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Research, public health and policy development

DAVID RANSOM

The management implications of information technology in research, public health and policy development are identified in this chapter. The dangers of applying global analysis to individual health care situations and vice versa are examined and the mechanisms that can be used to identify diffuse disaster in global and individual medical practice are explored. The chapter concludes by noting that a paradigm shift in health care policy towards client driven services has occurred. The implications informatics of this change for health are briefly discussed.

The avenues for research in medicine are almost unlimited. There is little doubt that information technology has made a major impact in the research carried out in many of the medical discipline areas. The field of public health and the related area of health policy formation has benefited very greatly from the rapid developments that have been made in the area of health informatics. Indeed medical epidemiology as a specialist area probably could not have developed the way it has in recent years were it not for the rapid advancements made in the field of medical informatics at a technical and organizational level. It must be remembered, however, that advances in technology and information theory do not of themselves lead to changes to medical research or practice. It is the acceptance by medical professionals of such new technology and the integration of new information handling practices into medical research and practice that has resulted in the advances we have seen in the fields of public health, medical epidemiology and health policy development. (Paul-Shaheen 1989)

It could not be said that developments in information technology have been the underlying stimulus for the development of new directions in health policy. Whilst the field of public health and health policy formation is highly reliant upon information technology much of the drive to advance these areas has come from the changing economic structure of health care. The economic pressures now placed on health care resources allocation and national and international health care budgets have been considerable. The upward spiral of health care costs seems inevitable. This appears to have prompted an almost frantic drive towards rationalization of health care. (Davis 1993)

The insatiable demand for health care information on the part of policy makers now faced with the economic reality of rising health care costs and effective reductions in health care budgets has artificially stimulated the field of health informatics. In layman's terms this scenario might be described as the field of health informatics having had a sudden rush of blood to the head. The explosion of ideas, network information systems, hardware and software platforms that resulted was both productive and destructive. Productive in that new information systems were appearing almost every week but destructive attempts to developing health informatics standards came too late. In many cases by the time the standards were published the health information field had moved ahead and developed in a way that made the new standard obsolete. Hopefully we are beginning to achieve a level of integration between the emerging standards and the technology itself. Indeed as the field of health informatics begins to spread into non medical areas and to integrate with other governmental, social and community based information systems the need for standards to facilitate data interchange has reached a high priority. Indeed health informatics providers at a technical information services level are now working with standards groups in a way that has not been seen before.

Medical health care providers have in the past been largely immune to the issues of cost efficiency at commercial level. Health care standards were set by professional medical bodies with little or no interest in the economic consequences of the health care policies. In the last ten years this attitude amongst health care professionals has almost completely died out. It is now clear to all that resources are limited and that economic factors will have an increasing role in shaping global and individual health care practices. Like it or not, health care providers are having to accept the fact that health policy is being determined by individuals from the fields of business and economics whose attitudes to health care outcomes, resource allocation and medical effectiveness may be very different to that traditionally found in health care professionals. (Feinglass ans Warren-Salmon 1990) The health power equilibrium has changed. If health care workers are to continue to play a part in health policy development they need to be empowered with the information and the skills in data analysis in order for their voices to be heard amongst national and international policy makers. The development of health informatics as a specialty for health care professionals is at last providing them with a new role as stake holders in health care planning. In this chapter we will look at a few examples of areas in which health care priorities and goals are being influenced by the growing resource to be found in health informatics.

Communication and data processing

When considering some of the technologies involved in health informatics it is important to recognise the distinction between information networks (communication) and the technologies involved in data processing. Health informatics in its broadest sense involves a very wide range of information technology including data processing, communication, networking and telecommunication. Indeed today telemedicine is one of the new emerging fields of health informatics and one which has the capacity to significantly alter the delivery of health care, particularly in rural areas and communities that are geographically isolated. A recent study (Scheider, Mann and Schiller 1992) predicted that in the United States of America 28 billion dollars could be saved in health care costs through the efficient use of telecommunications in the movement of patient management information. This study also identified that health care administrative costs could be reduced by 6.8 billion dollars through the use of modern electronic communications and data processing technology.

Recognition of the importance of electronic communications and the value of networking has resulted in a number of initiatives around the world. In Australia the development of the Health Communications Network is a sign of the significance that is placed on networking by health care policy makers. Medical information networks today comprise systems with advanced developments of central hubs and main data trunk lines. Many of the major medical and health care institutions are already connected electronically and developments in the links between these central sites will in the next few years lead to advances in the complexity and quality of the electronic data that can be communicated. Four major problems remain to be solved before telemedicine and the widespread use of health care information networks becomes practical reality.

The first of these is the education and training needs of health care professionals. A large commitment to training is required by health care institutions before these modern technologies become truly effective in the work place.

The second major problem to be overcome is that whilst the major institutions are well networked electronically the vast bulk of primary health care providers and indeed their clients are as remote from health care information and communication systems as they were ten years ago. This "last mile of wire" is almost certainly the most important mile as far as electronic communication and networking in health care is concerned (Blau 1993). The third major problem to be overcome relates to communication standards and electronic data interchange standards in health informatics. As commented before, it is essential that technology and standards develop in concert and until such a balance is achieved the absence of implemented international standards will remain a significant impediment to the establishment of worldwide health care related communications.

The final problem in health communications that has the capacity to significantly impair the development of research and health care policy is the community and social attitudes to telemedicine and health care networking. In particular issues in relation to medical ethics and the law with respect to privacy and confidentiality must be addressed. It must be said that medical ethicists and the legal professional have been slow to come to grips with modern information technology and the implication that it has for their discipline. Again it is essential that these areas are integrated with the development of health communications networks for such systems to be accepted by the community at large. For the field of health informatics to make any major impact on public health and policy development these issues relating to networking and electronic communication must be resolved.

For whom the bell tolls

The ability of policy makers to formulate health policy is intricately bound to the health care information service which provides them with the data they need. It has to be remembered, however, that the source of such health data ultimately comes from the grass roots level of health care. As we have already noted this is the very area which is least developed and prepared with regard to information systems. Despite this, health care workers in the field recognise the importance of information for health care planning. Whilst the task of data collection is onerous, there is now an increased understanding of the need for information in order that health services might be improved.

Where health interacts with non-health related agencies recognition of the importance of interchange of core information is less well recognized. This network disconnection can be seen particularly in the area of mortality data and death investigation. In many cases the individuals with access to this information do not come primarily from the health care field but instead from the legal and administrative organs of government. For health care planning to be truly effective health policy makers must be informed and provided with data from both the health care community and the associated legal and administrative services that impact upon health. The legal profession and the medical profession have at their roots a work practice that is related to the individual handling of cases so that work is carried out on a case by case basis dealing with each case as an isolated event. For many years, however, the medical profession in particular has reaped the benefits, in terms of research into the understanding of disease and health care planning, of the analysis of groups of cases that show similar features. Not only do such group analyses lead to increased understanding of disease processes, therapeutics and health care but they increase the efficiency in which medical professionals can undertake their work. Such analysis of groups or collections of like cases is rare within legal systems including death investigation systems such as coroners or medical examiner systems. Yet if we are to learn from those defects in society that result in death and injury we need to be continually reminded of the risks and dangers in the community. Similarly those who have the responsibility and power to make our society safer including health care policy makers need to be reminded and continually charged with that duty and alerted to the information that is available from the organizational areas outside health care.

The development of health care policy and health care plans for prevention of disease and injury remains at the forefront of public health. Many of the initiatives and directions taken to improve health and safety fall within the framework of community education. There are many clinicians, pathologists, epidemiologists and indeed lawyers who see this educational and preventative role as one of the most important goals of any health care information system. The reality, however, is that at the grass roots level those charged with the social investigation of death and injury are not integrated with the health care information system. If each injury and death is to play a part in moulding and shaping public health policy leading to a healthier and safer community the information revealed by such tragedies has to be communicated and analysed by policy makers. The absence of such data communication makes us all vulnerable. As Donne said "Ask not for whom the bell tolls, it tolls for thee".

Disaster and diffuse disaster

In examining the ways in which health informatics resources can contribute to public health and policy development it is useful to consider the notion of diffuse disaster. In a mass disaster the entire society including its medical, political and administrative officials is alerted. This is turn stimulates sympathy, concern and practical action in the form of response activities designed to deal with the injured, the loss of life and destruction of community and property. Inevitably in the case of mass disasters there is a post disaster investigation process that examines the cause and the response to the disaster. In addition detailed investigations are directed to determine processes and mechanisms to prevent the hazardous situation occurring again. Essentially it is the manner in which the extent of the disaster is communicated to the public and the response agencies that determines the nature of the eventual investigation and preventative processes. The diffuse disaster is very different Deaths, injury and disease are with us every day. They form part of our unconscious acceptance of life in our community. Not all of us will experience deaths or severe injury, not all of us are informed of death or serious injury, not all of us are aware of the suffering deaths or injuries cause but nonetheless such morbidity and mortality is present throughout our community. It is the wide temporal and geographical distribution of these events that prevents them being perceived by the community as a disaster. Yet if one was to view the incidence and prevalence of such morbidity and mortality with the temporal and geographical factors removed they would indeed form a true mass disaster. For example if one-tenth of the murders in Australia were to occur at a single place at a single point in time from the actions of a single person there would be a national outcry yet murders and other forms of violence and non accidental injuries occur throughout our community all year round. As a result of this failure to identify the collective nature of such diffuse disasters, their investigation is impeded and their significance is lost on the community. As a result the drive from the community for action in relation to the prevention of such deaths or injuries never occurs.

The above issue is easy to comprehend when one examines death, non-accidental and accidental injury. However, the concept of the diffuse disaster can also be found in the area in natural disease. The concept of the diffuse epidemic is well recognized and much medical research today involves the identification of similar or like cases of disease. Such pattern based disease analysis forms one of the cornerstones of medical epidemiology. However, our ability to identify patterns and trends in disease in the community is strictly limited by the quality and quantity of the data that are obtained and analysed. A disease process may be so rare that only a single case occurs in the world each year. Yet if we have one hundred years' worth of data a pattern and trend might be identifiable. The information gained on the diseases aetiology and pathogenesis might have implications for a number of co-related disease processes whose origin continues to remain obscure.

Examples

Infectious disease

Possibly the best example of the way in which health information has influenced research, public health and health policy development can be seen in relation to communicable diseases. Indeed the very foundations of medical epidemiology come from research that led to an understanding of the infectious nature and pathogenesis of communicable diseases. The outstanding success of organizations such as the Center for Diseases Control in Atlanta and the various Departments of Epidemiology, Community Medicine and Social and Preventative Medicine worldwide have established the place of medical epidemiology and statistics in medical science. Information gathering and data processing has certainly been one of the major tools employed in these disciplines. In recent years the rapid expansion in health informatics together with network and communications services has led to a transformation in communicable disease surveillance including the identification of infectious hazards. In 1984 an information system was established in France to provide for national surveillance of communicable diseases (Garnerin and Valleron 1992). This information system allowed both data entry and information retrieval as well as interpersonal communications. The backbone of the system was a relational database and a telephone dial-up network to a Videotext server provided the access to the system. This network was established by the National Department of Health and the National Institute of Health and Medical Research in France and was based on the belief that

"improving the quality, adequacy and rapidity of response of public health systems depends mainly on the ability to refine the processes implemented to collect, analyse and distribute needed information and reinforce interpersonal communication between different partners."

It should not be thought that the use of information and communication networks solves all problems with regard to the notification of infectious diseases. Studies from the Center for Diseases Control in Atlanta have demonstrated (Birkhead et al 1991) that delays occur even when data is reported via the National Electronic Telecommunications Systems Surveillance in the United States. These delays were recognized to occur across a very wide geographical area and reinforces the difficulty for health care planning when there is little standardization between the organizations that provide the basic data. It is clear that the difficulties in timeliness of data on national electronic networks does not relate to the complexity of the technology employed nor to the network structure. Instead the major difficulties are experienced at the grass roots level with the data providers. Education of staff and standardization of human organizational procedures involved in the provision of primary data sources is an essential step to take in ensuring the success of these national networks.

Quality assurance

Current economic models of health care delivery are looking more and more towards output measurement for identifying successful health programs and efficient health care services. Quality assurance and control are two essential elements in ensuring that health care provision is both effective as well as efficient. Whilst quality assurance systems can be found at all levels within the health care system they are most clearly identifiable within a hospital and laboratory environment.

Hospital information systems have in the past tended to concentrate upon the areas of financial management and patient administration. In recent years, however, there has been increased recognition that hospital based information systems have a role to play in health care quality assurance (Selbmann and Pietch-Breitfeld 1990). An important factor in these quality assurance systems is that if data are collected from the global health environment of a hospital it is possible to identify not only quality levels of individual items of health service but also information relating to total patient outcome. This whilst highly desirable in an economic and health policy sense carries with it a number of potential dangers if such global data taken alone is used to influence individual patient based health care practice. An example of this issue can be seen in the situation that arose in the Ford Pinto case. Here a situation arose in relation to vehicle manufacture. The company identified that a minor increase in the cost of the vehicle would have led to increased safety for the occupants. Whilst this would add a very small amount to the cost of each car it amounted to a substantial overall sum for the manufacturer. An individual purchaser of a car may have been prepared to pay the small increased cost of the modification had they known of the risks of not having the modification to the vehicle. The manufacturer would not have seen this small purchase cost factor as they saw the cost in terms of the millions of dollars of additional manufacturing costs. In the final event, however, the manufacturer when looking at global costs decided not to proceed with the modification. Subsequently successful legal action was taken against the manufacturer by injured parties demonstrating the danger of taking this global cost saving approach. Quality assurance issues in medical informatics also overlaps with the field of infectious diseases particularly in the area of infection control and antibiotic therapy (Scott Evans and Pestontnik 1994). Health informatics systems have much to offer in the area of monitoring of adverse drug reactions within hospital audit systems, patient outcome measures and planning of new or reviewed health care systems.

Assessing the quality of health care is now a mandatory task in almost all major health systems. The financial limitations placed on the growth of the health care industry in modern times makes the need for information, that can be used for health care planning, all the more intense.

Death investigation

Death Investigation takes place at many levels. Death investigation processes can be seen at their simplest level in the case where a medical practitioner assesses the death of their patient and signs a death certificate. In a hospital setting this same process can occur but with the added facet of a hospital autopsy and/or a clinicopathological audit process. Where formal investigations are performed it is the coroner's or medical examiner's systems that bear the brunt of detailed death investigation.

The legal process of such investigation processes, albeit carried out by medical practitioners, has in the past resulted in cases being investigated on a case by case basis with little concern given to the patterns of injury that might be identified by a systematic analytical approach to death investigation. The analysis of collections of like cases is rare within coroners' systems and yet if we are to learn from those defects in society that result in death we need to be continually reminded of the risks and dangers around us. On a random case by case basis this is extremely difficult for a coroner's system to identify potentially significant fatal hazards in our society and yet at the same time coroners and their supporting investigatory medical agencies are in a position of having access to a wide body of information relating to such groups of death. It is of particular interest that the coroners' and factors that have contributed to the death. While several countries today are attempting to collate and analyse national data from death investigation systems there is no coherent system available anywhere in the world.

Coronial systems were originally created to gain wealth for the crown. Despite this their potential use as agents for the identification of preventable hazards in society has been long recognized. In 1907 William Brend wrote that:

"the value of the (Coroners) statistics is diminished by the absence of coordination hence we have the anomaly that while a full enquiry is conducted into deaths from violent and unnatural causes, practically no subsequent use is made of the information for public health purposes" (Brend 1907 p.140).

In 1915 the same author wrote "if prevention of death is not now regarded as the main purpose to be served by inquest enquiry becomes of relatively little value." (Brend 1915)

In Australia today the role of the Coroner in the prevention of deaths is well recognized and medical informatics including data analysis, networking and communication systems is playing an increasing part in bringing together death and injury data for the benefit of the community. The National Injury Surveillance Unit is actively pursuing information system networking to allow investigatory agencies to analyse group death and injury data. National databases are becoming established with regard to particular health problems and Australia has the world's only national sudden infant death database which is available to researchers in the fields of medical epidemiology and basic medical science.

In 1991 the Australian Royal Commission into Aboriginal Deaths in Custody (1991 para 4.7.4) stated that:

"moreover, in human terms, thoroughly conducted coronial enquiries hold the potential to identify systemic failures in custodial practices and procedures which may, if acted on, prevent future deaths in similar circumstances. In the final analysis adequate post-death investigations have the potential to save lives."

The construction of a national coroners database is now underway in Australia. Recent case studies in Victoria have demonstrated the success of such an approach. In the three year period between 1987 and 1990, 20 fork lift related deaths occurred in Victoria. These deaths represented a significant increase over the 22 such deaths that had occurred in the previous ten years. Group analysis of these cases by the coronial systems led to identification of a number of risk factors resulting in these fatalities. Fork lift operation and design factors associated with fatal hazards were identified and a number of recommendations were made. The implementation of these recommendations have resulted in a significant reduction in such fatalities. (Coroners Case 1990)

Analysis of deaths related to Methadone overdosage in 1989 in Victoria revealed a sudden and unexpected increase in fatalities amongst intravenous drug addicts who had just commenced a Methadone maintenance program. As a result of the identification of these, recommendations were made regarding the assessment of drug dependent persons admitted to the program. Medical education and training regarding drug addiction treatment programs was increased and deaths from Methadone toxicity were substantially reduced (Drummer et al 1992). The difficulties of data collection and analysis in the area of death investigation are considerable. Countries with national death investigation systems are at a considerable advantage in having a uniform and consistent data source. The reality, however, is that legal death investigation systems are most commonly based on local jurisdictions which operate independently from each other. In the United States there are over 2,000 separate death investigation jurisdictions, each operating essentially independently of the other. Such a situation makes the task of integrating information systems almost insurmountable. The Center for Diseases Control in Atlanta has been working with the national association of medical examiners to resolve this problem. Today their stated goals are:

- to obtain more timely, accurate and complete information on sudden unexpected deaths
- to better understand the causes of those deaths
- to reduce the mortality from those causes that are amenable to public health intervention." (AJFMP 1989, p.88)

Death investigation is of course only a part of the picture. Injury analysis is receiving the same attention from public health practitioners and medical epidemiologists. The National Injury Surveillance Systems are beginning to address these issues. The cost of injury to our society has been grossly undervalued in previous years and injury control and prevention is only now becoming part of national health policy.

Organisation theory and health care

The organisation of health care systems have undergone a paradigm shift in recent years. Fiscal restraint, increasing commercialisation of health care, community pressures and reevaluation of health goals has led to a much changed environment. In many ways, changes in health care provision have followed the changes that have occurred in the world of business and commerce.

"The war of business has shifted onto a new battleground. In the 1960s marketing was the watchword to achieving competitive advantage. In the 1970s manufacturing became the hot topic and in the 1980s quality. Now competition has arrived at the fourth battlefield customer service." (Davidow and Ittal 1990).

The shift towards client services and client satisfaction as a marker for the success of health care systems represents a fundamental change in the way health care is delivered. The classic centralized systems of state based health care where policy decisions percolate down to the periphery of the health care system, is being replaced by regionalized systems where much health policy is made at a local level in response to the stated needs of communities. This devolution of policy and control represents an enormous challenge for health informatics systems in the next decade. Indeed it could be argued that for such a diffusion of health policy and power to be successful, health information systems will have to play a major part in providing the glue that holds these regional health care systems together. Current analysis of modern information technology itself recognizes the way in which informatics systems are becoming a crucial component of modern organizational structures.

There are major strategic developments in IT itself which are now maturing to the point of practical commercial application. Of key importance are:

- office systems and applications for the workplace.
- communication technologies which provide open networks and value added network services.
- information management techniques including imaging, hypertext and object orientated paradigms which enable the electronic capture and use of unstructured records and soft information, and also a richer interpretation of knowledge.
- fourthly, there is a growing maturity in the management of IT with the recognition that this function should be managed in the same way as for other parts of the business. This includes the need to manage IT expenditures as investments with the assets generated being managed as are other assets, including the concept of return on investment and life cycle maintenance." (Lovell and Olson 1991)

Many of the old views of information technology including those originally applied in the area of health informatics are being eroded. Today we do not see health informatics simply in terms of databases to be used for research, hospital administration, patient record systems or appointment systems. The availability of new technologies for the electronic communication of images and the analysis of textural and relational information have radically changed the way in which health informatics can take part in the formulation of health policy and contribute to medical research and public health.

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