

Information Technology in Palliative Care

(07/27/04)

Action For Health 2004-02-RP-1

Document Status:

- Published Paper Practitioner's Pointers
 Working Paper Briefing Note
 Report Research Tool
 Draft

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ACT4Hlth Case Study #1

“Information Technology Impacts in Palliative Care”

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Introduction

Although it is still a relatively new field of medicine, our aging population will substantially increase the need for palliative care services over the next several years. The use of information system (IS) technologies is one solution to enhancing palliative practice. The use of information to enhance healthcare is well documented including the Romanow Report where it states that leading edge information, technology assessment and research are essential foundations for the healthcare reforms recommended in the report (Romanow, 2002). The potential exists for using IS for a range of tasks from data collection to disseminating management strategies for symptoms such as pain. Healthcare has already seen the use of IS ranging from administrative support for scheduling or program planning to decision support or careplan development for clinicians about individual patients. Some areas of healthcare such as primary care are well established in terms of IS, whereas palliative care, largely due to its relatively recent emergence has yet to incorporate much IS into its practice. That presents fertile ground for research as palliative care has a number of unresolved issues such as symptoms management, which may benefit from IS based solutions. However, as in any IS project, the impact of the technology on the users must be considered. We realize that the determination of whether an implementation is successful or not is not merely a technical matter with some people going as far as saying that the decision as to whether or not a system is successfully implemented is socially negotiated (Kaplan, 2001).

This paper is phase I of a study on the use and impacts of technologies in palliative care. It will present the findings from a retrospective project where pilot pilots were used for data collection in palliative care. The results from this paper will be supplemented by a report on a current doctoral thesis project that will describe the design, implementation and evaluation of a computer based severe pain management tool.

Relevant Literature

Information Systems in Healthcare

Much of the literature on IS in healthcare has evolved through evaluation of system failures, although Berg points out that is because so many systems fail (Berg, 2003). When IS fails it is not always correct, although often done, to point to technical causes as the reason for the failure. However we have seen a shift in paradigm from the pervasive or technology view, which considers IS failures being due to technological factors such as bandwidth or access speed to the systems view that recognizes and attempts to make sense of the relationship between people, technology and care delivery.

Berg points out that poor technical implementation can be the result of a poorly managed development process of the system (Berg, 2001), not the technology itself. Examples of poorly managed system design is when users are not sufficiently involved in the design

process which can result in user-interfaces that are illogical from the users' point of view or the sequence of actions prescribed by the system may run against the users' working routines (Button, 1993).

One factor to consider with respect to success of an IS project is that success is a multi-dimensional concept that evolves over time and can be defined very differently by different parties (Berg, 2001). An example of evolving system expectations is shown by Massaro in his description of a physician order entry system at an academic medical centre (Massaro, 1993). Management initially felt the system would return financial savings in personnel costs but the system became more valuable in altering workflows leading to quality improvement through point of care order entry.

As the system view becomes more prominent we have seen the emergence of interventions that are ground in behavioral sciences in an attempt to improve the success of IT implementation (Kukafka et al, 2002). Among such theories are the Theory of Planned Behavior and the Technology Acceptance Model. The Theory of Planned Behavior reasons that intentions towards adopting new technology are best predicted by three perceptions: the technology must be one, personally desirable, two, supported by social norms and three, feasible (Ajzen, 1991). The Technology Acceptance Model states that behavioral intention towards technology is determined by the attitude towards the technology which is determined by both the perceived usefulness and perceived ease of use of the technology (Davis, 1993).

Evaluation of Healthcare IS

As valuable as theories on how individuals adopt and use IS are theories that evaluate how IS impacts healthcare delivery. DeLone and McLean describe a framework for measuring information system (IS) success that makes a number of clever distinctions. In particular it assesses system and information quality as separate entities as well as separating individual and organizational impacts (DeLone and McLean, 1992). While such distinctions may appear obvious, the separation of concepts has not always been done in information system evaluation studies. System usage gets described as user acceptance and positive organizational impacts often assume an underlying level of satisfied users.

There have been a number of theories for evaluating how technology impacts organizations, some of which are specific to healthcare organizations. Donabedian offers a framework for how healthcare innovations influence the healthcare system saying they may impact the structure, process and outcomes of the system (Donabedian, 1996). Friedman, Owens and Wyatt expand that view and present a listing of different aspects of what can be studied in evaluation including the need for the resource, development process, the resources intrinsic structure, resources functions and resources effects (Friedman, Owens and Wyatt, 2001).

One difficulty with traditional means of IS evaluation is that they focus on summative evaluations such as assessing how well implemented systems meet a set of pre-defined goals regarding issues of functionality, safety, and impact on outcome measures such as

cost of health care and work efficiency (Friedman and Wyatt, 1997). Such evaluation methods fail to consider the human aspects of system usage such as how the system affects care delivery or patient-caregiver relationships. A further shortcoming of only assessing pre-defined outcomes is that it may ignore unanticipated results such as the improved QI that arose from the physician order entry system described above.

A recent emergence has been evaluation methods that look at the cognitive aspects of how information systems influence healthcare organizations. Cognitive and usability engineering approaches to system evaluation consider factors such as how easy a user can carry out a task using the system, how users attain mastery of the system, assessing the effects of system use on work practices and problems users have interacting with the system (Kushniruk and Patel, 2004). Such evaluations provide valuable information about the actual process of using a system, rather than simply looking at whether or not the system successfully met predetermined goals.

A slightly different approach to cognitive evaluation comes from Orlikowski and Nash, who present a unique perspective on the assumptions, expectations and knowledge that people have about technology, which Orlikowski and Nash define as technological frames (Orlikowski and Nash, 1994). Their concept of a 'frame' draws on the notion of a schema from cognitive psychology. A schema is a built up repertoire of tacit knowledge that is used to impose structure upon, and impart meaning to, otherwise ambiguous social and situational information to facilitate understanding (Gioia, 1986). Specifically, Orlikowski and Nash use the term technological frame to identify that subset of members' organizational frames that concern the assumptions, expectations, and knowledge they use to understand technology in organizations (Orlikowski and Nash, 1994). It is emphasized that such frames include not only the technology itself but also the conditions and applications where the technology is applied as well as consequences of its use. Problems in developing and implementing technology occur when incongruent technological frames exist. Incongruent frames can occur for a number of reasons including lack of communication about project goals or objectives or technologies that shift practices of work (Orlikowski and Nash, 1994).

The reason the technological frame perspective was selected is that the frame concept and its origin in cognitive psychology are similar to a model for understanding how pain occurs in patients. Pincus and Morley present a model on pain called the 'schema enmeshment' model that defines three schemas: pain, self and illness (Pincus and Morley, 2001). The schema enmeshment model describes how the type of pain, such as chronic or acute, and how the pain impacts the person, such as preventing a person from working or taking part in social activities will impact the degree of enmeshment of the patient's pain schemas, which defines how the patient perceives the pain and how the pain gets managed. Pincus and Morley feel that studying the information processing bias (analogous to Orlikowski and Nash's frame) provides additional information for developing models about chronic pain and how it is treated.

The fact that both Orlikowski's frame theory for IS evaluation and Pincus and Morley's model for pain both use the schema concept is significant. It represents a common theme

of cognition and the use of schemas for influencing how information is interpreted in order to understand a person's actions. Because the schema concept is represented in both IS and medical domains it is worth pursuing as an theoretical approach for systems design and evaluation as it may provide a means of sense making to help bridge the design gap between IS designers and medical practitioners.

Technology in Palliative Care

Healthcare systems have traditionally had a high rate of failure among system design projects, which emphasizes the point about understanding the social context within which a system is implemented. Because palliative care is a relatively new and emerging field there has been far less informatics research done than in fields of medicine such as intensive care or primary care. Despite the lack of technology in palliative care, concern has still been expressed in the palliative community as to whether technology such as computing systems is antithetical to the goals of palliative care (Seely and Mount, 1999). The person-centered nature of palliative care requires particular attention to be paid to how the use of IS will impact care delivery including impacts to healthcare providers, family members and the patient. Seely and Mount describe technology as dealing with the material world and being impersonal, objective and generalizable, which is a contrast to the unique and subjective patient (Seely and Mount, 1999). Technology is also described as a means of distancing caregivers from the patient and it is further pointed out that despite advances in technology, palliative care is still unable to provide adequate pain management, even though the principles on pain management have been known for over a generation (Seely and Mount, 1999). A further challenge to technology is to ensure it is not perceived as extending a person's life beyond natural course. DeVecchio-Good et al. point out that biomedical technologies are sometimes perceived as being associated with medical futility or torture (DeVecchio-Good et al., 2004) and that statement gives much food for thought about how dying patient's or their family members will view high technology approaches to palliative care. Rooms in a hospice are different from those in acute care centres as respirators or heart rate monitors are not present. Hospice rooms are often defined by plants, wedding pictures or drawings from family members and other personal mementos. The focus is on people trying to maintain a good quality of life and is overall palliative care can be said to be technologically sterile. Other views of IS in healthcare and how it may dehumanize care have shown similar findings. Wilson and Howcroft describe how technology use is closely related to socio-cultural perspectives such as gender, roles and individual competency and overall health care workers associate IS and information technology to effectiveness and control, which is perceived as being in conflict to the traditional values of healthcare: care and humanity (Wilson and Howcroft, 2000). Clearly success using IS in healthcare and perhaps even more so in palliative care will come from achieving a balance and fit between the technological aspects and the humanity of care.

Summary of Relevant Literature and Application to the Study

The above cited literature provides a theoretical basis to this study in that we are looking at the entire spectrum (behavior, implementation and evaluation) of IS usage in palliative care. Although the literature cited above has questioned the use of technology such as IS in palliative care to date there has not been a detailed study from the perspective of how

technology impacts patient care and how staff, patients and families perceive technology in palliative care. Our approach of applying grounded theory to study the use of IS in palliative care will allow us to decipher detailed meaning of how technology impacts palliative practice and will allow us to identify the themes that signify may shed light on technology in palliative care.

In this study we provide information on views of technology before implementation of PDAs for data collection as well as post implementation analysis of the technological impact on people, workflows and patient care. If we summarize the above cited IS evaluation approaches and the current views on technology in palliative care we can see two separate streams that emerge. One is the technology itself. That raises questions such as does the technology provide value to our practice such as monitoring quality improvement (QI) to prevent medical errors or enabling us to incorporate best practice evidence? And does the technology make our day-to-day work easier such as by improving data collection and analysis? The second is how does the technology impact the people in the practice, which includes patients, families and practitioners? Those impacts are irregardless of how well the technology functions or how it enhances practice as it is possible for a system to work well technologically or be successful in what the system delivers (such as QI) but still be perceived as having a negative impact on patient care or the practice that provides the care.

Case – Palm Pilot Data Collection and Analysis Project at a British Columbia Hospice (BCH)

Description of the Project

This retrospective study describes the use of personal digital assistants (PDA) in palliative care. In July 2000 a local hospice initiated a project to use PDAs to collect and view patient data such as symptoms and medications. The specific data that was collected on patients through the PDA was: demographic (admission, discharge, room, bed), symptoms (pain, nausea, shortness of breath, fatigue), investigations (lab tests, x-ray), treatments (surgery, antibiotics, blood transfusion, radiation therapy) and medications (drug, dose, route, frequency).

The data was collected asynchronously so that the PDA needed to be ‘hot synced’ with a central database after collection in order to keep the database up-to-date. Although the symptom and medication data were recorded in the PDA and database the data still needed to be recorded in the paper chart as that was necessary for legal charting purposes. There was no paper versions available of the PDA data to supplement the data in the paper chart, although it was possible to view certain data such as symptoms and medications through a computer monitor located at the nursing station. Largely because of the lack of hard copy reports the nursing staff became frustrated with having to continually do double entry. Finally, the project was stopped in August 2002.

Research Method

Grounded theory (GT) was used as the methodology for this study. Although the roots of GT were developed through studying phenomena within sociology and the humanities,

GT has since been applied across other disciplines including IS projects as described by Orlikowski (1993), Baskerville and Pries-Heje (1999) and Sahay, Supratek and Lau (2001).

One of the features of GT is the high degree of methodological rigor that it applies to the research. The hallmark of GT is three coding cycles where data is coded and the derived codes are continually compared against new data. The resulting analysis is very rich as it emerges from multiple coding cycles.

The three GT coding cycles: open, axial and selective coding, are described briefly.

Open coding involves "breaking down, examining, comparing, conceptualizing, and categorizing data" (Strauss & Corbin, 1990). Open coding can be done line by line, which is the most tedious but also the most rigorous in terms of code and category development, or at the line, paragraph or even document level. Open coding is continuous and as new data is gathered and codes and categories are identified they go through a continuous cycle of comparison to existing codes and categories in a process called 'constant comparison'.

Axial Coding refers to the analytic activity for "making connections between a category and its sub-categories" developed during open coding (Strauss & Corbin, 1990). Strauss and Corbin recommend using a 'paradigm model' during axial coding that links data by conditions, context, actions/interactions and consequences (Strauss and Corbin, 1994). They feel that theory developed without the paradigm model will lack density and precision.

Selective Coding - The final phase of coding in the grounded-theory approach is called selective coding. This stage involves consideration of the multiple concepts that emerge from axial coding and identifying one or two core categories to which all other sub-categories relate. The core category becomes the means for building a conceptual framework from which to develop the grounded theory.

Research Design

The overall research design is presented in figure 1. The literature described in the preceding sections will serve as the knowledge for development of an initial conceptual model for palliative care and technology. The data from the retrospective palliative care PDA project will be coded using GT and analyzed and discussed. The conceptual model will then be revised based on the findings from the data analysis showing consistencies and inconsistencies with literature.

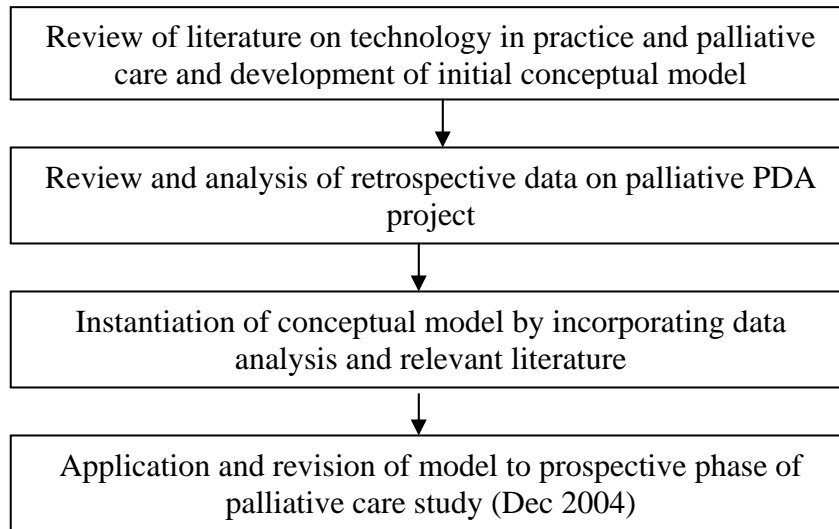


Figure 1. Research Design of Study

Data Sources

The hospice conducted a survey in November 2000, four months after implementation. The survey was intended to capture the perceptions of staff about the PDA project both before and after implementation as no pre-implementation survey had been done. The survey used a 10 point likert scale with 0 being the negative value such as ‘none’ or ‘not at all’ and 10 indicating a strong influence such as very extreme, helpful or difficult depending on the question. For example, one question asked ‘to what degree have you found it (PDA) helpful?’. A score of 0 indicates not at all and a score of 10 is very helpful. The survey had 13 questions, the first 7 referred to pre-implementation of the PDA and the last 6 referred to post-implementation. Appendix A shows the questions from the survey and illustrates the 0 to 10 scale.

The results from that survey served as the main source of data for this study. The survey data was supplemented with some interview data with nursing staff who participated in the PDA project. The survey was completed by 15 nurses and 3 physicians, with the answers presented separately for physicians and nurses. Among the nurses there were 7 full time, 3 part time and 5 casual. Although it should be noted that not all participants answered all questions, so some questions only have 12 or 13 responses from nurses.

Because this phase of study is retrospective in nature the majority of the data came from past surveys, which was somewhat limiting in terms of analysis. The survey does contain a page of reflective comments which provided detail about the results of the survey questions. But this phase of the study is meant to illustrate what happened in a previous IS implementation in palliative care and what are the lessons learned. That will help inform Phase II of this study, which is prospective in nature as it is being conducted as part of PhD research and therefore it will have full access to data sources including physicians, nurses and counsellors.

Table 1 shows an example of some of the reflective comments and codes and notes that were applied to the comments.

Comment	Sample Codes and Notes
I don't appreciate <u>anyone</u> telling the RN's what we haven't recorded, what errors we've made. We do our <u>best</u> ! Believe it or not my pt's symptom management comes first – plugging in their pain level or any symptom level is secondary to getting the pt settled	Control – technology was seen as monitoring the job nurses were doing, implication job not properly done, nurses autonomy being questioned Patient care – Implying PDA entry was taking away from patient care and practice norms requiring a choice of priority, workflow issues
Pts. get fed up being asked so frequently for pain intensity levels, nausea levels etc.	Technological control – requirements of technology causing disruptions to patient care, affects on people, workflow being forced by PDA People – Because nurses are on the frontline of care they may feel they get blamed for the constant questioning
I've found that unit clerks DO NOT enter admissions/discharges and drugs, e.g. drug profiles. This is very time consuming for nurses	Workflow – new task from technological artifact, not defined as to who does the task, adds time to existing workflow, Frustration/work tension - capitalization of DO NOT implies tension towards unit clerks
It doesn't tell me anything I don't already know	Value – No value seen from new technology, impact on practice/workflow/people with no perceived benefits
To take the item (PDA) and backtrack to put in all the meds is a drag and often on top of me not being able to take my breaks	Workflow – technology (PDA) dictates workflow and alters normal flow Practice Norms - Altered Priority, Control – normal work routine (breaks) are sacrificed to attend to technology
I find it extremely frustrating to input data when busy with patient care..having to care for the patient, give meds, chart and then input data – at time I've added all my data at the end of my shift rather than content with it during shift which makes me grumpy when I have to stay later	Workflow – altered by technology, tension and change in normal routine to accommodate technology, attend to patient or input technology choice People – Change in personality because of accommodation of technology – might impact patients?

Table 1. Coding and notes applied to comments from the survey

Results

GT Model of IS Use in Palliative Care

Using the literature described earlier and the codes such as those shown in table 1 we have drawn on the technological frame concept of Orlikowski and Nash and Schema Enmeshment Model of Pincus and Morley and identified five schemas (analogous to a frame) that emerged from the study data. The five schemas: technology, people, patient care, practice and workflow are illustrated below.

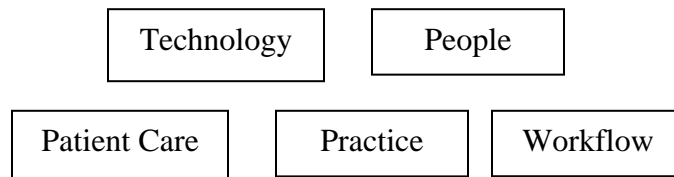


Figure 2. Representation of the five schemas involved in technology use in healthcare. The dotted line connecting the themes represents the state of balance.

The next four sections describe and show how the data instantiates the five schemas to establish the theory. Where applicable relevant literature will be incorporated to strengthen or refute the findings.

Results - Themes/Concepts from GT Analysis

A. Schema #1 Technology

Comfort with PDA technology

Prior to the study

Prior to initiating the palm pilot project there were more professionals who described themselves as somewhat or not at all computer illiterate. Out of 15 nursing responses, 13 stated they were somewhat or not at all computer literate, only 2 stated they were very computer literate. Physicians had an even split with 1 being very computer literate, 1 being somewhat and 1 being not at all.

Despite the potential novelty of the PDA project there was not total agreement with respect to using the PDA for evaluations and analysis, particularly among the nurses. Using the 10 point likert scale 6 nurses, representing 40% of those surveyed, scored 5 or less (0 being not at all and 10 being 5 very much) for the question 'To what extent do you agree with increasing our ability for evaluations and analysis in the unit using Palm Pilot?'.
A comment expressed in regard to using technology includes:

'we are supposed to be high touch- this is a bit high tech'

That comment is similar to the views by Seely and Mount described above about how technology fits into palliative care. Less than enthusiastic endorsement of the idea of PDA use, which in some ways foreshadowed the project decline, supports the previously described theories such as Theory of Planned Behavior (Ajzen, 1991) or Technology Acceptance Theory (Davis, 1993), both of which state that user predefined notions about technology have a strong bearing on outcome.

Four Months after implementation

Despite the lack of technological prowess the overwhelming majority of users of both physicians and nurses said it was easy to learn to use the PDA. 14/15 nurses scored 0 or 1 (indicating little or none) when asked 'what is your anxiety level now in the day-to-day use of the PDA'.

However, an important distinction was made between simply using the PDA and using it in the context of busy practice. A comment related to that question is a nurse who comments:

..anxiety level is 0 expect when busy with patient care then it (anxiety) raises to 10/10...

That comment was echoed by two others who state:

I find it extremely frustrating to input data when busy with pt. care, especially with a symptom crisis...

...my frustration level with using it is 6/10...

All the participants received a practical training session for learning how to use the PDA and the scores from both physicians and nurses were high when asked how helpful the session was. Among nurses, there were 13 responses and 11 scored 8, 9 or 10, indicating strongly that the sessions were very helpful. Of note though is the training took place off the ward away from the stress and business of clinical practice and away from the patient care that the PDA was meant to enhance.

The PDA was not felt to be a substantial burden on practice by the majority of nurses. The question was asked 'How much of an added burden is it impacting your practice?'. 9 nurses scored 5 or less (0 being no burden) whereas 6 scored 6 or greater with only 2 nurses scoring 9 or 10 (indicating extreme burden). But again the reflective comments tell a different story when busy with patient care as one comment stated:

It is an added burden when there is a patient in a crisis and my team is busy, particularly team 3¹...

Overall, with the survey results indicating a lack of anxiety about using the PDA and almost all of the responses (both nursing and physician) indicating it was easy to learn to use the PDA and the participants were clearly comfortable with using the technology. One comments from the survey said '*palm pilot entry is easy*', which illustrates the comfort level with using the technology.

¹ Patients are assigned into teams at the hospice with each team having a designated number of beds under their supervision

B. Schema #2 - Impact on Practice

Value of PDA data

When asked ‘to what degree have you found it helpful (PDA Data)’?, the overwhelming proportion answered negatively. 13 nurses scored 3 or less with 6 nurses giving a score of 0 (indicating no help) and 3 nurses giving a score of 1. Comments related to the degree of helpfulness included one nurse stating quite plainly:

I have not seen any data that helps in day to day practice...

Other comments included:

I can't judge if it is helpful because it doesn't tell me anything I don't already know...

I can appreciate the usefulness of PP (Palm Pilot) for data collection but personally it is not helpful to me. A glance at the board in the chart room and report provide me with the information I need...

Output of Data through Monitor

Although there was no hard copy reports available from the PDA data there was a monitor at the unit desk where caregivers could view results from the PDA data. Examples of results available through the monitor included the ability to see a patient's pain score at a point in time, over time or combined with their medications to review pain scores and medication usage. Figure 2 shows an image of the monitor display.

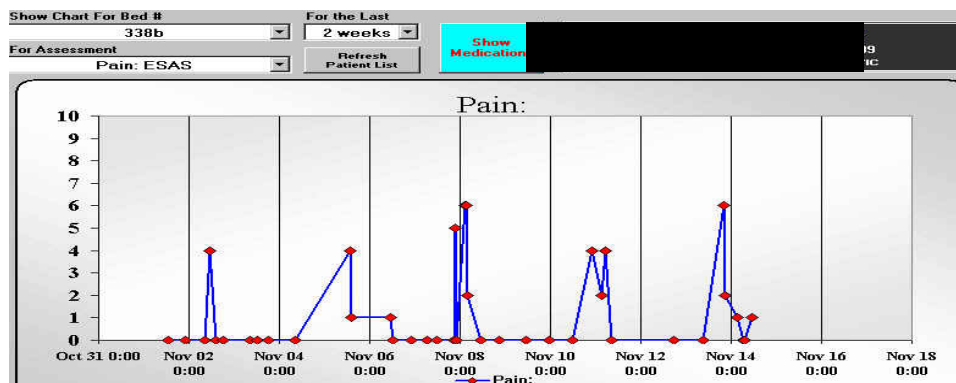


Figure 2. Display from monitor showing pain scores over time.

A question was asked ‘To what degree do you use the monitor to see changes in patient status on your team or another?’. The nurses responded overwhelmingly that they did not use the monitor at all with 10 nurses scoring 0 and 3 nurses scoring 1. Physicians also for the most part did not feel there was much value from the monitor as the 1 physician scored 1, 1 physician scored 2 and 1 physician scored 8. The score of 8 from the physician was the highest score of support for the monitor.

A second question about the monitor data was ‘Is the monitor. Helpful to you, either during the day or upon returning to work after several days off?’. Again, the nursing

responses were negative with 11 scoring 0 and 3 scoring 1. Physicians were mainly negative with 1 scoring 1 and 1 scoring 2, although 1 physician did score 10 indicating the monitor was very helpful upon returning to work after days off.

There were comments expressed that indicate that part of the reason the monitor was not well received was that staff was not familiar with how to use it. Two comments about the monitor were:

It's useless to me. Makes no sense!

The monitor would be helpful if I knew how to use it!

The lack of support towards the monitor, particularly from the nursing staff emphasizes the need for value from technological outputs. The fact that one physician supported the monitor quite strongly while no nurses did reflects differences between nursing and physician practice norms and the need for output of data to support those differences. Another way of looking at that is physicians and nurses practices possess different schemas by which data is considered relevant or not. In a study of sociotechnical requirements analysis Reddy et al. analyzed clinical systems and found variances in the views of data considered relevant by different healthcare professionals such as physicians, nurses and pharmacists. (Reddy et al., 2003). Such variances are also observed in palliative practitioners. Physicians require a view of patient outcomes and medications over time as they often only see patients during daily rounds and they require a detailed schema of knowledge over several days in order to update medications, plan discharges and order appropriate tests. Nurses on the other hand are responsible for a select team of patients on the ward and because they know their patients extremely well they may not benefit as much from ongoing results summary but would benefit more from detailed careplans for day-to-day care delivery as that detailed level is the level at which nurses provide care.

However, it was quite obvious the lack of hard copy data proved to be a critical issue in this project and was a biggest factor in why the project did not succeed. Because the nursing staff had to input data into the PDA as well as record it in the paper chart it required more effort on their part. They had been promised hard copy reports from the collected data in order to provide them with information to enhance practice and reduce data entry however the hard copy data never materialized and that ultimately is what brought the project to an end.

C. Schemas 3&4 - People and Patient Care

The written comments about how the PDA project impacted people looked for the most part at two groups: patients and nurses. With respect to patients there were two comments expressed about patients being continually pressed for symptom assessment scores and that the patients were becoming annoyed at continuously being asked to provide assessment scores.

Pts. get really fed up being asked so frequently for pain intensity levels, nausea levels etc.

The hard part is continuing to press patients for answers and to give a number

Those comments imply that the technology was actually becoming a wedge between the healthcare provider and the patient. Technology is often purported to be a means of achieving better patient care but in this case it was implied that it was really a distraction.

There were also comments expressed that implied that nurses felt they were being looked at in different ways. Some nursing staff felt like the technology was being used to monitor their data entry as there were two comments (one is shown in table 1) about nurses not appreciating being told when they failed to input an assessment score or medication. In a traditional paper chart it is not as obvious that a pain score has been missed but it is much easier to notice in an electronic record.

A second way is how the nurse is perceived by the patient or family when they are in the patient's room. Because nurses are the frontline workers in a hospice they are most likely the ones who are in the room doing the data entry and therefore they are the ones continually asking the patient for symptom scores. When the patient gets annoyed by that it is the nurse who takes the brunt of the patient's annoyance and the nurse may feel they have lost some of the special relationship that a palliative nurse and patient often share.

As shown in table 1 and in some of the earlier quotations there were comments that indicated personality changes such as a nurse staying late after her shift to back entry PDA data and being 'grumpy' afterwards about staying late.

D. Schema #5 - Workflow

One of the outcomes on workflow was that PDA use disrupted the normal flow of nursing practice. The term flow refers to a state of consciousness characterized by some common elements: a balance between the challenges of an activity and the skills required to meet those challenges; clear goals and feedback; concentration on the task at hand; a sense of control; a merging of action and awareness; a loss of self-consciousness; a distorted sense of time; and the autotelic experience (Csikszentmihalyi, 1996, 1997).

In particular the autotelic experience is an important way of referring to how technology impacts patient care. Autotelic comes from the Greek word "autos" meaning "self," and the Greek word "telos" meaning "purpose." In the autotelic nature of patient care a practitioner becomes so involved with caring for the patient that it becomes personally meaningful and the central focus of the work routine. The reward and satisfaction for the practitioner is the care provided to the patient. Technology such as the PDA and data entry from this study, and future benefits, such as reports or analysis from the PDA become second to the current situation. That emphasizes the need for Technology to support the present, and not only promise future rewards.

Patient care is often done through a flow that is comfortable to the caregiver and comes from practice experience. A caregiver gets to know their patients, for example some patients do not like to be woken at particular times of the day, which becomes the flow for that patient's care, and caregivers use that knowledge to best provide care for the

patient. The PDA proved to be a distraction to that flow on several levels. First, some nurses felt it dictated when assessment scores had to be entered. That caused a big ripple in the flow as the sometimes unstructured nature of patient care was suddenly being dictated by the timing of data entry for a PDA. Referring back to the above section on impacts of technology on people a nurse used the term ‘having to press the patient’ in referring to continually getting an assessment score from a patient. ‘Press’ implies pressure or unnatural routine, which goes against the flow that defines nursing.

The literature review referred to a case described by Massaro where new technology brought about a change in the form of outcomes that was unanticipated but positive. We saw the reverse of that in this study as where there was a comment expressed (see table 1) that implied tension expressed towards the unit clerks for not entering certain data. The extra data entry was an outcome directly due to the PDA and added extra work to the nurse’s workflow.

One factor related to workflow which may contribute to nurses giving a lower score than physicians in most of the questions is the difference between nursing and physician workflows. There are some factors in nursing workflow that are susceptible to larger impacts from PDA entry than for physicians. One factor is the volume as nurses do much of the charting and therefore more data entry will have a large impact on nurses. There were a total of 79599 symptom assessment scores entered through the PDA and 49877 of the scores were entered by nurses with 26926 scores entered by physicians (the remaining 2796 assessment scores were entered by unit clerks or the nursing manager). A second factor is time. Because of shift work nurses tend to be entering data more in off hours where there is typically less staff, which leads to more stress, and puts more of an emphasis on the need for the technology to produce reports and outcomes that will enhance practice. Out of the physician entries only 92 entries occurred between 8PM and 6AM, whereas nurses had a total of 18126 entries during the same time period.

Figure 3 shows an example of a number of the workflow concepts (including some codes from table 1) describe above and how they all converge around alterations in workflow.

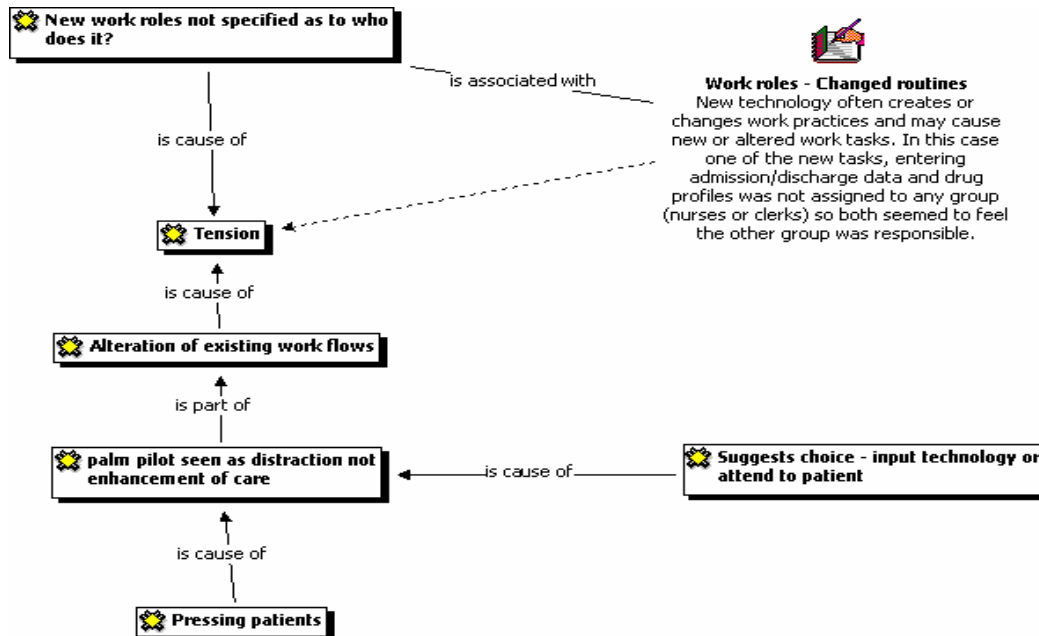


Figure 3. Concept map of various aspects of PDA project and how they ultimately converge on workflow issues.

Establishment of Core Category and Refinement of Model

Referring back to the five schemas from figure 1 (technology, people, patient care, practice and workflow), I found it obvious that workflow is the core category. As shown in figure 3 above all of the issues such as personality issues (tension, frustration, ‘grumpiness’), work routine disruptions (pressing patients for assessment scores, missing breaks) and lack of perceived value from technology output can all be tied to workflow. Figure 4 is the GT model from this study and shows how the concepts discussed in this study all relate to workflow.

There were alternate core categories considered with value, a concept that was discussed in the context of practice, being a concept that could easily fit as core category. But ultimately what defines value is the workflow. The lack of perceived value from the monitor output is an example of something in which the nurses found very little added value to their practice. The fact that one of the physicians gave high scores to the monitor display indicates the physician found much value from the monitor and confirms the difference between physician and nursing workflows. Nurses and physicians found different value from the monitor output despite the fact they were caring for the same patients in the same hospice. That illustrates that value and its modifiers such as practice norms cannot be assumed or perceived but it must be understood by interacting with the participants.

The impact on people was another theme that has merit for being the core category. Although palliative care is defined by its patient centered approach to care there were comments expressed that implied the PDA was making that approach difficult. Some nurses felt like they had to make a choice between entering data in the PDA or attending to the patient during a symptom crisis. Others commented that the patients were getting

annoyed or fed up with constantly being asked to give symptom intensity scores. As described earlier, nurses have a special relationship with their patients and it seems that relationship was being strained by the PDA. But again, that impact on people can be tied to workflow. The PDA data entry structure was dictating nursing workflow and making patient care more unnatural, which in the nurse's eyes was disrupting their practice and impacting patient care.

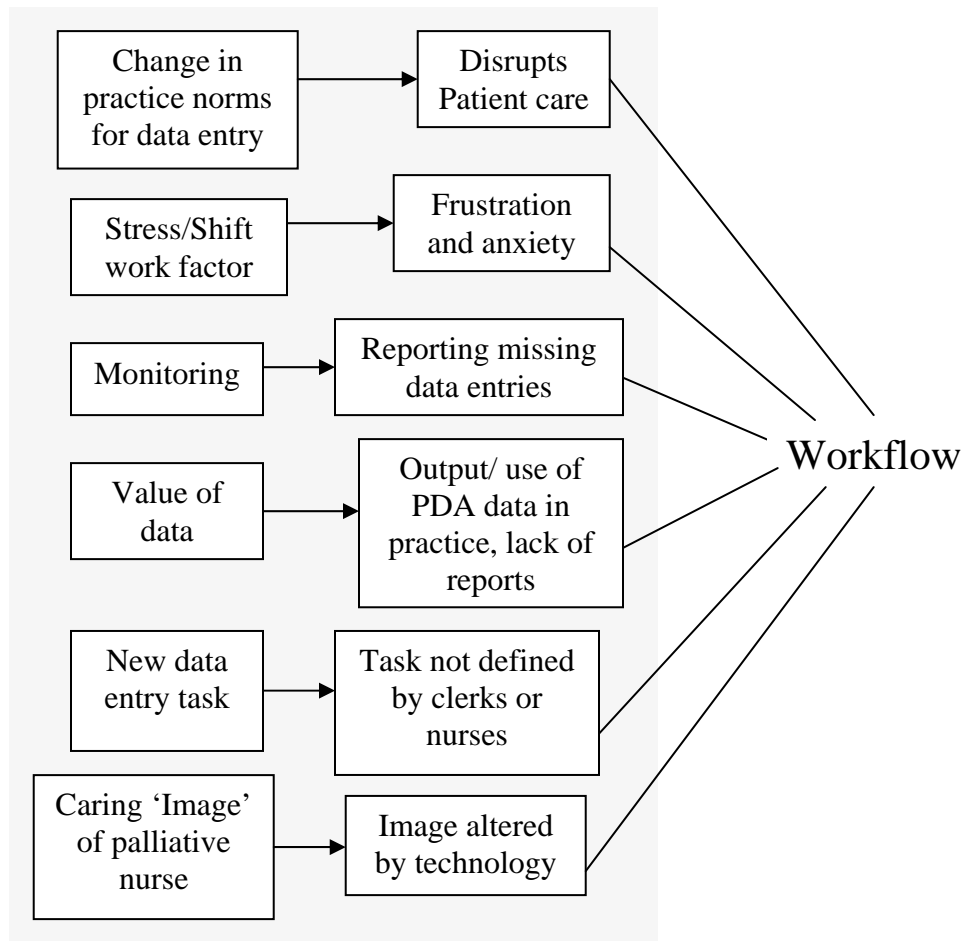


Figure 4. Linking together of various categories to core category of workflow

Discussion

This study brought forth a number of meaningful results about designing and implementing information systems in palliative care. The behavioral theories (Theory of Planned Behavior and the Technology Acceptance Model) described earlier certainly resonated in this study as there was apprehension before the study about using technology and that apprehension appeared to stay with the caregivers throughout the implementation. With the nurses in particular there seemed to be ongoing skepticism and the technology was never fully accepted. The issues of impact on workflow described earlier in detail was an issue that continued to fester until the nurses finally would not use the technology anymore and the project was stopped. The main issue related to workflow was the lack of deliverables such as charting documents that would have prevented the

nurses from having to do double entry. Because the nurses did not perceive any value from the PDA data or monitor output it made other issues from the PDA such as extra data entry tasks or constant patient assessments become much more significant.

The other issues related to workflow such as impact of shift work or the stress that accompanies a symptom crisis also needs to be considered when implementing technology. Those lessons learned will provide valuable insight for phase II of this study as the severe pain tool is intended for use during severe pain management, which is a particularly stressful time for patient care. Grounded theory is being used in phase II to understand how the severe pain tool can be designed to help during pain management. The researcher is spending time in phase II observing the delivery of care on the ward to gain an idea of how the severe pain tool impacts care so that it can be designed to maximize positive impacts while minimizing negative ones. In particular the researcher will be gaining input from physicians, nurses and counsellors in order to gain a perspective on their different approaches to palliative care delivery.

Conclusions

The lessons learned from this study emphasize the need to consider the system view and understand the relationship between people, technology and practice (including workflow) when implementing technology. Both the palliative nurses and physicians indicated the PDA was easy to learn and they had no anxiety about using it so the issues that brought an end using PDAs for data entry were not technology related. Rather the technology made a significant impact on workflow, particularly for nurses that included creating more work, more stress and altering the normal workflow of nursing practice. In the end there was not enough value provided through PDA and monitor output to compensate for the impact on workflow.

References

Ajzen I. "The theory of planned behavior". *Organ Behav Hum Decis Process*, 1991;50:179-211.

Baskerville, Richard & Jan Pries-Heje. (1999) "Grounded action research: a method for understanding IT in practice." *Journal of Accounting Management and Information Technologies*, 9, pp. 1-23.

Berg M. "Implementing information systems in health care organizations: myths and challenges" *International Journal of Medical Informatics*, 64 (2001) 143–156

Berg M, Aarts J, van der Lei J. "ICT in Health Care: Sociotechnical Approaches" *Methods Inf Med*, 2003;42:297-301.

Button G. (Ed.), *Technology in Working Order. Studies of Work, Interaction, and Technology*, Routledge, London, 1993.

Csikszentmihalyi, M., 1996. *Creativity: Flow and the Psychology of Discovery and Invention*. HarperPerennial, New York.

Csikszentmihalyi, M., 1997. *Finding Flow: The Psychology of Engagement with Everyday life*. Basic Books, New York.

Davis FD. "User acceptance of information technology: system characteristics, user perceptions and behavioral impacts" *Int J Man-Mach Stud*, 1993;38:475-87.

Delone WH, McLean ER. "Information Systems Success: The Quest for the Dependent Variable". *Information Systems Research*, 3:1, (1992), 60-95.

DelVecchio Good MJ, Gadmer NM, Ruopp P et al. "Narrative nuances on good and bad deaths: internists' tales from high technology work places" *Social Science and Medicine*, 58 (2004), 939-953.

Donabedian A. "Evaluating the quality of medical care". *Millbank Memorial Quarterly*, 1996, 44:166-206.

Friedman CP, Wyatt JC. *Evaluation methods in medical informatics*. New York: Springer; 1997.

Friedman CP, Owens DK and Wyatt JC. Chapter 8 "Evaluation and Technology Assessment". In Shortliffe EH, Perreault LT (eds). *Medical Informatics: Computer Applications in Health Care and Biomedicine*. Springer 2001.

Gioia, D.A. 1986. Symbols, Scripts, and Sensemaking: Creating Meaning in the Organizational Experience. In H.R. Sims Jr. and D.A. Gioia (Eds.) *The Thinking Organization*. San Francisco CA: Jossey-Bass, 49-74.

Kaplan, B., "Evaluating Informatics Applications—Social Interactionism and Call for Methodological Pluralism," *International Journal of Medical Informatics*, 64(1): 39-56, 2001.

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Kukafka R, Johnson SB, Linfante et al. "Grounding a new information technology implementation framework in behavioral science: a systematic analysis of the literature on IS use" *J Biomedical Informatics*, 36 (2003), 218-227.

Kushniruk AW, Patel VL. "Cognitive and usability engineering methods for the evaluation of clinical information systems". *Journal of Biomedical Informatics*, 2004, In Press

Massaro TA, Introducing physician order entry at a major academic medical center: I. Impact on organizational culture and behavior, *Acad. Med.* 68 (1993) 20–25.

Orlikowski, W. (1993) "CASE tools are organizational change: Investigating Incremental and Radical Changes in Systems Development," *MIS Quarterly*, (17:3), pp. 309-340.

Orlikowski WJ, Gash DC. "Technological Frames: Making Sense of Information Technology in Organizations". *ACM Trans. Inf Syst* (2): 174-207 (1994)

Pincus T, Morley S. "Cognitive-Processing Bias in Chronic Pain: A Review and Integration." *Psychological Bulletin*. 2001, Vol. 127, No. 5, 599-617.

Reddy M, Pratt W, Dourish P, Shabot MM. "Sociotechnical requirements analysis for clinical systems" *Methods Inf Med*, 2003;42:437-444

Romanow RJ. *Building on Values: The Future of Health Care in Canada*. Commission on the future of health care in Canada, final report, Ottawa, Canada. November 2002.

Sarker S, Lau F and Sahay S. (2001) Using an adapted grounded theory approach for inductive theory building about virtual team development. *Database Journal* 32(1):38-56.

Seely JF, BM Mount "Palliative medicine and modern technology". *Journal of the Canadian Medical Association*. (1999) 2 Nov, 161 (9).

Strauss, A., and Corbin, J. (1990). *Basics of Qualitative Research*, Newbury Park: Sage.

Strauss A, Corbin J. "Grounded Theory Methodology: An Overview" In *Handbook of Qualitative Research*, 1994, N.K. Denzin and Y.S. Lincoln (eds.), Thousand Oaks: Sage, pp. 273-285.

Wilson, Howcroft, 2000, The Role of Gender in User Resistance and Information Systems Failure, Proc. of IS 2000 edited by Baskerville et al., IFIP WG 8.2, Aalborg Denmark.

