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From Bridges to Super-Highways: Transmitting Meaning Within and Between Professions, and Across Time and Space - Beginning the Process

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Abstract. As development of health informatics, including electronic patient records, proceeds apace there is an innate tendency to focus on acute and primary care, and upon bio-pathological data sets. This is where virtually all research and investment is being directed. However, the core purpose of health care (and mental health care in particular) is to improve and maintain the individual's functioning and sense of well-being, not simply to eliminate adverse pathology. It is therefore vital for health care records to contain subjective, descriptive, and self-expressed components if the record is to have true health meaning. This in turn raises challenges about meaning and context, terms and language. Most informatic systems run the risk of being Islands of Automation, linked at best by bridges conveying data sets rather than knowledge. If health informatics is really to serve people and their health, attention needs to be given to developing the recording, communication, and understanding of perception through shared meaning. Only then will informatics systems be full supporters of the people's health, and record system linkages become Super-Highways of Knowledge between patients and their supporting professionals.

1. Introduction - the Communication of Health Perceptions

Mental health services (which comprise 10% of all healthcare need and expenditure) are by their nature diverse, with care being provided by numerous professional groups in a variety of settings. Moreover, mental health care is dependant upon patients' subjective descriptions of their feeling states which are then interpreted according to the perspective of the individuals who record these occurrences. Therefore, the patient record has a pivotal role as a means of communication and co-ordination of care.

Somatic (acute physical care) services may feel that their recording and communication requirements are more objective, empirical and straightforward, but this denies the essential human focus of healthcare - the enabling of persons to optimise their health, wellbeing, and functioning in society. Whilst mental health services are fundamentally based on patient perception and wellbeing, other services are enriched if they too adopt functioning and belief components, and avoid the trap of developing a solely biological data warehouse model of electronic records matching a repair shop model of health care.

However, the recordings made by individual clinicians and the meaning attributed to these, which form the basis of clinical decision making in mental health and should inform clinical care in all sectors, have a high linguistic and interpretative vulnerability. The reliance on patients' subjective accounts, and subsequent interpretation of this data by various professional disciplines, presents a number of challenges when attempting to progress towards a truly holistic and integrated approach to patient care. The major challenge is that of sharing the meaning of the data in a way which reflects the patients' reality and coherently informs clinical intervention.

2. Meaning and Language

Attempting to define meaning has occupied the minds of linguists and philosophers for centuries and as yet has not been satisfactorily resolved [1]. While there is no generally accepted definition of meaning, this does not absolve health care professionals from exploring and grappling with such issues. Semiology and anthropology emphasise the structural nature of meaning. Within these perspectives meaning is determined by symbols, which are associated with social life and determine thought and perception. Thus meaning is socially constructed and language has a critical role in shaping the social construction of reality.

In the health care setting the meaning-making process is a social one, and being able to make sense of what is going on as a health care professional requires making sense of this sociability [1]. Making sense of sociability, however, requires more than simply attaching a personal meaning to the experiences of others. Sharing meaning in social relationships involves the deep processes of understanding someone else's ways of thinking about their experiences in the world [2].

Language is the medium by which meaning is conveyed between persons. However, this is more than a vocabulary comprising words with attached definitions - semantic rules are necessary to provide the context, which creates significant meaning. Moreover, the meanings of words also change with culture and geography, and this is particularly significant with vernacular language, which is often a key element of patient self-expression and description of their health problems and perceptions. Given the intensely personal and dialogue-based nature of mental health care and its related assessment and recording, recognition of the context-specificity of words, and of formal terms, is essential in the long-identified challenge of developing a common language of care [3].

Within the health care domain there exists among professionals a variety of conceptual systems that inform the construction of meaning. Navigating through such complex systems increases the risk of misunderstanding within and between professional disciplines. Moreover, and inappropriately, they have the effect of alienating the patient [4].

How then do we begin the process of attempting to reconcile our differences? How do we build bridges within and between disciplines and with patients in an attempt to make health care meaningful and effective?

3. Meeting the Challenge

Within mental health care the patient record is the primary means through which meaning is transmitted, and in this recognition of the value of the integrated record mental health has been ahead of other domains [5]. The significance of the record is further enhanced given the likelihood of such a document supporting the patient for a considerable portion of their life span. Added to the complexity of transmitting meaning for a particular episode of care between professionals and patients is the challenge of transmitting it across a time span complicated by changes in knowledge, understanding and fashions in approaches to treatment and care.

The value of the electronic record in mental health as a means of building bridges between care providers for an individual patient has been identified [6]. However, without a means of conveying meaning across those bridges they remain merely expensive architectural impositions on the landscape. In attempting to meet these challenges the Hospitaller Order of St. John of God is proceeding towards developing an holistic, integrated electronic patient record which represents the patient rather than a multiplicity of differently formulated views of the patient [7]. In so doing it is drawing on earlier lessons and analyses [8-10] and in particular the importance of accommodating human values as the core element [11].

However, simply structuring the record to collate and present facts is not enough - such structures of themselves merely act as navigation tools around Islands of Automation [12]. The patient record, rather than being a static account of discreet episodes of care, must become a dynamic tool, which is an active means of transmitting meaning between individuals. Included in the dynamic record must be components, which represent patient circumstances and preferences, and future plans of action mapped against purpose and intended outcome [13,14]. The dynamic element of the record must include automatic indication of when health or care delivery deviate from the expected or the intended [15,16], and all these factors must be capable of meaningful anonymised aggregation to provide service level information.

4. The Hospitaller Order of St. John of God Project

The Hospitaller Order of St. John of God, County Dublin, a mental health service provider, is working towards a comprehensive, clinically driven patient-based record, available on multiple sites, in real time, which would capture, store, retrieve and process a longitudinal and holistic representation of the patient's health status in order to support multidisciplinary care and treatment [7,17]. The system is modular, comprising Active X components. It was initially developed as a series of simulations using Borland's Delphi. Following extensive end user feedback [18] it has been rebuilt using a Visual Basic front end running on Windows NT and an SQL Server, and after prototyping is in process of phased roll out. Input is stored both as textual reports and coded for statistical output. A Viewer displays a list of all stored data items within an individual patient record as active keys to the data with options to view the stored report or through construct views which display selected data for specific purposes. As the data are stored according to contacts and episodes a longitudinal view of the patient's care and treatment over many years and multiple episodes can be obtained with easy access to historical data.

Point and click data entry, utilising recognised clinical frameworks such as the Mental State Examination and Orem's model of nursing [19], result in meaning being captured in a clear context and from an unambiguous professional viewpoint, including labelling as mild,

mocerate, or severe; where drop-down sub-menus still do not enable sufficient detail or specificity the opportunity to add text is given. To complement this structured and context-specific record core, text fields give opportunity for richness of message, but with the drawbacks of possible degradation of meaning through ambiguity of language, and limitations on searches.

5. Deeper Personalised Meaning - The Tall Order

However, having built these bridges linking professionals and services, what deeper meaning will travel over them? In so far as bio-pathologic data are concerned, and completed structured assessments, there is no major problem. But that is only part of the optimal mental health record. It is the building in of the attitudinal and evaluative information, in structured unambiguous terminological format [4], which is the challenge. Given the lack of corporate progress internationally in these areas of terminology, it is a tall order for a single health care provider to achieve alone. The Order has therefore been actively seeking solutions to what are important issues in developing clinical communication and record-keeping, linked to modern information technology opportunities, and endeavouring to find others interesting in pushing for progress.

6. A Catalogue of Frustration

International terminology systems such as ICD10 and DSMIII are diagnostic, and do not accommodate the topics of interventions or intentions. Likewise, nursing taxonomies have adopted this diagnostic approach which presupposes the existence of a curative intervention. Such systems tend to ignore or at least shy away from dealing with the less concrete and more complex situations which are the everyday reality of patients' lives and professional practice in mental health [4]. Proposals have been put to the European Health Informatics Standards Body CEN TC251 by one of the co-authors to develop a meta-taxonomy for mental health interventions, and secondly to define a generic framework for care plans. Both proposals have been accepted onto the group's 'long list', but neither has reached the top of the list to obtain resources in the face of competing bids from apparently more attractive domains. More specifically in mental health, a group convened informally by the World Health Organisation identified the issues which needed addressing [20], and a visioning paper took the debate into the American setting [21], but again only moral support but no finite action resulted. A European collaboration paper in the policy context [22] met a similar fate. There are no specifically mental health initiatives within the European Telematics Application programme (TAP), nor in earlier EU research phases, whilst the generic programmes give little support to mental health, and approaches have not been fruitful. This lack of input also applied when the project addressed the hitherto unanswered aspects of data protection and ethics for persons not mentally competent at particular moments of time [23].

In the setting of health informatics bodies, the frustration is similar. A proposal to develop a working group of the International Medical Informatics Association (IMIA) to consider issues specific to mental health (but which would, like the mental competence issue, be likely to illuminate the wider health informatics field), which was encouraged by one outgoing IMIA President, did not produce any formal response when considered by the IMIA Board. Fortunately, the World Psychiatric Association is more progressive, with the recent establishment of an Informatics and Telecommunications section, and has resulted in

special workshop strands at the biennially alternating global and European meetings. Unfortunately, important though this is, it is perforce primarily a uni-disciplinary and reporting occasion.

7. Conclusion - Under-Used Bridges

Practitioners in mental health should find the process of transmitting meaning, and not just bio-pathologic facts and schedules of physical interventions, an essential core of their work. Therefore, as health informatics techniques are harnessed in mental health to further improve care delivery, information systems should be capable of holding and transmitting such patient-based subjective meaning. It should also transcend different professional models of care when applying to one individual [24].

However, mental health professionals should not be alone in the health community in this respect. If health is truly to be considered in the terms enshrined in the World Health Organisation's founding charter as being "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" [25], and with the increasing recognition that health should now be defined in relation to the individual and his or her expectations, and to his or her optimum level of functioning in everyday living [26], then all health practitioners have a need to be able to communicate this richer meaning.

The Hospitaller Order of St. John of God, in its desire to run a modern, quality-based service, has sought to build informatics bridges. That has been challenging, but not impossible. However, in terms of transmitting across those bridges meaningful and relevant information and knowledge, as opposed to bio-pathological data and images, it feels at a very early pioneering stage. More worrying, it finds itself very much alone in caring about this problem.

Possibly, and hopefully, a scientific conference in the setting of a newly emergent democracy which is building on strong cultural values but reviewing its methodology afresh will provide an appropriate and fruitful setting to enable rediscovery of healthcare meaning. This kind of proven fresh thinking and return to core human values is needed in the quest for the optimisation of health information and thus health informatics - namely to develop an effective focus on recording the perceived and expressed personal health status and functioning of the individual person, thereby turning informatics bridges into super-highways of knowledge.

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