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Simulating information exchanges in order to investigate the utility of public health websites

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Keywords
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SIMULATING INFORMATION EXCHANGES IN ORDER TO INVESTIGATE THE UTILITY OF PUBLIC HEALTH WEBSITES

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Abstract

This paper explores the nature of communication and information flows in critical medical environments to inform the design of public website support. Results are presented of a study of communication in Intensive Care Units (ICU), where data was collected from the website owners, public users of the site and ICU clinicians who traditionally find communication with families of patients difficult. The paper presents the results of this research aimed at understanding the situation and needs of potential website users. The study has provided a greater understanding of how information technologies can help to resolve problems that arise with the ad-hoc, face-to-face communication that currently occurs in this area. To underpin the research a systems-dynamics model of information flows in an ICU, was developed in an evolutionary fashion using Stella software. The modelling process was informed by a review of literature, as well as data from various stakeholder groups. The model provided a means of re-interpreting the data, encapsulating the knowledge gained from the study and visualising the research findings in an innovative way that is enabling the project to move forward.

Keywords: Web-based services, Intensive Care Unit, public communication, systems dynamics modelling, crisis situations.

1 INTRODUCTION

The area of public healthcare has always been particularly information intensive, with health authorities having engaged in collecting, disseminating and communicating information long before the advent of computers. Information and communications technologies (ICT), together with the growth of the World-Wide Web, have brought about immense changes that provide many new opportunities for processing information and supporting communication. These opportunities can be exploited in innovative information systems, which can improve health outcomes by supporting information exchanges between healthcare professionals and the public. However, web-based systems, which inform and connect people to people directly or indirectly, are complex and dynamic, and can best be understood as the interrelationship of organisational, human and technical elements (Boland & Tenkasi 1995). When conducting research in this area it is therefore essential to take a holistic approach that integrates the latest ICT tools and processes with the needs of all stakeholder groups. The research presented in this paper adopts such an approach to understand the role of a website in meeting the information needs of critically ill patients in Intensive Care Units (ICU). It does this through the use of system dynamic modelling to simulate information flows and communication between clinicians and family members of patients.

The study presented in this paper is part of an ongoing project, in a central coordination and monitoring unit for ICUs established to provide centralised information resources to the ICUs across the state. The unit has created a web-site to be an information source for families providing basic facts about the functions and operations of an ICU and answering some of the most commonly asked questions in the ICU. The research addresses not only the technological considerations but also the needs and situations of a variety of stakeholders. The stakeholders include the staff of the state coordination and monitoring unit, who initiated and now manage the design and content of the web-site, the clinicians and administrators in the hospitals, ICU patients and their families as well as members of the general public. This paper presents the results of this study aimed at developing a better understanding of such crisis situations and of information needs of potential website users.

The paper begins with some background to the particular project studied and an analysis of relevant literature. The research approach is then described followed by a summary of data collected from three sets of stakeholders, namely; 1) those developing the web service, 2) the ICU clinical staff and 3) the families of patients. This data is used, together with insights from the literature, to simulate the information flows of an ICU, using systems modelling to explore and display the issues in a dynamic and holistic way in order to gain a greater understanding of the communication process and the role of the website in this process. The resulting conceptual model is then presented and described and this description is followed by a discussion on what has been learnt so far together with an informed proposal for future work.

2 LITERATURE REVIEW

When a loved one is admitted to an ICU, families are often in crisis and have emotionally charged responses arising from stress, anxiety and confusion, which affect their ability to understand information presented to them (Thorne et al 2006). Clinicians working in intensive care units play a vital role in helping patients and their families cope with the emotional distress associated with these crisis situations. The professionals however frequently lack the time and opportunity required to adequately communicate with non-professionals, such as patients and their family members. While relatives have a desire to obtain information about the condition of the patient, and want to fully understand the high technological environment of the ICU, their lack of scientific knowledge, makes it difficult for them to absorb the medical information that is provided to them. This study aims to provide a greater understanding of this situation and how information technologies, can be used to resolve some of the problems that currently arise with regular yet ad-hoc, face-to-face communication that occurs in this area. In the selected literature concerning this topic presented here, it is noted that tradition research methods of surveys and interviews are invariably used. Our study takes this research in a new direction using a systems modelling approach so literature on this techniques is also presented and justified here.

2.1 Information Exchange in Cases of Critical Care

The communication between medical professionals and the general public can often be difficult; due to time limitations, cultural differences and even language barriers (Ton et al 2005). Many researchers and clinicians have recognised the need for families of critically ill patients to have access to information that will reduce their feelings of uncertainty, confusion and helplessness when their loved one is admitted to an intensive care unit. Molter (1976) investigated the needs of families in the ICU setting using structured interviews of relatives of patients who were critically ill. The needs reported include feeling that the hospital cares about the patient; knowing the prognosis; to having questions answered honestly; to knowing specific facts about the patient's prognosis; and having explanations given in understandable terms.

Molter (1979) developed the Critical Care Family Needs Inventory (CCFNI); an instrument that has been used extensively in most studies of families in critical care setting. Leske (1986) modified the

tool and reported results similar to Molter of a descriptive study of 45 family member. In a more recent study, Warren (1998) used recorded interviews to categorise positive aspects of nurses' behaviours. The categories of perceived caring nursing behaviours by critical care families were labelled informing, enhancing, touching and spiriting. The interpretation of the findings of this study are that nurses must continually meet the family and may actually from a bond with the family through the use of these caring behaviours, which will ultimately benefit the family, nurse and patient.

Kosco and Warren (2000) conducted a survey of family members and found it important to have a specific person to call at the hospital when they were unable to visit and to have someone be concerned with the relative's health. The family also perceived that the need to visit anytime was important. It is clear that the family remains the most important social context to consider when determining intervention to positively influence patient outcomes. Anxiety from perceived unmet needs by the family member may prove to be detrimental to patient care through distrust of nurses, anger, and dissatisfaction with care or disregard for treatment.

Auerbach et al. (2005) reported that more interpersonal contact with ICU staff encourages family members to participate in the patient's care and this leads to a reduction in the high levels of depression and anxiety often found in family members of critically ill patients. The research of Azoulay et al., (2003) also demonstrated the necessity of providing effective information to families. In a recent longitudinal study Azoulay et al (2005) held telephone interviews with family members of patients who were either discharged or died after admission to intensive care unit. This study found that the degree of psychological distress present during period the patient was in ICU was influenced by the nature of the information the family members had received.

Bijtteber et al (2001) reported that nurses, physicians and relatives of critical care patients all considered 'good' information was the most important need of patients' relatives. The same study found that relatives perceived that nurses were the main source of honest, understandable and up to date information rather than physicians. Timmins (2005) also stresses that good nurse-patient communication is essential to assist the individual and their family in coping with the very challenging events in their admission to ICU. In critical illness situations family members are frequently required to make important life decisions. This crucial decision-making heightens their anxiety and the need for information is consistently cited as a primary need by patients' families (Molter 1979).

Many researchers , including Auerbach et al. 2005, Azoulay et al. (2003) and Engstro¨m & So¨ derberg (2005) have reported that it is interpersonal contact with ICU staff that can best help meet the information needs of patients' family members However, Mitchell and Courtney (2005) claim that written information is essential to reduce family members' anxiety and is helpful in answering their questions when they are unable to get regular information from ICU nurses. Han and Lee (2001) reported that it is important to develop web-based intelligent call centres to facilitate communication between ICU staff and families of critical patients.

2.2 Using System Thinking Modelling Tools

Von Bertalanffy, (1968) commenced development of General System Theory in the 1930s in response to developing the theory complexities of the scientific era, and further developed the theory over the next three decades in view of modern technology within computer, behavioural and social science. A systems dynamics approach has been regularly accepted in the areas of information systems and management but can also succeed in conceptualizing complex notions in stressful family contexts within health and nursing domains.

The use of simulation techniques is now increasing in the health-care system where modelling enables decision-makers to improve the quality of care that is delivered to satisfy the needs of patients and their families Dellmo & Gardner (1990) and Lane et al. (2003). Dangerfield (1999) illustrated some system dynamics models for healthcare system in European hospitals by using different types of simulation models to address special issues in healthcare. Eldabi et al. (2002), has identified many

advantages of using simulation in health-care systems. These authors state that simulation offers features to cope with both problem understanding and problem solving. It also helps users to make a systematic examination of their underlying assumptions.

Wolstenhome (1999) and Derrick et al (2004) have used stock-flow modelling technique to study the implications of new programs in the UK health services. Wolstonholme's work looked at patient flows whereas the study of Derrick et al addressed the consequences of the reduction in hospital hours of trainee doctors both to their learning and their contribution to provision of clinical services in the hospital. These studies, together with the models of Hitchins (2003 p400) on work flows and Richmond (2004 p 8) on the learning process have strongly influenced the approach taken in our research.

The particular approach to stimulation using systems thinking with stocks and flows is recommended by Sterman (2000) who reported that system dynamics modelling is important tool for complex real world systems. He recommends that modern systems modellers to use stock-flow networks in systems in preference to others tools of system thinking, such as causal loops as these have the limitation of being difficult to simulate. Sterman uses the computer simulation application Stella based on stock and flow modelling (ISEE Systems 2006).

In the realm of healthcare, both Hichins (2003) and Dellmo & Gardner (1990 p27) stress that system thinking and Stella software are "powerful tools" for health-care management since system thinking techniques introduce a new rigor and discipline into management thinking on complex issues. These authors confirm that using Stella greatly enhance the analytical power of management in health-care systems.

Using Stella software is a computer-aided way for effectively constructing effective models and simulation activities. Stella provides a easy to use graphical interface for constructing dynamic models that visualise and communicate how a system work through a stock flow diagrams. In the Stella language the stocks are nouns and are presented by rectangles, while flows which occur in and out of stocks are verbs that represent actions and activities. The other elements in the Stella language are converters, represented as circles, that are used to modify the verb productivity and connectors that link converters to stocks, flows or other converters. With this basic understanding the Stella model presented here should not be difficult to interpret.

3 THE RESEARCH DESIGN

3.1 The Research Driver: a State Web Based Information Service

Every year in the constituency where this research was conducted, thousands of patients are admitted into Intensive Care Units. These units are designed to deliver the highest of medical and nursing care to the sickest of patients. These units are in hospitals spread across the State and organised in Health Areas. Some smaller rural and urban hospitals do not have ICUs. The larger metropolitan hospitals have specialised ICUs and take serious patients from the smaller units on a regular basis

An ICU is a high demand service with limited equipment and clinical resources. Efficiency is important in all facets of their operations including information access for both clinical and public use. A division was established within the State Health Department, to provide centralised information resources to the ICUs across the State. This has taken the form of an online service to facilitate communication between and among the state's regional ICUs so that information is shared with Clinicians, patients, their families and the community. The original driver of this research was to study the development and use of this Web based Information Service in order to provide informed recommendations with regard to its ongoing improvement. This paper presents the results of research aimed at understanding the situation and needs of potential website users.

3.2 The Research Process

The aspect of this study reported here is an exploration of the communication issues between clinicians and the families of ICU patients. The analysis was done by building a system dynamics 'stock and flow' model using Stella software to represent and visualise information flows and subsequent increases in understanding of participants. The foundation for the model is a review of literature on the topic together with data collected from the various stakeholders. Suitable methods of data collection from each group were designed as follows:

Web-site owners and developers: Data was gathered from interviews with the state-based staff responsible and from documentation provided by them on the rationale for the web-site.

ICU administrators and clinicians: A study using Q methodology (Meloche 1999) was used to gather attitudes to the website from these stakeholders. Q methodology was adopted because it provides one of the most developed methodologies for the collection and analysis of individual understandings of an experience or a topic. The first part, the Concourse, was used to ascertain subjective views of the situation in the form of a set of statements collected from clinicians and ICU administrators in representative hospitals across the State. In the next stage the same subjects are asked to consider the set of statements and to arrange them in an order that reflects their view of the statements, usually from strongly disagree to strongly agree. This process is called a Q sort where each participant's own views on a topic are used to rank the statements (Brown 1980). A sort grid is provided so that the largest number of statements will be placed in the centre and the least amount of statements at each extreme point. The sorts are then analysed and interpreted to produce models of sets of views on the topic. While the complete process was followed in the research, only the statements collected in the concourse were used in the model development as the results of the sorts were not available in time.

Families of patients: For ethical and logistical considerations it was decided not to attempt to get primary data from families of patients in ICUs. As the web-site is public and all members of the public are potential users, it was decided to use a simulated approach. Data on this group of stakeholders was gathered using activity-based usability tests replicating the ICU situation in a Usability Laboratory.

3.3 Developing the Model

A systems dynamics model was developed using Stella software in an evolutionary fashion in parallel with the literature review as well as the collection and analysis of data from the three sets of stakeholders. Initially the basic elements of the communication process were set up in a conceptual model. This model was enhanced as new insights were gleaned from the literature and the data analysis and as feedback was received from other researchers and members of the three stakeholder groups who were shown newer versions of the model.

4 THE DATA COLLECTION AND PRELIMINARY ANALYSIS

In this section of the paper we present the analysis of collected data from the three stakeholders.

4.1 The view from the State-based staff and web-site developers

Most members of this state-based team were nurses who had worked in ICUs. According to the interviewees the web site provides relevant general ICU information in ordinary language. It was never intended to replace personal communication but it was designed to help to provide more support for family members who are in shock and under stress as they can't absorb medical information well. From the teams' experience families need more explanation sometimes the best way to give information is in written form rather than verbally. Information that can be downloaded or printed

from the web can be accessed by the public whenever they need it. It can also save the valuable time of nurses who often have to explain the same issue multiple times to different family members or even to one person who is stressed and confused.

4.2 The view from ICU units

The Q study was conducted through visits and conversations with ICU staff in 8 different ICU's, across the State**.** Twenty-six participants, clinicians and administrators in eight hospitals, contributed to the statements collected regarding three main questions concerning their communication with patient's families. Q1: Does the web information service help? Q2: How does it help? Q3: What other services could it offer? A full report of the finding of this study is published elsewhere (authors' reference removed for reviewing).

After the concourse, the collected statements were analysed by inspection. The respondents consider that although it is quite new, the website seems to be an important source of information for families in specific areas. They agreed that it would save their time if they could download information from this web and give it to patient's relatives. The most significant feedback received from all the ICUs visited was that, as far as they knew, families of critical ill patients didn't use the web site and it is not yet used by them at this time to help with communication with families. However they could see its potential. They suggested that it could help in providing general information such as accommodation, visiting hours, other hospitals services, access to hospitals web sites. They also suggested that it might be used more if the web had visual information and even video clips would be helpful.

4.3 The view of patients' relatives

The website was tested using activity–based usability testing from the end-user perspective, i.e. families of critical care patients. This approach involves surrogate users who are given scenarios as realistic as possible to simulate what occurs in an ICU. In this case small groups were shown a suitable movie clip of a critical care story where they could feel some of the emotions of concern for the patient and where there was information on the web-site that could be used in the case. The group activity was then recorded as they were guided to access this information on the website. This followed the procedure of a typical usability test as the group played the role of the family and evaluate their experience of using the web-site for information. A debriefing session at the end of each session was used to collect their views. Finally a typical usability report was generated summarising and interpreting the data collected.

The basis findings were that the surrogate family members declared that they are not completely satisfied with what they found on the web service since it lacked any provision to have up-to-date and detailed medical information about 'their' patient. They emphasised the belief that verbal communication is better than written communication in critical situations as they wanted to meet clinicians face to face to have more explanation and to know more about the treatment in the ICU.

5 DEVELOPMENT AND PRESENTATION OF THE MODEL

This section describes how a stock-flow model was developed to represent the communication between the ICU and patient's families. The researchers used the literature review and data gathered from the three groups of stakeholders to create and improve the model through a series of iterations.

While this approach has traditionally been used to represent stocks and flows of physical materials, it can also be used for non-material entities such as information, understanding and knowledge. Such entities are used in our model but it is important to note that there is one significant difference where they are concerned. When something physical such as water flows it leaves one stock and moves to another. When something like information flows it does not diminish the source in the same way, for

example if I tell you some piece of information I do not lose it when you gain it. This has implications for stock-flow models in that, while separate stocks have inflows and outflows the relationship between these is not a simple flow from one to the other as one might intuitively think. The following description of the model developed for this project should be viewed with this in mind.

5.1 The Model Design

From the analysis of data gathered from two groups of stakeholders that participate in the communication, key corresponding STOCKS were identified with appropriate in and out flows as shown in Figures 1-3. For the family members this was the UNDERSTANDING of what was happening to their loved one while for the clinicians it was RELEVANT MEDICAL KNOWLEDGE generated by, and applicable to, the case at hand. Both these stocks mediated, and were mediated by, the patient's condition which is represented by the stock PATIENT CRISIS LEVEL.

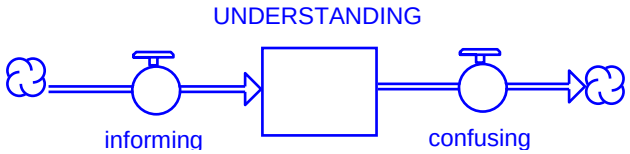

Figure 1: The stock UNDERSTANDING refers to that of family members. It is increased by the inflow informing and decreased by the outflow confusing.

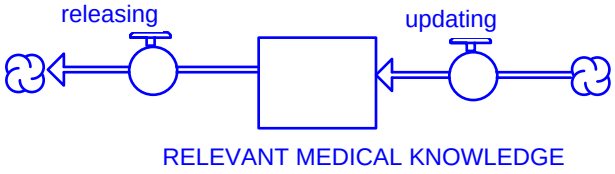

Figure 2: The stock RELEVANT MEDICAL KNOWLEDGE refers items that the ICU staff have that they should release to the family. It is increased by the inflow updating and decreased by the outflow releasing.

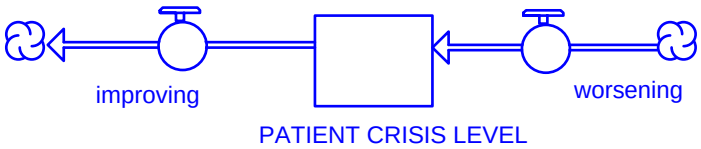

Figure 3: The stock PATIENT CRISIS LEVEL refers to the patient's condition. It is increased by the inflow worsening and decreased by the outflow improving.

Using these three stocks as the foundation, an integrated conceptual model was created and improved over several iterations with feedback from researchers and stakeholders as describe elsewhere (author's reference removed for reviewing). The current version of the model is depicted in Figure 4 and its components are explained below.

We found that the issues that influenced in the stocks and flows were:

- The amount of UNDERSTANDING acquired from information provided to the families was affected by their level of medical knowledge, the quality of the communication and their level of stress due to the patient's condition. These are supported both by the literature and our research and are represented in the model by the three converters family knowledge, communication and stress level respectively.
- The stock of working RELEVANT MEDICAL KNOWLEDGE is required by the ICU staff at any time both to treat the patient and to inform the family. Its updating is triggered by changes to the patient's condition (improving and worsening) and questioning from the family. It is also influenced by the medical capability of the ICU clinicians and the quality of both their general medical knowledge and their knowledge of things specific to the ICU (converter ICU Knowledge).
- The converter communication on the left-hand side of the model is critical and the results of the research have been used extensively to incorporate various parameters into this section of the model as follows:
  - The quality of traditional *verbal* communication affected by converter *communication* skills
  - The role of a *static web*-based information service as is currently the case in the study.
  - The possible role of a *dynamic web*-based information service as many stakeholders reported that is this is important to meet users' needs for specific and query-able information about their patient. However the web-site owners at State level indicated that this would be affected by factors represented by converters *legal* and *technical*. Issues of security, authorised access etc were raised by them.

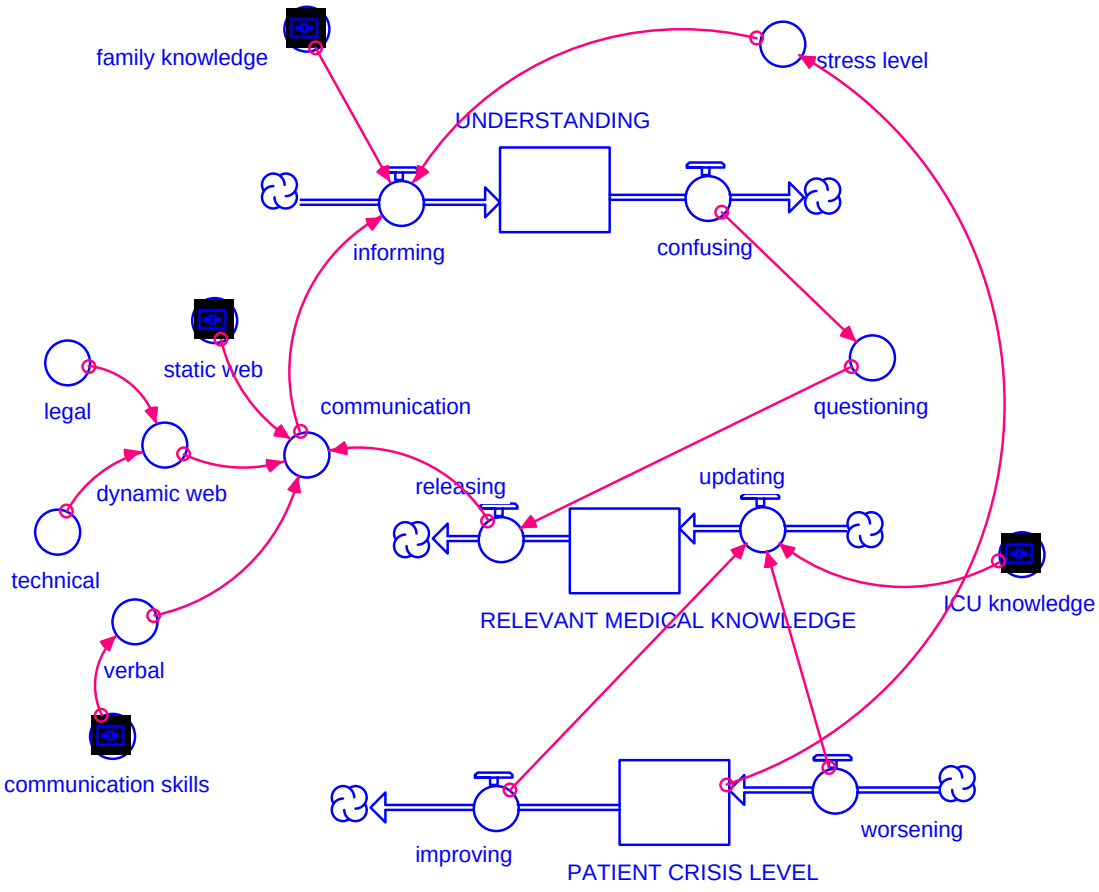

Figure 4: The current state of conceptual model integrating the three stocks with converters and connectors based on the literature and analysis of data from the research.

This holistic conceptual model provides a means of *displaying* the findings of research based on qualitative data as recommended by Miles and Huberman (1994). The model has been a vehicle for interpreting the data by the researchers in combination with representatives of the stakeholder groups as it has evolved over many months to its current form. The model *encapsulates* the knowledge gained from the study showing the elements that are important and how they are interrelated. The model also *visualises* the research findings in a way that will enable the project to move forward. Some preliminary attempts have been made to run the model driven by periodic changes to the patient's conditions using sine functions the flows in and out of the PATIENT CRISIS LEVEL stock and broad assumptions on initial values and converter parameters. This work is ongoing.

6 DISCUSSION

It is evident from the data that the central State coordinating unit who own and developed the web-site see it as appropriate, neither the ICU staff nor patient's family are actively using the site as intended. The modelling process that we have used maybe one of the only ways to formally investigate what could, and maybe should, be happening rather than what is. This is important as all believe that effective communication between ICU staff and their patients' family members is a vital component of quality care leading to good health outcomes.

The conceptual model presented in figure 4 is based on a literature review and the analysis of the data collected from the three sets of stakeholders: members of the State-based ICU Coordination Unit, responsible for the web-site; the ICU clinicians and surrogate family members. This model represents:

- Family members' need for information about the patient's condition and general medical information.
- ICU staff (administrators/nurses/physicians) support for relatives of patient with necessary information in a digestible form and with answers to their questions.
- Support for communication between the ICU staff and families including a web-based information service.

Through the analysis of the statements offered by staff working in ICU, we concluded that they view the communication with families is important but difficult. They recognise that the web-site can deliver correct and understandable information to family members so that they participate in medical decisions and improve the general knowledge about ICU operation and vocabulary. In stressful situations, online health information services may help meet some family needs for information since written information provided through web-site may ease the ICU and other medical concepts and terms. However, families seem to be more satisfied with information given to them verbally than by web-site information service. So, providing verbal information together with written or web-based information is an important issue that assist in more effective communication between intensives and families of patients resulting in a higher quality health care service.

The researchers developed a stock-flow model to represent the two types of information flows between families and clinicians and the attributes that affect these. The starting point for the building the dynamic model was simple mapping of the key stakeholders for this case (ICU staff and family members) following a review of the literature and the collection and analysis of primary data from the various stakeholders as described above, then getting useful primary data from the family members of patients in an ICU was a particular challenge that was met through the use of simulating realistic scenarios in a Usability Laboratory.

From the applied perspective it is important to consider how web-based information systems can create and enhance the knowledge of people who needs information in complex and crisis situations at the time it is required. Family members and relative seek information because they realise that their knowledge about their patient's medical condition is incomplete. In the ICU situation information relevant to the patient's medical condition are constantly changing. The State ICU unit needs to

consider whether a static web-site with well-produced, correct information can be useful in this situation or whether a dynamic one can be built within legal and technical constraints.

7 CONCLUSION

Communication with families in intensive care setting is complicated because the admission to ICU is often unexpected and the families will be emotionally strained. Clinicians do not always have the skills, training, time or will to deal with family concerns making direct interaction between ICU clinicians and family members limited. In response to its primary aim, this study shows a clear interest in the provision of a web-based support service for critical ill patients for providing general health information and explanation of medical terms. However families still expect and prefer to communicate directly with clinicians to obtain information specifically related to their patients' medical conditions. This research continues to investigate whether providing updated information to the families through different communication channels might be helpful to decrease families' stress and assuring their certainty of patients' progress.

A secondary aim of this study was to simulate the type of communication that takes place complex stressful settings, such as in intensive care units, using stock-flow modelling technique. The results, to-date, demonstrate the value of this technique for visualising the entire system, identifying its element and relations between them. The researchers are then able to manipulate these elements and relationships through simulations of the model to gain an understanding of the dynamics of the situation and determine future directions for the investigation. The use of systems dynamics modelling has been shown to be valuable in facilitating discussion among disparate groups of stakeholders, in this case the researchers, health-care professionals, government health administrators and end users of their website.

This study is both limited by, and made innovated through, the use of the creative techniques used to collect, analyse and represent data, namely: the use of the Q-method to collect and analyse data from the ICU staff, usability testing on surrogate family members to evaluate the situation from their perspective and then the use of systems dynamics modelling to bring the findings from the three different data sets together. This type of modelling for this type of research is quite original, particularly where information flows are included, but our work demonstrates its potential for holistically and dynamically exploring, analysing and visualising results of research into complex, changing crisis environments where current information technologies are an evolving tool in the communication between professionals and the public.

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