EVIDENCE-BASED MENTAL HEALTH CARE & POLICY:

Filling the gap between clinicians, decision support experts and care decision makers

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Abstract

Evidence-Based Healthcare (EBH) group together heterogeneous data from the real world to make decisions with regard to resource allocation, planning, incentives and setting up barriers. The complexity, uncertainty, dimensionality and multiscalarity of the questions posed in mental healthcare planning, make it necessary to integrate a whole array of different disciplines, research fields and techniques of analysis. In this conceptual paper we provide a brief outline of three main areas of interest with regard to EBH in mental health: Outcomes Management (OM), Knowledge Discovery from Data (KDD), and Decision Support Systems (DSS). The increasing complexity of the information transfer and the knowledge induction process creates gaps between different stakeholders and experts in the processes of EBH. It is important to promote bridging strategies among these new fields in order to enhance communication and information transfer between the different parts involved in mental health decision making: 1) clinicians and epidemiologists, 2) decision support experts, 3) care policy makers and 4) health providers, 5) consumers and other end-users. The example of the PSICOST/RIRAG research network in Spain is presented to illustrate this collaboration with care planning agencies, particularly with the Catalan Department of Health .

Key words: Mental health care, Outcomes management, Knowledge Discovery from Data, Decision Support Systems

Introduction

In the late 1980s three seminal events set up the pillars of what is now called Evidence-Based Healthcare (EBH). In 1988, Paul Elwood conceptualised Outcomes Management (OM) within the public health and epidemiology context as ‘a technology of patient experience designed to help patients, payers and providers make rational medical-care related choices based on better insight into the effect of these choices on the patient’s life’ (1). The term “Knowledge Discovery from Data” (KDD) was used at the 1989 “International Joint Conferences on Artificial Intelligence” to define the overall process of finding and interpreting patterns from data, involving the application of specific data mining methods and the interpretation of the patterns generated by these methods (2). Computerised Decision Support Systems (DSS) are defined as interactive computerised systems which provide operational and/or heuristic support to end-users in decision process of otherwise formally intractable problems. Mental health decision support systems and Information Technology (IT) started in the public administration sector in the USA in 1989 (3). These multidisciplinary fields address similar problems in different contexts and use overlapping tools. They are concerned with real world data collection, large data base analysis and the derived knowledge relevant to adequacy, equity, efficiency, and effectiveness. When Gray set up the grounds of EBH in 1997 (4), he just mentioned four techniques applied to decision making in EBH: statistics, meta-analysis of medical interventions, health economics and decision support modelling (i.e. markov analysis) (4). Neither OM, DSS or KDD were included in Gray´s EBH construct. As a matter of fact, at

that time, the gap between the ideal scenarios of randomised control trials and real healthcare world constituted a practical difficulty in EBH as being discussed. In order to reduce the gap between experimental research and real world decision making, it has been necessary to apply increasingly complex techniques coming from very different fields, including engineering, business or even agriculture. This multidisciplinarity and the distance created by merging different fields produced communication barriers between the consumer, the decision maker, the service provider, the clinician and the decision support expert. These difficulties mirrored the problems between clinicians and health economists during the mid 1980´s, when the concepts of equity, effectiveness and efficiency were making their way into the health policy arena. Since 1997, KDD, OM and DSS have begun to merge and EBH has incorporated specialists from very different disciplines. Setting up communication links and bridging between the different health parts is a key aspect of this process. We provide here a brief summary of these interconnected fields and the bridging process which is taken place in Spain in relation to the PSICOST/RIRAG research network.

Outcomes Management in mental healthcare

Paul Ellwood foresaw four major characteristics of Outcomes Management in 1988 [1]: 1) Appropriateness which relied on standards and guidelines that physicians could use in selecting appropriate interventions; 2) Routine Outcome Assessment (ROA), which should be based on routine and systematic measures of patients' functioning and well-being, along with disease specific clinical outcomes at appropriate time intervals; 3) the link to data mining, in order to pool clinical and outcome data on a massive scale; and 4) a focus on dissemination and impact analysis that should take into account the segment of the data base more appropriate to the concerns of each decision maker .

He also stated that the assessment of effectiveness and efficiency should be based, not only on the outcome of individual patients, but on the outcome of health services as well. ROA incorporated many more domains than traditional clinical research, such as well-being, functioning, general health status, disability, satisfaction, health preferences, service use and burden. Each of these domains can be represented by a wide variety of indicators and sources of data, part of them being large health databases. Computers and automated clinical information systems could be used for monitoring clinical practice, and that links OM to DSS. The problems in obtaining psychiatric information from primary care records, and the technical aspects of ROA have been revised elsewhere (4).

OM has not penetrated into the mental health sector as in other areas of medicine. This may be attributed to the characteristics of the target population (particularly the complex interaction between functioning and symptoms, and the unique care pattern of specific groups such as drug-addiction, child psychiatry or intellectual disabilities), the special characteristics of the mental healthcare system in comparison to general health care, the overlapping of health and social care in psychiatric interventions, the different data sources which in many occasions differ from general data sets, the lack of internationally agreed indicators, and the diversity in service availability and their changes over time (5).

In the last decade, a significant progress has been made with regard to the standardisation of research methods on services and outcomes in mental health. Among these contributions we may highlight the Thornicroft and Tansella Matrix for the description of mental health care (6), the design of a comprehensive system for coding and comparing services in small

health areas (7,8); the development of a minimum set of indicators for international mental healthcare assessment (9, 10); and the standardisation of a number of instruments for the assessment of geographical areas, services, outcomes and costs. Psychiatric epidemiology has incorporated the outcomes management approach, particularly in the context of international studies. Outcomes management epidemiology focus on domains relevant to health policy such as service use, burden, satisfaction or costs (11, 12, 13, 14, 15, 16). The World Health Organisation has contributed to the expansion of OM epidemiology (i.e.WHO World Mental Health Survey Consortium) (17). WHO has also played a major international role in increasing the visibility of mental disorders into health policy by mapping mental health indicators worldwide (10), and by analysing the burden and related cost-effectiveness of mental diseases (18).

Knowledge Discovery from Data in mental health care

"Knowledge Discovery from Data" (KDD) combines data mining methods with different tools for extracting knowledge from data in burden, cost-of-illness, effectiveness and efficiency analysis. In KDD methods from statistics, operations research, computational science, information systems, artificial intelligence, visualization and association algorithms are used in a cooperative way to face the knowledge acquisition mainly from huge data bases. KDD was originally developed and used in the business sector and in environmental research. The complexity problems faced by information analysis in these two sectors have been recently described by Spate and colleagues (19) and they are common to the healthcare field:

1) Multidisciplinarity. KDD is a multidisciplinary field where integration of different social and scientific disciplines and techniques is necessary.

2) Ill-structured and non-linear domains. As nature and environmental systems, healthcare is non-linear. Due to its high complexity it is difficult to formulate with a mathematical theory or a deterministic model. Ill-structured domains are mainly characterized by involving heterogeneous data (quantitative and qualitative data) and by the existence of additional knowledge of the domain, which is usually partial and non-homogeneous (21)

3) High dimensionality and multiscalarity. Multiple factors are acting at many different spatial and temporal scales.

4) Heterogeneity of data: Health decision making in the real world should take into account data from numerous sources.

5) Uncertainty and imprecise information. As in environmental research, data collection in healthcare "is often expensive and difficult, measurement error is often large, and spatial and temporal sampling may not fully capture system behaviour. Records may also contain missing values and highly uncertain information" (19).

Other two problems are particularly important in mental healthcare in the real world, low controllability of the processes and intrinsic non-stationarity. Environmental processes (and mental healthcare) are in general not static, but evolve over time. The assumption of stationarity cannot be justifed in many processes related to mental health.

In 1996, Fayyad and colleagues (2) set up the principles of KDD. The basic knowledge discovery process included a series of steps and a broad spectrum of techniques from different sources (19). A significant contribution of KDD was the development of strategies alongside the data mining process to improve information transfer from clinicians and

decision makers to the KDD expert and viceversa, using mixed qualitative-quantitative techniques. These steps include:

1) Developing and understanding the domain, capturing relevant prior knowledge and the goals of the end-user,
2) Selection of target data from the large (health) data base,
3) Data mining process (pre-processing, transformation, cleaned dataset processing),
4) Interpretation and evaluation of data mining results to produce explicit knowledge from the original database (post-processing).

A series of procedures have been developed to enhance communication and information transfer both for selecting target data and at the pre-processing stage (i.e. ClBR: Clustering based on rules and Knowledge Discovery in ill-structured domains) (22). It consists of a mixture of two main elements: on one hand, an Artificial Intelligence process that manages a knowledge base (KB), which includes prior medical knowledge, even if partial, and on the other hand, a later clustering process that is biased according to some induction on the KB.

Pre-processing includes data cleaning, outlier detection, missing value treatment, transformation and creation of variables. The different techniques involved in the outlier detection and handling of missing information have been thoroughly revised by Spate and colleagues (19). Automated techniques for identifying and carefully removing unhelpful, redundant or even contradictory variables usually take one of two forms: statistical examination of the relevance properties of candidate variables and combinations of the same, or searching through the space of possible combinations of attributes and evaluating

the performance of some model building algorithm for each combination. Principal Component Analysis (PCA) and Boolean (presence/absence) marker have been used for reducing datasets that may contain redundant or irrelevant variables. Other techniques are based on feature weighting (23). A key phase both in pre- and post-processing of data is visualization. Visualization techniques enhance information transfer between KDD experts and clinicians.

A large number of statistical and AI methods are used to classify elements in KDD. Clustering techniques are used to discover the underlying structure of the target domain, if this is unknown. When the identity of the target classes are known, the goal is to find those variables that best explain the value of this target, either for description or prediction of the class of a new element. Three AI methods used in KDD problem-solving and reasoning are Case-Based Reasoning (CBR) , neural networks and decision trees. The last is the best known models of classification. Classical linear regression and nonlinear regression are mainly used for prediction of the target variable, and for identifying which variables have the strongest influence on the behaviour of the response variable. Regression trees are middle way methods between these two approaches of classification and regression.

Rule induction or rule extraction is the process of discovering rules summarising common or frequent trends within a dataset (i.e. which variables and values are frequently associated). Association analysis is the process of discovering and processing relevant relations from a dataset. Rule extraction algorithms, are used both for variables´ association and classification.

At last, knowledge management includes the validation of the results and the integration of different knowledge patterns for a predictive task, or planning, or system supervision, together with mixed artificial intelligence and statistics techniques. As a final stage it is important to consider the knowledge use by policy makers or health decision makers (19).

The incorporation of a knowledge-base strategy to the data analysis process implies a considerable advance. It improves the quality of information analysis from large health databases (24), or small samples (i.e. use of Data Envelopment Analysis to estimate technical efficiency of small health areas in the USA) (25). Other interesting approaches are the use of bayesian analysis in cost of mental illness (26); new applications of multivariate analysis to health care (i.e. Centroid Voronoi tessellation in service assessment) (27), or spatial analysis in mental health econometrics (28). Spatiotemporal data mining is a growing field of interest in KDD. It may be useful for spatio-temporal pattern identification (as in pattern analysis, neighbourhood analysis), data segmentation and clustering (spatiotemporal classification), dependency analysis, correlation analysis and fault detection in data (outlier detection), trend discovery, sequence mining (as in regression analysis and time series prediction). Geographical Information Systems (GIS) are computerised systems to analyse, map and visualise geo-referred spatial data. These are useful tools for assessing spatial relationships of health indicators, programs and resources in public health care. The usefulness of GIS in mental health have been shown in several recent studies (29, 30).

Decision Support Systems in mental health care

In 1989 Walter Leginski and his colleagues in the U.S. Department of Health and Human

Services argued that the questions asked by clinical managers and service administrators could be reduced to a set of five general questions: “Who receives what services from whom, at what cost, and with what effect?” (3, 31). Leginski set up the principles of service assessment, taxonomy and the indicators to be included in a minimum data set to be incorporated to decision support systems in mental health care organisations. Computerised Decision Support Systems (CDDS) include data on population, enrolment, financing, service use, human resources, organization, performance indicators, and consumer outcome data. This interactive computerised systems provide support to end-users in the decision process of real world care problems under conditions of uncertainty. Several DSS have been developed in mental healthcare. A number of them derive from previous clinical information systems. The Medical Informatics Network Tool (MINT) is a software system that supports the management of care for chronic illness used in schizophrenia (32). The *Decision Support 2000+* has been developed by the US Mental Health Statistics Improvement Program (MHSIP), supported by the Centre for Mental Health Services (CMHS) and the Substance Abuse and Mental Health Services Administration (SAMHSA). It is intended to improve decision making, services, accountability, and effective communications within the mental health system as well as between it and other human service systems. It is intended to span the entire mental health system, from epidemiology, to service delivery and to outcomes; to link with information systems in a broad range of agencies, locations, programs, and organizations; and to facilitate clinical and organizational decision-making and enhance the quality of care (33, 34). DisMod is a specific DSS software tool developed by the WHO Statistical Information System (WHOSIS) (35). It was primarily designed to help disease experts arrive at internally consistent estimates of incidence, duration and case fatality rates for Burden of Disease

Study. DisMod uses a life-table approach in following an initially disease-free cohort over time while applying the risks (incidence, remission and case fatality rate etc.) associated with a disease, and the competing risk of all other diseases, as represented by general mortality. The model then uses the age composition of a given population to derive epidemiological measures consistent with the assumed levels of incidence, remission, and case fatality. Thus, the model requires four inputs for each disease. These are: a) Incidence rate; b) Remission rate; c) Either case fatality rate or the relative risk of mortality (that is, the excess of general mortality attributable to the disease). In the real world, exposure of a susceptible population to risks of disease occurs continuously, rather than at the end of discrete time intervals. DisMod simulates this phenomena by means of an exponential decay function. In other words, the size of the susceptible population is viewed as continuously decreasing as individuals progress to disease. Using this competing risk approach, the DISMOD software calculates the relative proportions of each cohort that will develop, recover from, or die from the disease, die from other causes of mortality, or continue to live disease-free.

DSS are capable of demonstrating associations between patterns of care and patterns of outcome, but at the local level, they cannot provide unequivocal answers that the patterns of care have caused the patterns of outcome (31). Thus, managers need additional data on other patterns of performance to support decisions stimulated by effectiveness results. The DSS may not be limited to the above mentioned computerised systems, but it may integrate all the other methods and techniques mentioned in OM and KDD.

The PSICOST/RIRAG approach to KDD/DSS in mental health

In 2002, the Spanish Health Research Funding Agency (Instituto de Salud Carlos III) funded a research network on Outcomes Management in Mental Health and in Disabilities (RIRAG). The PSICOST/RIRAG research network incorporated data analysts from different fields (data mining, operations research, statistics, Bayesian analysis, and GIS), as well as clinicians, public health experts and epidemiologists. The research network hold national 8 meetings from 2002 to 2005 in order to agree a common terminology, and a framework in mental health EBH. It started applied research projects with several health and social agencies within Spain in order to facilitate bridging and information transfer with decision makers and planners both in the health and in the social public administration. This cooperation was set up with the National Agency of Social Affairs (IMSERSO) to develop a standard assessment system of services for mental illness, disabilities and the elderly population based on information technology (36). We also worked with the Spanish Ministry of Health providing specific reports on the mental health care system in Spain (outcome management epidemiology; financing, health data bases, and other aspects), in cooperation with the Spanish Society of Psychiatric Epidemiology (SEEP). Other part of our work related to key care policy foundations within Spain (i.e. Fundacion BBVA) and to the regional agencies on mental healthcare and social care in a number of Autonomous Communities (ACs) in Spain.

PSICOST/RIRAG made an analysis of the Catalan mental healthcare system in comparison to other three ACs in Spain and in Italy (8). This report was discussed with different stakeholders in four Spanish ACs and it was taken into account in the development of the new Mental Health Plan of Catalonia (37). This project was part of the knowledge-building

objective of the mental healthcare agency of Catalonia to enhance mental health EBH planning in this AC. Other collaborations with PSICOST/RIRAG members include the development of a minimum indicator set, a unit cost listing for mental health care, the mental health atlas in several Spanish ACs, service use, health economics and outcomes management epidemiology studies. The participation of some of the groups of the network in the WHO Mental Health Surveys Initiative (http://www.hcp.med.harvard.edu/wmh/) has allowed the analysis of unmet need and adequacy of care in mental health.

This supplement includes a series of studies derived from the cooperation between research networks in mental health and related agencies in Spain, particularly with the mental health agency at the Catalan Department of Health. Salvador-Carulla and his colleagues present a coding system and a standard a instrument developed for the Spanish Agency of Social Affairs (IMSERSO) to describe and classify disability services (DESDE). It is is based on the European Service Mapping Schedule (ESMS) an has been adopted in several ACs as a core information system for future DSS in disabilities (www.proyectodesde.com). Pizzimenti and colleagues from the RIRAG research network, describe the service utilisatition patterns of patients with schizophrenia in one small area in Catalonia in comparison to other three Spanish local health areas. Gutierrez-Recacha and colleagues analyse the cost-effectiveness of psychiatric interventions for schizophrenia in Spain using the WHO's disease modelling tool for burden estimates and projections, DisMod II, based on disability-adjusted life years (DALYs) averted. Serrano-Blanco and colleagues from the ETAPS group and the RIRAG network present a study funded by the Catalan Agency for Health Technology Assessment and Research on the cost-utility of selective serotonin

reuptake inhibitors (SSRIs) for treating depressive disorders prescribed in Primary Care (PC) in Catalonia.

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