting visual computer techniques. Range of applications in current programs available in Australia include:

- Comprehensive health assessment.
- A personalised computer report of positive health aspects and those needing improvement.
- Interactive lifestyle appraisal.
- Identification of areas for counselling.
- Accumulated data on groups for population-based studies.

## Efficacy and effectiveness of HRA instruments

The major questions to assess the efficacy and potential effectiveness of HRA instruments that may be considered are:

- How accurately does the instrument assess the individual's risk factors?
- How effective is the instrument in motivating behaviour change?

Some of the guidelines have been developed through research to assess the HRA instruments, which may be considered for future research or when selecting a HRA instrument for a program (Beerby et al 1988).

The assessment of a HRA tool should gauge the interest and participation of clients, the effectiveness in communicating the relationship between lifestyle and health risk and information on risk behaviour, the change in health behaviour (Seydel et al 1990). Other criteria include its ability to develop a database and provide an index for health risk and health-related behaviours.

While the efficacy of HRA instruments has been challenged (Smith et al 1987), many proponents of HRA have fostered unrealistic expectations about the role of HRA in effecting behaviours change. It has been indicated to be a priority as a motivational tool to stimulate behaviour change (Beerby et al 1988), which need to be tested in future research. When used along with counselling, HRA can serve as a fulcrum upon which users of the instrument can balance both the health assessment and behaviour change efforts in a health promotion program. Computer-assisted instruments of risk appraisal are low in cost and easily accessiblity to the participants, are personalised and assist the health promotion practitioner in processing essential information quickly to enable effective counselling.

## Consumer education

In recent times consumers are more vocal towards their rights to be involved in decisions that affect their health. Types of information required by consumers relate to the acuity and stage of the condition. For acute conditions this information is mostly on action they need to take to obtain medical services, while for chronic conditions more information is needed as usually there is more than one problem and increasingly the patient has to be empowered to direct their own care. In some cases patients require information on the alternative choices available for treatment (e.g., Breast Cancer) and their implications on their future life style. Such information is necessary to ensure that informed consent is given.

Typically most of this information is provided to patients during consultations with their practitioner. A vast amount of information needs to be transferred to a patient who may not be in the most receptive state during a consultation. Patients also need time to reflect on this new information before taking decisions. There is also evidence that the lack of time has led to only a fraction of the opportunities for health education being used by GPs (Boulton 1983).

On the other hand some consumers who require information that concerns their health have been reticence in asking their doctor and have had to depend on sources such as newspaper agony columns, help line and phone-ins (Grunder and Garrett, 1986). This leads to the postponement of usually a preventive action until it becomes an issue that needs a visit to the doctor. Socially underprivileged groups are especially at a disadvantage, especially in countries where health is not provided under social welfare.

A project that illustrates many of these concepts is based in Cambridge, Massachusetts. The Harvard Community Health Plan, an HMO type of health service which envisages that over 5000 of their clients will have a home terminal connected to the health centres. In a pilot study of 150 households consumers received medical advice and general health information from the centre via a modem. The computer collects symptoms directly from the patient using an interactive protocol and generates advice, either recommending home treatment or to make an appointment. The information provided by the client is also channelled to alert staff to contact the home if there is a possibility of serious illness (Bergman 1993, Winslow 1992).

The advantages of this system are that it allows consumers to access the centre without delay, the patient's information is captured in the centre's electronic medical record and in a high percentage (30%) of times a visit is not required and it saves time and money for both the consumer and the Health Plan. In addition the system allows consumers access to a computer library to research over 250 relevant topics.

A similar concept of home terminals have been used in Minneapolis for patients diagnosed with cancer. This computer connection allows the patients to sieve information on options for treatment and prepare questions when they next visit the consultant (Gustafson 1992)

A public computer network is utilised in Cleveland to provide home-bound individuals to reach peers and professionals. Two ComputerLinks ( sets of specialised programs and utlities residing in the network) were provided, one for persons living with AIDS and the other for caregivers of persons with Alzheimer's disease (Brennan 1994).

In the eastern suburbs of Sydney a disability information and referral center has developed a computerised database that assists disabled persons (and service providers) to find services they need. This database has also enabled proxy measures of community needs for planning and indicators of consumer expectations and satisfaction to be ascertained (Ousman, 1994).

## Efficacy and effectiveness of consumer education

The main benefits of IT for consumer education are due to its ability to store large amounts of data (Bergman 1993) allow manipulation by the user and to address specific concerns (Tongue & Stanley 1991). In addition information is accessible to consumers without

restrictions in time. Advances in telecommunication has made it possible for consumers to access information from their home and networking has allowed the exchange of information among consumers (Milio 1992).

Computers are being used as repositories of community information. In Mersey Regional Health Authority, the access to health education material in computers in patient waiting areas are used to monitor health concerns and determine health education needs for populations ( Tongue & Stanley 1991).

The ComputerLinks in Cleveland were evaluated through randomised field experiments. This showed that it lead to improved confidence in decision making and facilitated the participation of clients in the health care delivery process (Brennan 1994).

## Future developments

Major advances in IT would have a considerable impact on computerised education for preventive action in the future. The main areas where current potential is seen are advances in:

- telecommunication technology
- data storage technology
- artificial intelligence
- use of multimedia

Advances in telecommunications would provide the backbone for carriage of digitalised information from consumers to central health units or providers. Networking capabilities would enable consumers requests to be transferred to the appropriate node. Consumers would benefit from computer conferencing between providers and through access to large databases that would suit their information needs. In a similar manner to the Educational Technology Network (ET net) where the US National Library of Medicine offers access to health professionals, a number of 'disease/disability' specialty libraries would be made available for special groups of consumers. Consumer managed 'bulletin boards' would enable them to exchange information including their experiences. Some of these have already been realised. On the other hand when such massive 'overload' of information is easily accessible to consumers, protocols need to be developed to guide consumers in using them efficiently.

The advances in data storage including optic disk technology would enable not only alphanumeric information but high quality graphics to be available for patient education and consumer education. Increasingly the computer games are developing the capability of providing children with visually appealing messages. A project utilised this concept even before such quality software was available to teach children how to manage their asthma by using a computer game called Asthma Command (Rubin et al 1986).

Developments in artificial intelligence, especially in expert systems and neural networks also have potential for preventive health. Typically they have been used to provide non-experts with the knowledge of experts in decision making. A great advantage expert systems possess, is their ability to feedback the reasons(decision rules) and assumption used. Consumers can be provided this information to verify whether these assumptions are correct

for decisions taken regarding their treatment choices. Such systems therefore have the potential to empower the consumer in decisions regarding their health.

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